

Bringing the Magic of Life: The Power of Co-Constructing Digital Storytelling with People with Dementia

by
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B.S., (Biomedical Engineering), University of Virginia, 2015

Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of
Master of Arts

in the
Educational Technology and Learning Design Program
Faculty of Education

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SIMON FRASER UNIVERSITY
Summer 2018

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Abstract

The number of people living with dementia is continuing to increase. Past research found benefits of digital storytelling for persons with dementia, including enhanced relationships, communication, improved well-being, and social citizenship. My research explored the experience of digital storytelling for people living with early stage dementia as part of a cross-Canada project including three sites: Edmonton, Vancouver and Toronto. The Vancouver research was conducted as my thesis research. In Vancouver, six participants were recruited from retirement residences, a care facility, and the Alzheimer Society of B.C. I met with participants for 6 to 16 sessions to create digital stories. Data collected included observational field notes, audio recordings from the sessions, and interviews that were transcribed and analyzed. The process illuminated the experience of digital storytelling for people living with dementia. Aspects of participant's experience included creating a legacy, dementia awareness-raising, facilitated reminiscence, engagement in the process of creation, and generativity.

Keywords: Digital Storytelling; Dementia; Legacy; Awareness-Raising; Reminiscence; Generativity

Dedication

I would like to dedicate my thesis to my family and community of friends that have supported me at every step.

Acknowledgements

I would like to acknowledge the incredible support of my senior supervisor David Kaufman. I truly had the best supervisor who inspired me with knowledge, creativity, and patience, and I loved your jokes haha! I also want to acknowledge Robyn Schell for your help with my data analysis and for your encouragement and creativity. I want to acknowledge each and every friend who supported me and prayed for me throughout this process. Your love and patience made this possible. I am truly grateful for each participant that participated in my thesis. I learned from your life and experiences, and I am inspired by your courage and perseverance.

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Chapter 1. Introduction

1.1. Overview

Currently, 564,000 Canadians live with dementia with a predicted increase to 937,000 by 2031 (Alzheimer's Society Canada, 2012). Past research has found benefits of digital storytelling for persons with dementia including enhanced relationships, communication, improved well-being, and social citizenship (Capstick, Ludwin, Chatwin, & Walters, 2016; Stenhouse, Tait, Hardy, & Sumner, 2013; Davis et al., 2010; Crete-Nishihata et al., 2012). Digital storytelling is a form of narrative that creates short films using media including photos, sound, music, and videos (Rule, 2010).

The purpose of my thesis research is to explore and understand the experiences of digital storytelling as perceived and expressed by the storytellers - persons with dementia. I met with participants from 6 to 16 sessions, and people living with dementia created digital stories and talked about their experience. The sessions varied for each participant depending on their story and background. Data included observational field notes, audio recordings from our sessions, and interviews that were transcribed and analyzed. Participants enjoyed the process of creating digital stories, despite some challenges with communication, memory and using technology. Four themes were unique to each participant's experience including relationship with the family caregiver, learning about technology, building trust, and meaningful and transformative experience. Five themes came up across more than one case study that illuminated the experience of more than one participant including value of legacy, generativity, facilitated reminiscence, engagement in the process of creation, dementia awareness-raising.

The act of sharing stories was positive, stimulated memory and recall, and was an effective way to preserve memories for their family and children. For some participants, their digital story connected with viewers to create a dialogue about their disease and allowed them to tell their story before their disease progressed. One participant stated, "I know that I will eventually probably lose my ability to speak, so then I won't be able to tell my story that well verbally. But there it is digitally." Participants' experience of creating their digital stories evoked a range of emotions from joy and laughter to sadness and tears. The process provided insights into best practices for

digital storytelling for persons living with dementia. Figure 1.1 shows the researcher working with one participant in his home to create his digital story. For people living with dementia, digital storytelling appears to be a meaningful, rewarding, and viable way to share and preserve stories.

Figure 1.1. Creating a digital story together



1.2. Research Questions

Throughout my research process, my research questions evolved (Stake 1995). I refined my research questions three times during my research. I chose to use one of my original research questions because it was broad enough to explore the experience of creating a digital story from the perspective of the storytellers. The three iterations of my research question are as follows.

Original Research Questions:

1. What is the experience of digital storytelling for adults with early stage dementia?
2. How does digital storytelling affect their quality of life in terms of relationships and sense of identity?

Refined Research Questions on 10.9.17:

1. What is the experience of digital storytelling for adults with early stage dementia?
2. How did they create their digital stories?
3. What can be learned about their experience during the process of creating digital stories?

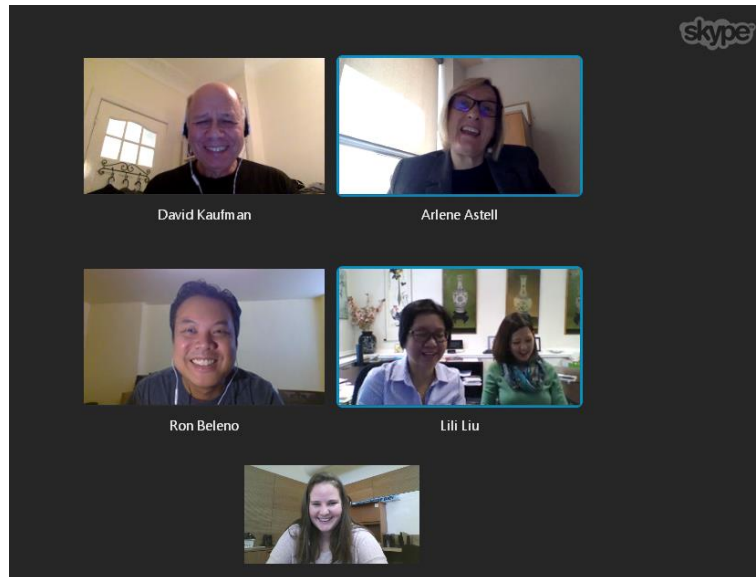
Final Research Question on 11.29.17:

1. What is the experience of digital storytelling for adults with early stage dementia?

1.3. Study Organization and Research Team Responsibilities

My thesis is part of a larger research project carried out at three sites in Canada: Edmonton, Vancouver and Toronto. The larger research project involved the University of Alberta, Simon Fraser University, the University of Toronto, and family caregivers in Toronto. I was the leader of the Vancouver site, and my thesis reports the data I collected from the Vancouver site. The Edmonton site met with adults with early stage dementia recruited from Alzheimer Societies' support groups at the Alzheimer's Society of Alberta and Northwest Territories, Edmonton, AB. The Toronto site met with adults with early and mid- stage dementia recruited from Alzheimer Societies' support groups at the Alzheimer's Society of Ontario, Toronto, ON and an adult day program called Memory and Company. At the research site in Vancouver, participants were recruited from a retirement residence, an independent living residence, a residential care facility, and the Alzheimer Society of B.C. Each research site explored the experience of digital storytelling for people living with dementia. I created the interview protocols in collaboration with the post-doctoral researcher (Dr. Elly Park) at the Edmonton research location. I recruited and carried out the research with the participants at the Vancouver location. Each location adapted the SFU Elder's Digital Storytelling Course curriculum to suit the needs of their participants. All three research sites had bi-weekly or monthly meetings via Skype to discuss our collaboration and progress of our research. The digital storytelling course that we adapted was funded by AGE-WELL Network of Centres of Excellence, and this cross-Canada research project was funded by the Canadian Consortium on Neurodegeneration and Aging (CCNA).

Figure 1.2. An across Canada team meeting on Skype with research team members in Vancouver, Edmonton, and Toronto.



1.4. Thesis Outline

My thesis includes five chapters. Chapter 1 is the introduction which provides a brief overview of my research, research questions, and discusses how my project fits into the across Canada research project. Chapter 2 is the literature review which provides the relevant literature for my research. Chapter 3 is the methods which describes the digital storytelling process, research design, ethics, consent and recruitment, data collection, data management, data analysis, and measures to promote trustworthiness. Chapter 4 discusses the findings including six case studies that describe the digital storytelling creation process for each participant and themes that illuminated my research question. Chapter 5 is a discussion and conclusion for my thesis research. The Chapter 5 discussion provides a summary of the major research findings to connect the themes across case studies and to the literature.

1.5. Digital Story Links

Each participant created their own digital story during this process. Six digital stories were created. I have listed the links to their digital stories in Table 1.1. Their digital stories can be downloaded for viewing from these links.

Table 1.1. Links to participant's digital stories

Participant	Digital Story Link
Janet	https://vault.sfu.ca/index.php/s/NkrN8rfwafIUHSI
Leonard	https://vault.sfu.ca/index.php/s/Qo7jvCS5kOGAcfv
Max	https://vault.sfu.ca/index.php/s/U9gSpMV6nCAY1Gr
Anne	https://vault.sfu.ca/index.php/s/yAYGxXI55vyEuZV
Chris	https://vault.sfu.ca/index.php/s/wgClogSJHxvJ2Zh
Ian	https://vault.sfu.ca/index.php/s/9Ow3p9KE2WWQ26K

Chapter 2. Literature Review

2.1. Introduction

A significant number of the Canadian population age 65 and older has dementia (Alzheimer's Society Canada, 2012). Dementia is broadly defined as a decline in cognitive abilities which includes learning, memory, complex attention, perceptual motor, or social cognition (Larson, 2015). Alzheimer's disease is the most common form of dementia, but there are several other forms of dementia (Larson, 2015). There are approximately 564,000 people living with dementia in Canada which makes up 15% of the older adult population over 65 years of age (Alzheimer's Society Canada, 2012). However, by the year 2031, it is estimated that this figure will almost double, and nearly one million people over 65 will be living with dementia in Canada (Alzheimer's Society Canada, 2012).

Dementia related short-term memory loss causes challenges for people living with dementia including social isolation, reduced well-being, and a breakdown of communication (Alm, Gowans, Campbell, Astell, & Ellis, 2007). Verbal memories are often affected first, but overlearned memories such as playing an instrument or reciting a poem and emotional memories are preserved until the later stages of the disease (James & Jackman, 2017). Some sensory functional changes for people living with dementia involve hearing and vision. Hearing changes often include difficulty filtering sounds and hypersensitivity to noise which effect communication (Alm et al., 2007). Some people living with dementia experience retained eyesight but impairment of the brain's processing of visual information (Alm et al., 2007). Vision changes include a narrowed visual field, loss of depth and speed perception, difficulty with pattern recognition, double vision, and visual hallucinations (Alm et al., 2007).

Digital storytelling offers many opportunities for people living with dementia including improved communication, well-being, and creating a legacy (Hausknecht, Vanchu-Orosco, & Kaufman, 2016a; Hausknecht, Kaufman, & Vanchu-Orosco, 2016b; Capstick et al., 2016; Stenhouse et al., 2013). Digital storytelling incorporates an audio recorded narrative that can tie together images, videos, music and effects to create a short video about a meaningful story in someone's life (Rule, 2010). This literature

review highlights the research on digital storytelling for people with dementia including the benefits and areas needed for future research.

2.2. Review of the Literature

2.2.1. Dementia Defined

Dementia is a broad term described as a major neurocognitive disorder (Larson, 2015). When a person is diagnosed with dementia, they present with a major impairment in one or more of these cognitive domains: learning and memory, language, executive function, complex attention, perceptual-motor function, and social cognition (Larson, 2015). The most common forms of dementia almost always impair the learning and memory cognitive domain (Larson, 2015). The most common forms of dementia include Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, vascular dementia, and Parkinson disease with dementia (Larson, 2015).

Alzheimer's disease is the most common form of dementia, and is characterized by progressive neurodegeneration (Wolk & Dickerson, 2016). Memory is affected first in Alzheimer's disease that is often accompanied by a variety of other neurological symptoms (Wolk & Dickerson, 2016). Alzheimer's disease most often affects people 65 years and older (Wolk & Dickerson, 2016). In contrast to Alzheimer's disease that affects the memory cognitive domain first, dementia with Lewy bodies is first characterized by impairments of attention and executive function as well as visuospatial cognition (Farlow, 2015). However, the cognitive domain of memory is affected later as the disease progresses (Farlow, 2015). Frontotemporal dementias are a collective term for behavioral frontotemporal dementia and primary progressive aphasia (Lee & Miller, 2015). Frontotemporal dementias are characterized by impairments of social behavior and personality (executive function) or language (Lee & Miller, 2015). This impairment of language is called aphasia. Frontotemporal dementia most often is not characterized by memory loss (Lee & Miller, 2015). Vascular dementia is characterized by impairments of the executive function cognitive domain resulting from vascular injury of the brain most often due to recurrent strokes (Wright, 2015). Memory impairment is generally mild for people with vascular dementia, and memory impairment often occurs in the later stages of the disease (Wright, 2015). Parkinson disease with dementia causes impairments of

the executive function and visuospatial cognitive domains, and memory is not affected until the later stages of the disease (Rodnitzsky, 2015).

2.2.2. Classification for Mild (Early Stage) Dementia

One way to understand the stage of dementia that a person is living with is by using the Clinical Dementia Rating (CDR) (Morris, 1993). The CDR lists several characteristics related to memory, orientation, judgement/problem solving, community affairs, home/hobbies, and personal care that provide some guidelines for understanding the characteristics for a classification for a person having mild, moderate, or severe dementia (Morris, 1993). My thesis research involved with people that identified as living with mild also called early stage dementia. The CDR describes a person as having mild dementia using the following terminology. The person experiences “moderate memory loss: more marked for recent events; defect interferes with everyday activity” (Morris, 1993). Orientation experiences deficits through “moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere” (Morris, 1993). The person also experiences “moderate difficulty in handling problems, similarities and differences; social judgement usually maintained” (Morris, 1993). Relating to community affairs, the person is “unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection” (Morris, 1993). While participating at home and in hobbies, the person experiences “mild but definite impairment of functions at home; more difficult chores, and complicated hobbies and interests abandoned” (Morris, 1993). Finally, while participating with their personal care the person “needs prompting” (Morris, 1993).

2.2.3. Meaningful Activities for People Living with Dementia

Because there is no known cure for people living with dementia, there are many non-pharmacological interventions that exist (Cooper, Mukadam, Katona, Lyketsos, Ames, Rabins, & Brodaty, 2012). Many of these interventions include therapies developed to improve the quality of life and well-being for people with dementia (Cooper et al., 2012). Older adults often believe that success of an intervention is better defined by quality of life improvement rather than disease related outcomes of treatment (Cooper et al., 2012). Participating in meaningful activities is often found to be important from the perspective of people living with mild to moderate dementia (Phinney, Chaudhury, &

O'Connor, 2007). These activities include "leisure pastimes, household chores, work-related endeavors, and social involvements" (Phinney et al., 2007). Remaining active by participating in meaningful activities allows people living with dementia to experience enjoyment, connection with others, and maintaining a sense of identity through contributing to their well-being and personhood (Mitchell & Agnelli, 2015).

2.2.4. Personhood

Personhood is defined as "generally to describe what makes up the attributes of being a person" (Mitchell & Agnelli, 2015). Personal histories are one contributing factor to a person's sense of personhood while living with dementia (O'Connor, Phinney, Smith, Small, Purve, Perry, & Beattie, 2007). Understanding personhood contributes to person-centered care for people living with dementia. The four elements that contribute to person-centered care include "1) valuing people with dementia and those who care for them; 2) treating people as individuals; 3) looking at the world from the perspective of the person with dementia; 4) providing a positive social environment in which the person living with dementia can experience relative wellbeing" (Brooker, 2003). Understanding the subjective experience of a person living with dementia is important when looking at the world from the perspective of the person living with dementia (Brooker, 2003).

2.2.5. Storytelling

Storytelling is a method of drama therapy that allows people with dementia to express themselves (Beard, 2011). Life story work is a method of storytelling that is often used in the care for people living with dementia (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010). Life stories are often autobiographies that create a narrative for a person's present, future, and past life experiences (McAdams, 2008). Benefits of creating life stories for people living with dementia include preserving a sense of identity, maintaining dignity, and enhancing person-centered care (Heggestad & Slettebø, 2015; McKeown et al., 2010). Participating in storytelling stimulates participation in conversations with others and "awaken memories" even for people living with intermediate and severe dementia (Holm, Lepp, & Ringsberg, 2005). Some people living with dementia share their story with others through publishing an autobiography (Page & Keady, 2010). Benefits of publishing their story as an autobiography include sharing their experience with a public audience and maintaining their identity and social networks

(Page & Keady, 2010). People living with dementia do experience some challenges when telling their stories (Hydén, 2017). One challenge is that the person living with dementia often tells an “entangled story” which requires the listener and teller to find shared meaning (Hydén, 2017).

The listener of their story often becomes the co-teller of the story to support the storyteller with filling in details of their story such as words, names or events (Hydén, 2017). Despite these challenges, people living with dementia benefit from and want to participate in storytelling (Hydén, 2017). The listener also needs to collaborate with the storyteller to understand their story because people living with dementia often express their stories through gestures in addition to their text and speech (Hydén, Martin, Kontos, & Ward, 2013). The listener may need to make an effort to make sense of their story through understanding that their gestures describe a word or phrase that the storyteller cannot express (Hydén et al., 2013). Despite the challenges, the stories told by people living with dementia often retain the four components of a personal narrative (Fels & Astell, 2011). The four components of their personal narrative include story text, context and sociocultural setting, audience or listener contribution, and performance/ownership/control of their story (Fels & Astell, 2011). These characteristics make up the normative model or framework of storytelling and suggest that storytelling engages people living with dementia in conversation (Fels & Astell, 2011).

One method of creative storytelling called *TimeSlips* engages people living with dementia by allowing them to express themselves using their imagination without the pressure of recalling a story accurately (Fritsch, Kwak, Grant, Lang, Montgomery, & Basting, 2009). *TimeSlips* is a group storytelling program based on person-centered care that involves small groups of people with dementia gathering on a weekly basis, and they create a story based on theatrical pictures using their imagination (Fritsch et al., 2009). The facilitators write down any contribution made by the participants and all answers are considered correct (Fritsch et al., 2009). The facilitators acknowledge that for many of the stories created, there is often a story behind the story influenced by the “hopes, dreams, anger, regrets, and humor” of the storytellers (Basting, 2003, p. 29). The stories created using the *TimeSlips* method help to promote public awareness by demonstrating that people living with dementia can participate in creative storytelling (Basting, 2006).

StoryCorp implemented another storytelling program for people living with dementia. StoryCorp's Memory Loss Initiative interviewed 42 people living with dementia to give them an opportunity to preserve their oral histories through storytelling (Savundranayagam, Dilley, & Basting, 2011). Their initiative sought to enhance the personhood of people living with dementia through storytelling (Savundranayagam et al, 2011). Some benefits of this storytelling activity were that it "allowed participants to acknowledge the beauty of the present moment, to reflect and engage in meaningful conversations, to re-affirm both the selfhood of individuals with memory loss and their relationships with family members, and to and be a part of national history while leaving a legacy for future generations within families" (Savundranayagam et al, 2011). Robb Lucy in his book *How Will You Be Remembered?: A Guide for Creating and Enjoying Your Legacies Now* further defines a legacy as something you can enjoy until the end of your life and leave behind to enhance lives when you are gone (Lucy, 2017, p. 11).

2.2.6. Digital Storytelling

Another alternative intervention that has been recently used for people living with dementia is digital storytelling (Stenhouse et al., 2013). According to the founder of the StoryCenter, digital storytelling is defined as a process for "gathering of personal stories into short little nuggets of media called digital stories" (Lambert, 2012, p. 1). Digital stories are meaningful and powerful artifacts of modern expression because they "weav[e] images, music, narrative and voice together, thereby giving deep dimension and vivid color to characters, situations, experiences, and insights" (Rule, 2010). Digital stories are generally three to five-minute films that combine images, text, narration, and music. The images are often personal photos from meaningful events in the person's life. The script is created by the storyteller to be incorporated into the film using a recorded voiceover (Stenhouse, 2013).

Digital storytelling is used in a variety of fields including education when used by teachers as a powerful tool in 21st century classrooms (Robin, 2008). Digital storytelling is also used in cultural studies as a method for creative practices and is used as an additional resource for oral and historical archives (Burgess, 2006; Klaebe, Foth, Burgess, & Bilandzic, 2007). Digital storytelling is also implemented globally as a resource for marginalized populations to share their stories (Sawhney, 2009). Several benefits of digital storytelling used in education include improved literacy skills,

promoting 21st century skills, and engaging students and teachers (Robin, 2008). Some other benefits of digital storytelling include improved self-efficacy and adoption of educational technologies (Heo, 2009). Benefits of digital storytelling among older adults include increased literary skills, connections to others and self, and creating a legacy after participating in a 10-week digital storytelling course (Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b).

I adapted the digital storytelling curriculum developed for the SFU Elder's Digital Storytelling Course for older adults to meet the needs of people living with early stage dementia (Hausknecht et al., 2016a). The SFU Elder's Digital Storytelling Course curriculum was created in September of 2014 using principles gathered from "the Center for Digital Storytelling (now called the StoryCenter), the Digital Storytelling Cookbook, creative writing and film techniques" (Hausknecht et al., 2016a). I am a trained facilitator for this digital storytelling course. I have co-facilitated and led several of these courses using this curriculum for older adults age 55 and older. Several benefits of this digital storytelling course curriculum were previously found for older adults (Hausknecht et al., 2016a; Hausknecht et al., 2016b). These benefits include: empowered participants; assisted social connections with course participants, friends, and family; provides a means for legacy creation; increased digital storytelling, technology, and internet skills; provides an opportunity to share stories with others and to learn something new (Hausknecht et al., 2016a; Hausknecht et al., 2016b).

2.2.7. Technology Use by People Living with Dementia

The use of computers and the internet by older adults is increasing (Madden, 2010). Using computers is beneficial for older adults and allows them to remain independent (Damodaran, Olphert, & Phipps, 2013). However, cognitive and physical decline create difficulties older adults when using computers and a barrier for them when learning to use computers (Damodaran et al., 2013). Because people living with dementia often experience physical and cognitive decline, they benefit from having additional support when using familiar and new technologies such as computers (Nygård & Starkhammar, 2007).

Nygård and Starkhammar (2007) use four domains to describe the difficulties people living with mild to moderate Alzheimer's disease experience when using

everyday technologies. The four domains are as follows: “conditions that interfere as hindrances in technology use”, “limitations in the participants’ knowledge of the technology and its potential”, “communication difficulties in the use of technology”, and “instructions for use - an illusion in support” (Nygård & Starkhammar, 2007, p. 148). The first domain “conditions that interfere as hindrances in technology use” (p. 148) is described as conditions related to the person and their context such as memory and environmental factors. The second domain “limitations in the participants’ knowledge of the technology and its potential” (p. 148) involves uncertainty and confusion about the use of the technology. The third domain “communication difficulties in the use of technology” (p. 148) involves understanding the information that the technology is communicating and the usability of the technology. The fourth domain “instructions for use - an illusion in support” (p. 148) involves understanding the instructions from the manufacturer on how to use the technology. Understanding these difficulties are to provide the necessary support for people living with dementia when using a computer to create their digital stories.

2.2.8. Reminiscence

Reminiscence is a “process which occurs in stages, involving the recall of early life events and interaction between individuals” (Dempsey, Murphy, Cooney, Casey, O’Shea, Devane, & Hunter, 2012, p. 176). Reminiscence therapy was first used in dementia care when Kiernat (1979) introduced reminiscence into the occupational therapy program for people living with dementia at a care facility. Reminiscence therapy often includes a discussion of past events and experiences with prompts and triggers such as photographs, household and familiar items, smells, music, archived sound recordings, and questioning (Woods, Spector, Jones, Orrell, & Davies, 2005). Pinquart and Forstmeier (2012) classified reminiscence into three categories including simple reminiscence, life review, and life review therapy. Simple reminiscence includes “mainly unstructured autobiographical storytelling with the goal of communicating and teaching or informing others, remembering positive past events, and enhancing positive feelings” (Pinquart & Forstmeier, 2012, p. 3). Life review is similar to simple reminiscence, but it uses a more structured approach to evaluate details from the person’s entire life (Pinquart & Forstmeier, 2012). Life review therapy is a process of life-review targeted specifically for people living with a mental illness (Pinquart & Forstmeier, 2012).

Reminiscence therapy stimulates the person with dementia and increases self-worth (Dempsey et al., 2012). Reminiscence is thought to improve the person living with dementia's quality of life, behavior, and mood (Dempsey et al., 2012). When used as an intervention for people living with dementia, reminiscence also reduces symptoms of depression and improves well-being (Gonzales, Mayordomo, Torres, Sales, & Meléndez, 2015). In a recent review of reminiscence therapy outcomes for people living with dementia, the benefits of reminiscence were associated with the person's living situation. (Woods, O'Philbin, Farrell, Spector, & Orrell, 2018). In a care home setting, reminiscence benefited people living with dementia's quality of life, cognition, and communication (Woods et al., 2018). When reminiscence therapy was conducted individually, the person living with dementia showed probable benefits in cognition and mood, and when conducted in a group or in the community the person experienced probable improvements in communication (Woods et al., 2018).

2.2.9. Digital Storytelling for People Living with Dementia

The 'Patient Voices Digital Storytelling Project' implemented a digital storytelling workshop for seven people living with early-stage dementia (Stenhouse et al., 2013). The workshop took place over four consecutive days, and the people living with dementia developed a story, wrote a script for their images, recorded voiceovers, selected music, and incorporated all their elements using a video editing software. Nursing student facilitators worked closely with each participant to help them create their digital stories. The goal of this workshop was to provide nursing students with an opportunity to develop compassion for people living with dementia (Stenhouse et al., 2013). Based upon observations during the workshop, the people living with dementia experienced positive outcomes from digital storytelling including increased confidence, communication, and connection as well as experiencing a sense of purpose (Stenhouse et al., 2013). The facilitators met at the completion of each workshop session to reflect on their experience (Stenhouse et al., 2013). Their reflective sessions illuminated three themes centered around engagement of participants with their story, with doing, and with others (Stenhouse et al., 2013). Crucial to the success of this workshop was the relationship between the facilitators and the participants (Stenhouse et al., 2013). When the participants experienced difficulties with telling their stories and using technology, the constant supervision from and relationship with the facilitators enabled the participants to

complete their digital stories (Stenhouse et al., 2013). The facilitators were nursing students paired with the people living with dementia, and the stories created were used for nursing education. Even with the assistance of the facilitator, constructing the story narrative was particularly difficult for the people living with dementia (Stenhouse et al., 2013).

Another form of digital storytelling for people living with dementia is called a Monogram booklet. It is a six-slide PowerPoint presentation that includes voiceover and personalized photos chosen based on the first letter of the name of the person living with dementia (Davis, Spake, & Gray, 2010). Five participants with dementia who were high or mid-functioning created monogram booklets (Davis et al., 2010). The researchers, a designer, and an activity director chose suitable photos for each person living with dementia (Davis et al., 2010). The participants created their monogram booklet during three sessions over six weeks (Davis et al., 2010). To investigate if participant's agitation and confusion were reduced and well-being improved, the researchers used pulse rates and a well-being picture scale before and after each session to understand participants' experience creating their monogram booklets (Davis et al., 2010).

A multimedia biography is a form of digital storytelling that allows people living with dementia to construct a story using images and videos to create a film (Crete-Nishihata, Baecker, Massimi, Ptak, Campigotto, Kaufman, & Black, 2012). Creating the multimedia biography allowed family members and the people living with dementia to choose their media (Crete-Nishihata et al., 2012). Family members often narrated the story after the media was selected. Research assistants helped construct the story and DVDs (Crete-Nishihata et al., 2012). Interviews with family members and video observations of the participants watching their multimedia biography were used to explore the psychosocial effects of viewing their multimedia biography (Crete-Nishihata et al., 2012). The psychosocial effects included factors such as reminiscence, emotions, and communication (Crete-Nishihata et al., 2012).

The current forms of digital storytelling for people living with dementia often incorporate reminiscence. Given the benefits of reminiscence and its ability to stimulate knowledge recall, incorporating reminiscence into digital storytelling is beneficial because the participant usually recalls knowledge of past events to create their story. With advances in technology, tangible multimedia are often incorporated into and

support methods for reminiscence for people living with dementia (Huldtgren, Mertl, Vormann, & Geiger, 2017). Several technologies exist to facilitate reminiscence for knowledge recall (Haron, 2014). An example of a digital storytelling technology used to support reminiscence is the Computer Interactive Reminiscence Conversation Aid (CIRCA) (Alm et al., 2007). CIRCA features a touchscreen with pictures, video, text, and other materials to draw upon the preserved long-term memory of people living with dementia. This device utilizes the benefits of reminiscence to allow people living with dementia to converse with their families or caregivers through presenting images that the person living with dementia can explain (Alm et al., 2007). CIRCA draws upon material from public archives, and a British Columbia, Canada specific version exists (Purves, Phinney, Hulko, Puurveen, & Astell, 2015). The developers of Computer Assisted Reminiscence Therapy (CART) expanded upon CIRCA to provide individual reminiscence therapy using a tablet in long-term care facilities (Pringle & Somerville, 2013). CART provides people living with dementia opportunities to reminisce using personalized photographs and music (Pringle & Somerville, 2013).

Communication often deteriorates as the person living with dementia progresses through the stages of dementia such as Alzheimer's disease (Stages, 2014). However, digital storytelling incorporates methods to facilitate communication. One of these methods is a digital photograph diary that uses photographs of everyday life events to facilitate reminiscence and conversation between the family caregiver and the person with dementia (Karlsson, Axelsson, Zingmark, Fahlander, & Sävenstedt, 2014). CIRCA also uses multi-media materials to allow people with dementia to converse with family and caregivers (Alm et al., 2007).

Photo elicitation is a form of reminiscence used in participatory video creation for people living with dementia (Capstick et al., 2016). Digital storytelling is considered a method of participatory video (Coghlan & Brydon-Miller, 2014, p. 268). Capstick et al. (2016) uses the term participatory video, but they used methods similar to digital storytelling. Digital storytelling used as a method of participatory video involves autobiographical stories, still images, and editing done by the authors (Coghlan & Brydon-Miller, 2014). Their goal was to use the term participatory video to emphasize the role of the person with dementia as the film director (Capstick et al., 2016). The aim of participatory video is to give people who are normally excluded an opportunity to tell their stories (Capstick et al., 2016). Photo elicitation was used in the first step of the

digital story creation process as a form of reminiscence to help the participants determine their story topics (Capstick et al., 2016). The process of photo elicitation involved showing the participants images such as family pictures on paper or a tablet, and then progressively making the images more personalized as the researchers formed relationships with the participants (Capstick et al., 2016). Photo elicitation is defined as a method for evoking information, feelings, and memories by using an interview process that incorporates photos (Harper, 2002). This method is often beneficial for retrieving memories and stories because “Photographs appear to capture the impossible: a person gone, an event past. That extraordinary sense of seeming to retrieve something that has disappeared belongs alone to the photograph and it leads to deep interesting talk” (Harper, 2002, p. 23).

Digital story creation using participatory film methods and photo elicitation included many benefits for people living with dementia, including improved well-being and social citizenship (Capstick et al., 2016). Using the Bradford Well-Being Profile as a measure, improved well-being was evident through the participant's demonstrating affection, creativity, and humor (Capstick et al., 2016). Increased social citizenship includes the person's involvement with their surrounding community and was measured using the Arnstein's Ladder of Citizen Participation (Capstick et al., 2016). Social citizenship was evident in the participants' creation of digital stories that are featured on websites and at film festivals (Capstick et al., 2016). The participants also attended events featuring their digital story and served on a panel as experts for their work (Capstick et al., 2016). The benefits experienced during their digital story creation process were dependent upon the relationships that the researchers formed with the ten-people living with dementia in the long-term care facility (Capstick et al., 2016).

2.3. Summary

The number of people living with a diagnosis of dementia is continuing to increase. Dementia causes difficulties including social isolation, reduced well-being, breakdown of communication, and sensory functional changes. Digital storytelling has been used in various forms as an intervention for people living with dementia. Several benefits of digital storytelling for people living with dementia were found using methods such as observation, surveys, instruments, scales, pulse measurements and interviewing their caregivers. These benefits include areas such as enhanced

relationships, communication, improved well-being, and social citizenship. Personhood and person-centered care is an area of growing emphasis in the care of people living with dementia. One focus of personhood for people living with dementia is understanding their subjective experience of living with dementia and looking at the world from the perspective of the person. The StoryCorp oral history project emphasized personhood and interviewed the storytellers who were people living with dementia to understand their experience. The goal of my thesis research is to understand the experience of digital storytelling from the perspective of the storytellers – the people living with dementia.

Chapter 3. Methods

3.1. Introduction

My research explored the experience of digital storytelling for people living with dementia. This chapter discusses the digital storytelling process; the methods used to collect the qualitative data; and how I analyzed the data.

3.2. Digital Storytelling

3.2.1. Introduction

I adapted the digital storytelling curriculum developed for the SFU Elder's Digital Storytelling Course to meet the needs of people living with early stage dementia (Hausknecht et al., 2016a). Additional details about the SFU Elder's Digital Storytelling Course were discussed in Chapter 2 - Literature Review. I modified this digital storytelling course curriculum to meet the needs of people living with dementia to explore their experience with digital storytelling. The specific modifications made to the digital storytelling curriculum prior to working with my first participant are discussed in the 'Process Details' section that follows. Further modifications were made to the digital storytelling course curriculum while working with my initial two participants, and these modifications are further discussed in my Chapter 4 - Findings.

3.2.2. Process Details

The SFU Elder's Digital Storytelling Course consists of 8 to 10 sessions over the period of 8 to 10 weeks with 1 session per week. For my thesis research, I initially planned to use the 8-session format over 4 weeks. I shortened the length to four weeks with 2 sessions per week. This modification was made because dementia is progressive, and I wanted the course to take place over a shorter time span to minimize the effects of disease progression. However, some participants needed varying amounts of sessions to complete their digital stories, so the number of sessions ranged from 6 to 16. Some participants were not available to meet twice per week due to their scheduling constraints, so we sometimes met once per week. Sometimes participants were not available during certain weeks, so we occasionally were not able to meet every week. I

also reduced the number of participants per course from 4 to 10 participants in each course (Hausknecht, 2016a) to working one-on-one with each participant. This modification was made to give the participants living with dementia more individual attention. I met individually with each participant, and their family caregivers attended the course sessions if their loved one with dementia requested their support.

3.2.3. Technology

Participants used computers to create their digital stories. I provided my laptop to use with the participants during the digital storytelling sessions. The video editing software used in this course is called WeVideo. I created a WeVideo account for each participant with their email as their username and a password. If the participant did not have an email, I created a gmail account for them. The participants' accounts were upgraded from the free version to the paid version of WeVideo using the WeVideo licenses that were previously purchased for the SFU Elder's Digital Storytelling Course. The participants audio recorded their story scripts using the Yeti Blue™ microphone to enhance the quality of the audio recordings. The images for their stories were digitized and edited using the CamScanner by Insig application. One participant asked me to help him record videos for his story. I used a Sony HDR-CX190 High Definition Handycam Camcorder to film the videos for this participant.

3.2.4. Content and Timeline

A description of each course session used in the SFU Elder's Digital Storytelling 8-session course is shown in Table 3.1 (Hausknecht, 2016a). In the first session of the course, participants normally sign consent forms and discuss how this course is part of a larger research study. However, I met with the participants individually before the digital storytelling process began to discuss the study. When I started working with participants, I planned to initially follow the SFU Elder's Digital Storytelling session timeline with the modifications discussed in 3.2.2 Process Details. As discussed in Chapter 4 - Findings, this timeline was adapted to meet the needs of people living with dementia through working with my first two participants. Table 3.1 shows a general timeline with the session content adapted to meet the needs of my participants. This timeline is further discussed for each participant in Chapter 4 - Findings.

Table 3.1. Digital storytelling course outline and adaptations.

Session	SFU Elder's Digital Storytelling Course	Adapted Digital Storytelling Timeline
1	Introductions and WeVideo accounts	Introductions, Sign the consent/assent forms, discuss the interview questions
2	WeVideo introduction	Edit and discuss their story ideas from session 1
3	Story script drafts	Continue discussing and creating their script
4	Script sharing and editing	Edit their final story script
5	Gather images and create storyboard	Record narrative using the script
6	Record narrative using the script	Gather images and create storyboard (happens throughout the entire process)
7	Music and sound effects, edit in WeVideo	Music and sound effects, edit in WeVideo
8	Edit and publish in WeVideo	Publish in WeVideo, final interview questions

3.3. Research Design and Rationale

3.3.1. Research Paradigm: Constructivism

The case study research framework developed by Stake (1995) is based on a constructivist research paradigm (Baxter & Jack, 2008). In a constructivist research paradigm, individuals construct knowledge based on their own perspective and experiences in a social environment (Stake, 1995; Baxter & Jack, 2008). A constructivist paradigm is suited for my project because I worked closely with each participant to allow them to express themselves through their story (Baxter & Jack, 2008). I closely

collaborated with my participants which gave them an opportunity to share their constructed knowledge of reality to understand their lives and actions.

3.3.2. Case Study Research Framework

My qualitative research design was developed using the case study model for qualitative inquiry defined by Stake (1995). According to Stake (1995), a case study is defined as “the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances” (p. xi). A case study illuminates a phenomenon of interest to provide insight from multiple sources (Baxter & Jack, 2008). Stake (1995) further defines a case as having “a boundary and working parts” that have a purpose, and together they create an “integrated system” (p. 2). People or programs are often cases that are studied using this definition (Stake, 1995). For my thesis research, the digital storytelling process for people living with dementia is the system that was studied. Boundaries include the timeframe of weeks and working one-on-one with each participant. A working part is the digital storytelling content.

Case studies are also broken into three categories by Stake (1995): intrinsic, instrumental, and collective. My case study was a combination of aspects from instrumental and collective case studies. A combination is normal according to Stake (1995) because it is often difficult to classify a case into one category. My case study was mainly instrumental because I have a particular research question to understand the bigger issue of how people with dementia experience digital storytelling. My inquiry also has aspects of a collective case study because I worked with six different participants recruited from several locations with various forms of dementia and of different ages to deepen my understanding of how people with dementia experience digital storytelling. My methods for data collection were guided by Stake’s (1995) recommendations for data gathering for case studies. As discussed in the data collection section, I used interviews and observations with thick descriptions of the context (Stake, 1995).

3.4. Ethics

I obtained ethics approval from the SFU Office of Research Ethics Board prior to beginning my research. I am listed as the principle investigator for the ethics application

at SFU with Dr. David Kaufman as my senior supervisor. The other research sites in Edmonton and Toronto applied independently for their ethics board approval.

3.5. Consent and Recruitment

3.5.1. Consent and Assent

Consent was obtained from each participant at the beginning of the study. The participants were given the option to also complete a release form after completing their digital stories. I created forms for consent and assent (proxy consent). According to the life enrichment manager at Thornebridge Gardens and the recreation and volunteer manager at Harmony Court, the participants recruited could provide their own consent because they were considered to be independent and capable of making their own decisions while living at Thornebridge Gardens and Harmony Court. The participants recruited from the Alzheimer Society of B.C. were living independently in the community, so they also provided their own consent. We included an assent form in our ethics application for cases where the participant was not capable of providing informed consent. In this case, the participant completed an assent form and asked their family caregiver to complete the consent form. At the Normanna residential care facility, the participant completed the assent form, and his sister completed the consent form because she identified herself as the participant's power of attorney. Based on literature regarding informed consent and assent, a person living with dementia in its early stages generally retains their ability to understand and provide informed consent (Meulenbroek et al., 2010). Before the stories were shown to a public audience, the participants were given full disclosure about how, when and where the stories would be used. Participants had copies of their digital stories, and the digital stories were shared only if they signed a release form giving consent.

If a participant wanted to withdraw or modify anything they shared including their data, they were free to do so. They were informed at the beginning of the study as well as multiple times throughout the study of their options. Participants had access to their digital stories and could change or withdraw anything they wished.

3.5.2. Participant Information

Participants

The participants recruited for my thesis were adults aged 45 years and older assumed to have a diagnosis of dementia and in the early stage of the disease. Participants could fall into one of two groups- early onset and typical onset. Both male and female participants were included. Participants living in the community were recruited from a retirement residence, an independent living residence, a residential care facility, or the Alzheimer Society of B.C. Participants needed to communicate in English, or have a caregiver who could translate for them. I recruited 6 participants. Demographic information was collected in the pre-course interview with participants before the start of the digital story creation process. The demographic information collected for each participant is presented in Chapter 4 - Findings.

Sample Size

My sample size reflects the resources available and my study's approach. This project included approximately 6-16 sessions over several weeks. Each session was intended to last approximately 30-120 minutes. I met one-on-one with each participant. Due to the large number of sessions with each participant, there is a relatively small sample size to allow for increased interaction between the participants and me.

3.5.3. Recruitment

I recruited six participants from four different locations. I began by recruiting two participants through Thornebridge Gardens, a retirement residence at 649 Eighth Avenue, New Westminster, BC, V3M 2R2. I co-facilitated an SFU Elder's Digital Storytelling Course at Thornebridge Gardens, so I approached the Life Enrichment Manager. I asked her if some residents at Thornebridge Gardens were interested in participating in my thesis project. I emailed the life enrichment manager my study details and an invitation letter. I submitted the signed permission letter for Thornebridge Gardens to participate in my study to the SFU Office of Research Ethics. The life enrichment manager personally knows the residents at Thornebridge Gardens, so she met with some residents to ask them if they were interested in participating my study. I was also available to answer questions from interested participants and to assist the life

enrichment manager in the recruitment process. A poster was provided for Thornebridge Gardens to distribute. A sample flyer is shown in Figure 3.1. We recruited two participants assumed to have a diagnosis of dementia and in the early stage of the disease.

I then recruited one participant from Harmony Court, an independent living and residential care facility at 7195 Canada Way, Burnaby, BC V5E 4A6. I previously volunteered at Harmony Court, and I was a research assistant for my supervisor's digital games study at Harmony Court. I approached the recreation and volunteer manager, and I asked her if some residents at Harmony Court were interested in participating in my thesis research. I then sent the volunteer manager my study details and an invitation letter. I emailed the signed permission letter for Harmony Court to participate in my study to the SFU Office of Research Ethics. The volunteer manager identified a resident that was interested to talk with me to learn more about participating in my study. One participant was recruited from Harmony Court.

The Alzheimer Society of B.C. located at 300-828 W. 8th Avenue Vancouver, B.C. V5Z 1E2 also assisted with recruitment. The director of Advocacy and Education, Marketing and Communications from Alzheimer's Society of B.C. supported participant recruitment efforts by sharing information about my research in the form of a poster with the Society's Resource Centres located in the Lower Mainland. I received two emails from potentially interested participants. Two participants were recruited from the Alzheimer Society of B.C.

I recruited my final participant from the Normanna residential care facility at 7725 4th Street, Burnaby, BC, V3N 5B6. I was referred to this participant through his friend that participated in an SFU Elder's Digital Storytelling Course that I co-facilitated in SFU's continuing education program. The participant's friend connected me with the participant's family caregiver. The family caregiver said this participant was excited about participating in my research. I received a signed permission letter from the director of clinical care at Normanna. I then met up with the interested participant to discuss my project. I recruited one participant from Normanna.

Figure 3.1. This is a sample flyer used for recruitment.

Creating and Sharing Stories: Digital Storytelling Workshop for Adults with Dementia



We will do a workshop to make a five minute film based on one or two important events in your life. This workshop will take about 4 weeks. We will meet in small groups and learn how to use technology to create stories that you can keep and share with loved ones.

If you are interested in participating in this workshop or if you have any questions, please contact Hollis Owens.

This workshop series (Digital Storytelling and Dementia) was made possible by a grant from the Canadian Consortium on Neurodegeneration in Aging (CCNA) and Age-Well National Centres of Excellence. After each workshop session, participants will be asked to take approximately 15-20 minutes to answer some questions for research purposes. This is not required to attend the workshop.



3.5.4. Payment/Reimbursements

I gave each participant a small gift to show my appreciation for participating in this research. The gift is a small keepsake in the form of a USB with a copy of their digital story. Participants who withdrew from any part of the study would have received their USB to keep with or without their completed digital story depending on if they completed their digital story before withdrawing. However, no participants chose to withdraw from this research. The gift has sentimental value, not monetary value, and should not constitute coercion.

3.6. Data Collection

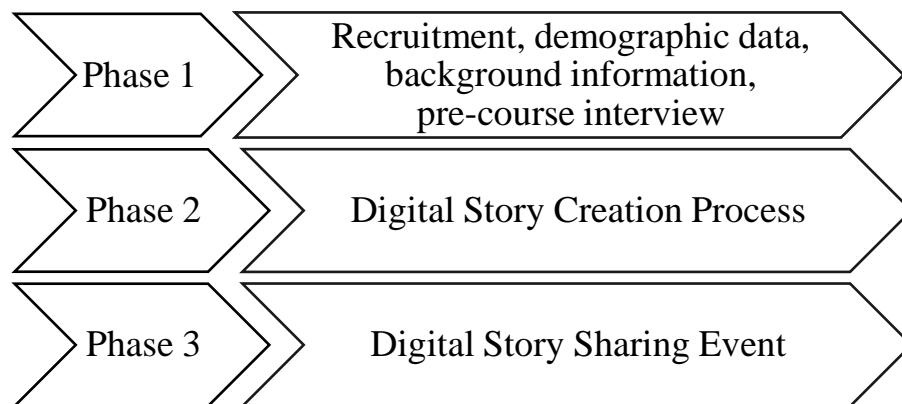
3.6.1. Phases

My data collection took place over nine months. The three phases of my data collection are described below and shown in Figure 3.2. After ethics approval, I recruited interested participants from four locations. The three phases of data collection were iterated for each new recruitment location. The order of recruitment locations are as follows: 1. Thornebridge Gardens, 2. Harmony Court, 3. Alzheimer Society of B.C., and 4. Normanna. The first phase involved recruitment, collection of demographic data and background information during the pre-course interview. One participant also chose to complete the Mini-Mental State Exam (MMSE) during the first phase. I obtained informed consent and collected demographic data during this phase as part of our pre-course interview. If the participant agreed, I administered the MMSE to provide additional background information for each participant to help estimate their severity of cognitive impairment. One participant chose to complete the MMSE during phase 1, and three participants chose to complete the MMSE at the completion of phase 2. Two participants chose not to complete the MMSE.

During the second phase, the participants created their digital stories. Table 3.1 outlines the general timeline and content for the digital story creation process sessions. I led the sessions, took field notes, and audio recorded the sessions as part of my data collection. Family caregivers attended the sessions if their loved one with dementia requested their support. The caregivers in attendance observed the session and provided assistance if requested. During these sessions, we used the online video

editing program called WeVideo to create their digital stories. The third phase included a sharing event of their digital stories to an audience of their choosing. One participant chose to also share his digital story on social media and within his Alzheimer Society support group. The Thornebridge Gardens participants had their own ‘sharing our stories’ event. The sharing our stories event was combined for the Harmony Court and Alzheimer Society of B.C. participants. The Normanna participant shared his digital story with his family and friends at his birthday party.

Figure 3.2. Three phases of our data collection plan occurring for each recruitment location including Thornebridge Gardens, Harmony Court, the Alzheimer Society of B.C., and Normanna.



3.6.2. Instruments

I took field notes and audio recorded the sessions as part of data collection. The amount of field notes that I wrote during each session was limited because I was working one-on-one with each participant. Therefore, after each session, I wrote additional field notes with reflective journaling about my experience while I listened to an audio recording of the session. A pre-course interview was used to gather demographic data and background information including the participant’s use of technology, storytelling experience, current life themes, and visions for the future. The MMSE was administered to provide additional background information for each participant to help estimate their severity of cognitive impairment. After the final session, each participant individually answered the post-course interview questions about their experience in the process to create their digital story.

Semi-Structured Interviews

The demographic data and background information questions were created using selected parts of the pre-course survey used in the SFU Elder's Digital Storytelling Course curriculum. The questions were created to learn more about each participants' demographics, background information, and their experience with technology and storytelling. I asked each participant these questions before their semi-structured pre-course interview during their first course session. The demographic and background information questions are as follows:

1. Can you tell me how old you are?
2. Do you know what kind of dementia you have been diagnosed with?
 - a. Alzheimer's Disease
 - b. Dementia with Lewy Bodies
 - c. Frontotemporal Dementia
 - d. Parkinson Disease with Dementia
 - e. Vascular Dementia
 - f. Other, please specify: _____
3. How long have you been living with dementia (years)? _____
4. Did you immigrate to Canada? Yes___ No___ If yes, in what year? _____
5. What is your living arrangement? Alone___ In a couple___ With family___ With other___ In a care facility___
6. What is your highest level of formal education you have completed? _____
7. Do you have access to a computer? Yes, at home___ Yes, elsewhere___ No___
8. If yes, what type of computer? Yes, PC desktop___ Yes, PC laptop___ Yes, iMac___ Yes, iPad___ Yes, tablet___ Other _____ No___
9. Do you use e-mail? Yes___ No___
10. How often do you use the internet?
 - a. Once a month___
 - b. Once a week___
 - c. Several time a week___
 - d. Every day___
 - e. Several times a day___
11. What is your skill level in using computer and/or internet?
 - a. None (Never used computer technology)___
 - b. Beginner (Low level)___
 - c. Intermediate (Middle level)___
 - d. Expert (High level)___
12. Do you have a smartphone? Yes___ No___

If yes,

How often do you use it? Once a month___ Once a week___ Several times a week___ Several times a day___

What do you use it for (i.e., phone calls, texting, email, camera, music, etc.)?

What is your skill level?

 - a. None (Never used computer technology)___
 - b. Beginner (Low level)___

- c. Intermediate (Middle level)____
 - d. Expert (High level)____
13. Do you have a tablet or iPad? Yes__ No__
- If yes,
- How often do you use it? Once a month__ Once a week__ Several times a week__ Several times a day__
- What do you use it for?
- What is your skill level?
- a. None (Never used computer technology)____
 - b. Beginner (Low level)____
 - c. Intermediate (Middle level)____
 - d. Expert (High level)____
14. Do you have experience in any of the following (check all that apply)? Digital storytelling__ Creative writing__ Telling stories__ Writing in a journal__ Other (please describe)_____

I also created semi-structured interview questions to facilitate our conversation around storytelling, and the role it had in their life. Through this conversation, I learned more about what is meaningful to each participant and their experience with storytelling before we created their digital story. These questions aided participants to reminisce and begin thinking about stories they wanted to tell. The questions are as follows:

- A. Introduction (goals and needs)**
 - 1. What has been important to you over the past few years?
 - 2. Tell me about your life right now. What do you care about?
- B. Major life themes**
 - 3. What are some things you hope you never forget?
 - 4. Do you think you are changing now? In what ways?
 - 5. What matters most to you now? What do you worry about now?
 - 6. Is there a time in your life you want to go back to? Why?
 - 7. How would you describe yourself to yourself at this point in your life?
- C. Visions of the future**
 - 8. When you think about the future, what makes you feel uneasy/nervous/scared?
 - 9. What gives you the most hope?
- D. Storytelling**
 - 10. Can you share a story that is meaningful to you?
 - 11. Do you like to tell stories? If yes, what kinds of stories do you like to tell?
 - 12. Who do you share stories with?
 - 13. What do you think is the reason (purpose) of telling stories?
- E. Closing**
 - 14. Is there anything else you would like to share?

During the final session after each participant viewed their final digital story, we discussed the post-course interview questions about their experience during their digital story creation process. These questions were created to learn more about participants' overall experience during the process. I used the initial goals/aims for my project to

create these interview questions. The goals/aims for our project are show in the Appendix. The post-course interview questions are given below:

1. What was your experience creating your digital story?
2. How has the process of creating your own digital story affected your life?
3. What were the benefits of creating your digital story?
4. What were the challenges of creating your digital story?
5. Is there anything you would change?
6. Can you describe how you felt throughout this experience?
7. What do you think are the benefits and drawbacks of working in a setting with other adults with dementia?
8. Did this storytelling activity change your life? How? (or in what way? Or tell me more)
9. Do you want to create more stories? Or, would you do this activity again?
10. Is there anything else you would like to share?

Mini-Mental State Exam (MMSE)

The MMSE was administered to gather additional background information for each participant to help estimate the severity of their cognitive impairment. Four out of the six participants agreed to complete the MMSE. Depending on the participant's preference, I administered the MMSE during our initial or final session. One participant completed the MMSE before the digital story creation process, and three participants completed the MMSE at the completion of our digital story creation process. The completion time for the MMSE is approximately 15 minutes for people with dementia (Mitchell, 2017). The MMSE is a quick and easy cognitive assessment which can be used to estimate the level of cognitive impairment and dementia severity (Folstein, Folstein, & McHugh, 1975). The following MMSE scores were used to estimate dementia severity: 21-25 (mild), 11-20 (moderate), and 0-10 (severe) (Perneczky, Wagenpfeil, Komossa, Grimmer, Diehl, & Kurz, 2006). The MMSE does not perform well as a confirmatory tool for diagnosing dementia; however, the MMSE is used as a screening tool for dementia (Mitchell, 2017). We used the Standardized MMSE questions and instructions because they contain additional instructions for administration and scoring (Molloy, Alemayehu, & Roberts, 1991). The Standardized MMSE questions are included in the Appendix.

Observational Field Notes

I took field notes and audio recorded the course sessions as part of the data collection. Because I worked on-one-on with the participants, taking detailed field notes

during the course sessions was difficult. I used the audio recordings to clarify, support, and elaborate upon the field notes gathered during the sessions. Following each course session, I added to my observational field notes while listening to the audio recordings. I also added reflections on my experience during the sessions. The observational field notes included an “relatively incontestable description” of the events and interactions during the course (Stake, 1995, p. 62). An incontestable description “lets the occasion tell the story, the situation, the problem, resolution or irresolution of the problem” (Stake, 1995, p. 62). Stake (1995) also recommends that observations for a qualitative case study focus on “finding the good moments to reveal the unique complexity of the case” (p. 63). The observational field notes include thick descriptions of the context of the case including the physical environment and the participants (Stake, 1995). Because this case study is mainly an instrumental case study, detailed description of all contexts becomes less important (Stake, 1995). For this reason, I focused my observations on the events and interactions occurring between participant and myself during our sessions (Stake, 1995).

3.7. Data Management

3.7.1. Recordings, Transcription, Data Organization

The interviews and course sessions were recorded using a digital audio recorder. I then transcribed the audio recorded interviews with participants. The audio recorded course sessions were used to supplement my observational field notes. I managed the coded interviews using NVivo software for qualitative research.

3.7.2. Participant Confidentiality Measures

Participants’ contact information such as email, telephone and mailing addresses are not considered to be confidential information. We are the owner of this contact information and will not release it to the public. All audio recordings collected were anonymized and can only be accessed and analyzed by the research team. However, all the contact information and audio recordings were kept confidential. Pseudonyms were used for the participants after the demographic information was collected. These pseudonyms replaced the names in the data, and when some of the qualitative data is published, the identities and any identifying information are kept confidential. Recorded

interview digital files were destroyed immediately once they had been transcribed into digital text using pseudonyms of participants. All interview transcripts (digital format), contact information, consent forms, and field notes were kept securely in a password locked flash drive, and kept in a secured cabinet in the office of Dr. David Kaufman for four years before it will be destroyed. Any additional personnel working on this project will sign a confidentiality agreement letter. All six participants wanted to share their digital stories with a public audience, so they chose to sign a separate release form.

3.8. Data Analysis

The interview transcripts were independently coded by myself and another researcher (Dr. Robyn Schell) and analyzed using thematic analysis to establish themes. The themes focus on the experience of creating digital stories from the participants' perspectives.

3.8.1. Thematic analysis

I used the six steps of thematic analysis described by Braun and Clark (2006) to analyze the post-interview transcripts. Thematic analysis is defined by Braun and Clark (2006) as "a poorly demarcated, rarely acknowledged, yet widely used qualitative analytic method" (p. 2) that is a useful "method for identifying, analysing, and reporting patterns (themes) within data" (p. 6). I chose to use thematic analysis for my data because it is suitable for a small data set and accessible for novice researchers since this is my first qualitative research project. I used the six steps of thematic analysis described by Braun and Clark (2006) to analyze the post-interview transcripts. The six steps are described in detail as follows.

1. Familiarization with the data

I transcribed all the interviews to become more familiar with the data. I worked with one other researcher (Dr. Robyn Schell). We independently read and reread the post-interview transcripts. We made notes as we read the transcripts for some initial ideas or sections that stood out.

2. Coding

Codes are distinct units of meaning within the data that are relevant to my research question. The coding process helped us organize our data into a variety of codes that provided meaning to help us answer my research question (Braun & Clark (2006). Based on our familiarization with the data, Robyn and I coded two post-interview transcripts together. We then coded the remaining transcripts independently. We met up again and cross checked our codes with each other. We consolidated our codes, added new codes and recoded portions of our transcripts to create our final set of codes for all the post-interview transcripts. All the transcripts were coded using a pen and different colored highlighters to mark the different patterns in our data. We read over all our transcripts for a final time to evaluate our final codes. I used NVivo to mark a set of final transcripts with our consolidated codes.

3. Searching for themes

This phase involves collating the codes into relevant groups to form themes. To do this, I first took my different codes for each participant, and I printed them individually onto small pieces of paper. I shuffled these pieces of paper around grouping codes together to form “theme-piles” for each participant (Braun & Clark, 2006, p. 19). Then using each theme pile, I used NVivo to collate the data to each code within their respective theme pile.

4. Reviewing themes

In this phase, I read through the transcript data associated with each theme pile (Braun & Clark, 2006). I determined if some of the themes needed to be combined or eliminated as well as created new themes if necessary (Braun & Clark, 2006). I read through my entire data set again to determine if these themes illuminate my research questions. I re-coded and re-organized, combined, or eliminated parts of my theme piles as necessary (Braun & Clark, 2006).

5. Defining and naming themes

Using my theme piles, I refined each theme (Braun & Clark, 2006). I determined the story behind each theme and how each theme adds to the story behind the entire analysis (Braun & Clark, 2006). During this phase, I also refined the theme names to fully encompass their meaning (Braun & Clark, 2006).

6. Writing up

I completed this phase in Chapter 4 (Findings) of my thesis. I used selected quotes from my transcripts to support my themes and to tell the story behind my analysis to illuminate my research question (Braun & Clark, 2006). I also used excerpts from their pre-course interviews and field notes with reflection to further illuminate the themes I identified.

3.9. Trustworthiness

According to Creswell (2012), credibility of qualitative research involves validating the accuracy of the research findings using methods such as triangulation, member checking, and external auditing. I used triangulation to enhance the credibility of my research findings. Triangulation involves using multiple data sources including interviews and observations (Moen, 2006). Using multiple methods of data collection is desirable according to Maykut and Morehouse (1994) because "convergence of a major theme or pattern in the data from interviews, observations, and documents lends strong credibility to the findings" (p. 11). I triangulated my data by supporting my thematic analysis for my post-interview transcripts with excerpts from their pre-course interviews and observational field notes to look for overlapping major themes across the data sets.

According to Maykut and Morehouse (1994), building an audit trail also increases credibility. I built an audit trail as I worked involving my research journal, interview transcripts, field notes, and steps from our thematic analysis process (Maykut & Morehouse, 1994). According to Moen (2006), prolonged engagement and persistent observation which involves working "with people, day in and day out for a long period" (p. 8) is also important for credibility in qualitative research. Elements of this approach include "building trust with participants," "learning the culture," and checking for misunderstandings or misinformation (Moen, 2006, p. 8). Some ways to build trust between in a participant-researcher relationship include reciprocity throughout the process, "empathy, credibility, rapport, and breaking down power relationships, to increase researcher trustworthiness by demonstrating their probity and commitment to those with whom they are doing research" (Emmel, Hughes, Greenhalgh, & Sales, 2007). I built trust with my participants through getting to know each participant to build rapport, shared about the goal of my research, and answered their questions about my

research before, during, and after their pre-course interview. The process used to create their digital stories involved meeting with participants over 6 to 16 sessions over several weeks.

In Chapter 4 - Findings, I practiced reflexivity to maintain credibility (Holloway & Biley, 2011). I also practiced reflexivity in my observational field notes. Reflexivity is defined as the “the researcher’s own reactions to the study, their position and location in the study, and the relationships encountered, which are reciprocal” (Holloway & Biley, 2011, p. 971). I dispersed reflexivity during my process throughout Chapter 4 – Findings. My reflexivity included my experience with digital storytelling and facilitating digital storytelling courses as well as my relationship with my participants at Thornebridge Gardens, Harmony Court, Alzheimer Society of B.C. and Normanna.

3.10. Summary

My Methods chapter discussed the plan I used to collect data for my digital storytelling creation process for people living with dementia. I used and adapted the SFU Elder’s Digital Storytelling course curriculum. The research methodology informing my data collection methods is a case study approach defined by Stake (1995). I used interviews and observational field notes to collect my data. The post-interview transcripts were analyzed using thematic analysis. Triangulation, building an audit trail, prolonged engagement, and reflexivity contributed to the trustworthiness of my analysis.

Chapter 4. Findings

4.1. Introduction

Several modifications were made to the SFU Elder's Digital Storytelling Course curriculum to meet the needs of people living with dementia as shown in Table 4.1 (Hausknecht et al., 2016a). I met with participants one-on-one rather than in a group to provide the support they needed to complete their digital stories. We met twice per week when possible to minimize their dementia progression throughout our process. As described in each individual case study, I met with participants for 6 to 16 sessions to complete their digital story. I assisted and collaborated with the person living with dementia to co-create their digital story. When possible, each participant acted as the director while I executed their ideas in WeVideo under their guidance. My pedagogy involved co-structing their digital story while observing their understanding of the process and adapting to meet the needs of my participants. Pre-course and post-course interviews were used to replace the surveys used in the SFU Elder's Digital Storytelling Course. Homework was not assigned, and participants developed a relationship with me instead of with other participants.

Table 4.1. Modifications made to the SFU Elder's Digital Storytelling Course curriculum to meet the needs of people living with dementia.

Digital Storytelling and Dementia	SFU Elder's Digital Storytelling Curriculum (Hausknecht et al., 2016a)
One-on-one sessions in their homes, care home, retirement residence, at another specified meeting location	Group of 4-10 in the library or retirement residence
Met twice per week whenever possible	Meet once per week
6-16 sessions	8-10 sessions
Assistance from the researcher (Hollis Owens) and family caregivers	Individually completed with minimal facilitator guidance
Limited learning how to use the WeVideo Program, Participant acted as the director while I executed their ideas in WeVideo under their guidance	Learned how to navigate and use the WeVideo program
Pre-course and post-course interviews with facilitator	Background surveys completed before and after course

Digital Storytelling and Dementia	SFU Elder's Digital Storytelling Curriculum (Hausknecht et al., 2016a)
No homework assigned, however some participants would gather images and music and help edit their script	Weekly reflection and journaling activity
Developed a close relationship with researcher, not with other participants	Emphasis on social interactions/friendships with other participants

I also modified the SFU Elder's Digital Storytelling Course content to meet the needs of people living with dementia as shown in Table 4.2. I created this general process timeline simultaneously while I worked with my first two participants. As described in each case study, this timeline varied for each participant based on their needs, and I modified this timeline to meet the needs of each participant.

Table 4.2. General timeline for the digital story creation process.

Session	Content
1	Introductions, Sign the consent/assent forms, discuss the interview questions
2	Edit and discuss their story ideas from session 1
3	Continue discussing and creating their script
4	Edit their final story script
5	Record narrative using the script
6	Gather images and create storyboard (happens during the entire process)
7	Music and sound effects, edit in WeVideo
8	Publish in WeVideo, final interview questions

My Findings Chapter describes an individual case study for each participant and concludes with a summary of the themes for each participant. For each case study, I provide an introduction for my participant including descriptions from their pre-course interview questions. For each case study, I also describe the digital story creation process during which we created their digital story. The themes section for each case study describe the themes that illuminated my research question for each participant based on their post-course interview responses. Table 4.3 provides an overview for each participant including their including their demographic information and digital story theme and length.

Table 4.3. Demographic information collected for each participant during the pre-course demographic interview questions and digital story theme and length.

Person	Age	Diagnosis	Length of Diagnosis	Living Arrangement	Story Theme	Digital Story Length
Janet, Female	89	Un-determined	Un-determined	Lives in a couple with her husband in a retirement residence	Family move across Canada from Winnipeg to Vancouver	7 min. 57 sec.
Leonard, Male	91	Un-determined	Un-determined	Alone in a retirement residence	Soldier during World War II	5 min. 27 sec.
Max, Male	85	Alzheimer's Disease	5 years	Lives in a couple with his wife in an independent living residence	Growing up during World War II	4 min. 17 sec.
Anne, Female	62	Frontotemporal Dementia	17 years	Lives with her mother in an apartment	Advocate for people living with dementia	7 min. 45 sec.
Chris, Male	68	Vascular dementia	9 years	Alone in his own home	Living and coping with dementia	7 min. 56 sec.
Ian, Male	73	Lewy Body Dementia	4 years	Alone in a care facility	Adventures while studying as an exchange student in Paris	5 min. 3 sec.

4.2. Case Studies

4.2.1. Janet

Introduction

I was referred to Janet through the life enrichment manager at Thornebridge Gardens retirement residence. Janet is 89 years old, and she was my first participant.

Her type of dementia was undetermined. Janet lives with her husband in an apartment in their retirement residence. Janet is a natural storyteller. She enjoys telling stories, but she was unsure if she had a story to tell. She also discussed that she is skilled at standing in front of a crowd and telling stories. Here is an excerpt from her pre-course interview:

Hollis: Do you like to tell stories? If yes, what kinds of stories do you like to tell? [Question 11]

Janet: Oh, I like to tell stories, umm. Boy, I love to tell children stories. I love to do that. But uh if I had to stand up and tell a story as long as I know what I'm talking about I can do that. And I enjoy it. But I'm not likely to have a story to tell again. You never know, but I have always enjoyed telling a story. I can speak out and be heard, yes. A lot of people really you don't know what their saying. And uh I try to speak out so that if I were in a big room, I could be heard.

Janet also believed that stories are beneficial for the storyteller. In her pre-course interview, she discussed that the storyteller learns from telling stories to an audience. Here is an excerpt from her pre-course interview:

Janet: Well, I think for people to stand up and tell a story is just like having new medicine, somebody's given you medicine. And you can do, it's helped you, you're going to be better. I really do.

Janet's relationship with her husband was very important to her. She mentioned her husband several times during her pre-course interview, and he supported Janet to create her digital story throughout the process. Here is an excerpt from her pre-course interview:

Hollis: What gives you the most hope? [Question 9]

Janet: That my husband and I are together. When one goes we both go...I want us to be together. And that's umm I don't worry about it...I just wouldn't want to be alone, I wouldn't want to miss, I'd miss him terribly. He really looks after me. All my friends say, oh you're so lucky. He does everything for me. And I don't like to use that word [spoiled] but they do. [laughter]

Janet did not specify her type of dementia, but she discussed that she struggled with her memory. During one session, she became worried and confused that someone was trying to steal her story. Having dementia was difficult for Janet, and she did not like to discuss it. Here is an excerpt from my field notes on Thurs., Feb. 16 at 3 pm:

Hollis: Janet also became worried that someone else was trying to come take her story, but I reassured her that I would look into it and that was not the case...Janet seemed more confused and worried than she was previously. She also discussed that she felt very tired. She said that she has had trouble remembering things and that the doctor called it dementia. But she did not like this word and she was very sensitive about the topic and her memory loss.

Janet said she remembered stories from when she was a little girl. Here is an excerpt from her pre-course interview:

Janet: I can remember back to when I was a little girl. My family, family things are very important to me. And that was as important to when I was a little girl. I can remember how I was being treated when I was three years old for instance. I was a little girl, and I was passed from my mom to her sister because her sister didn't have any children...so I got a lot of attention from aunts and uncles. And um you might say I was spoiled. And my mum made, our mother was a good seamstress, our mother had been, and she had been taught. And we had all homemade clothes pretty well. And um well dressed, we were well dressed always. Dad was a CN agent as I said. So that meant we always had money coming in. So, there was money to spend on such things as that and sports and umm trips away and so on, yeah.

She experienced difficulty remembering details from stories beyond her childhood. Her husband Doug said that some of the details in Janet's story were different from the actual story. Her husband thought one of details was important, so I helped Janet edit her narration. Her husband said the main purpose of her story is to create a memory for their children, and that everything did not have to be factual. Here is an excerpt from my field notes on Thurs., Feb. 23 at 3 pm:

Hollis: And the project was bringing up some memories that were difficult for Janet because she could not remember it accurately. For example, Janet said that her husband was not on the trip across Canada, but he was there in reality. So, taking what her husband said I removed the recorded part from her story about husband being in Toronto...Her husband said that the main purpose of this story was for their children so the accuracy and recording did not matter as much for him.

Janet did not complete the MMSE. Here is excerpt from my field notes on Tues., Feb. 14 at 3 pm explaining the reason that she did not complete the MMSE:

Hollis: I was also supposed to do the MMSE with Janet, but I could tell that she was not having a good day. She seemed not as engaged as usual and a bit more confused than usual. She also told me that she does not have a good memory, so I did not want to push her in this session to do the MMSE. She talked about how her memory has not been as good in the past couple years.

Janet completed her degree in teaching at the College of Saskatoon. She did not have an email, and she did not have access to a computer, smart phone, or tablet. She self-identified as having no skill level using a computer or the internet. She said that she had some experience with digital storytelling. I later learned that she took two SFU Elder's Digital Storytelling Courses that my senior supervisor offers for older adults to create their own digital stories. She brought her folder that she used during these courses to one of our meetings. She discussed that she did not remember what she learned. I facilitated SFU Elder's Digital Storytelling Course for older adults at her retirement residence while I was working with Janet. Another facilitator taught Janet during the digital storytelling courses that she took previously. I was excited to work with Janet one-on-one to give her the support she needed to create her digital story. Here is an excerpt from my field notes on Fri., Feb. 3 at 1:30 pm and Tues., Feb. 7 at 3 pm:

Hollis: Janet previously participated in the normal digital storytelling course at Thornebridge, but she was not able to participate in the last or current normal digital storytelling course due to her cognitive decline.

Hollis: Janet took her folder for digital storytelling out of her walker and placed it on the kitchen table. I remarked wow that's awesome, it was a folder from the previous digital storytelling courses she took at Thornebridge Gardens. Her husband told me while she was gone that there is not much in this folder.

Digital Story Creation Process

Table 4.4. Timeline showing the sessions and content for the creation of Janet's digital story.

Session	Content
1	Introductions
2	Discuss the information letter, sign the consent form, discuss the background information and interview questions
3	Discuss her story ideas I typed up from session 2 and additional story ideas
4	Discuss and edit the story script her son prepared, watch an example digital story
5	Discuss her story script that I edited from session 4, discuss the pictures I printed from Google, discuss recording her story in session 6

Session	Content
6	Record her narrative using her edited script
7	Listen to her edited narration, discuss the pictures I printed for her digital story, and storyboard I created
8	Watch and discuss her digital story in WeVideo, Choose and add music to her digital story, discuss adding sound effects
9	Watch her final digital story, publish her digital story in WeVideo, discuss final interview questions, sign release form, give her USB and DVD copies of her digital story

Session 1

During our first session, the life enrichment manager at Janet's retirement residence introduced me to Janet. I also met her husband. Janet was excited to share her stories, and she was interested in participating in my research. During our introduction, she enthusiastically told stories about living on the prairies in Canada. She also talked about her three sons. Janet was the person who participated in my research along with Leonard who lived at the same retirement residence. I was a little nervous at first about meeting her, but she was so friendly that I was excited to work with her.

Session 2

I went into the common room of her retirement residence to greet Janet. She was excited to see me, and I was excited to see her. She told me though that she couldn't chat too long because the storytelling person was coming to meet with her. I told her that I am the storytelling person, and we both laughed. I realized that she had forgotten who I was since the week before, and I should remember to introduce myself each time we meet. She wanted to walk to her apartment to meet with me. Her husband stepped out while we chatted. I read over the information letter and answered Janet's questions. She wanted to participate in my study and signed the consent form. I also asked her the pre-course interview questions. During her pre-course interview, Janet said that her sons wanted her to tell the story about their move across Canada. Janet said that she wanted to create this story for her children. She did not remember the details of the story, so she did not share the story with me.

Session 3

Before Janet and I met, I typed up some her story ideas from session 2. I showed her a printed copy of her story ideas. She could not read the very large font that I had

used. Janet was having problems with her eye sight, and she has difficulty reading. I read the ideas for her. Her husband also wrote some notes about Janet's background and family, and we read through his notes. She wanted to tell her story about moving across Canada. I encouraged her to ask her son if he could write what he remembers from the trip, and we could use this to help create her story. Janet could not remember much about that trip because she said her memory was declining in the past few years. Janet and I also discussed finding pictures for her digital story. She did not have any pictures because they were lost when she moved. I discussed with her that she could ask her son about her story and pictures. I later learned that Janet and her family had no pictures because they were all lost when she moved.

Session 4

A visiting research scholar through my supervisor came to this session to observe and to help me take field notes. She wanted to learn more about my thesis project. Originally, I thought this was going to be a group session, so I wanted help taking field notes. My second participant, Leonard, did attend the group session because he was meeting with his daughter. Due to the different schedules of my participants, I learned that meeting them one-on-one was more feasible. During this session, Janet brought a typed story that her oldest son prepared for her about their journey from Winnipeg to Vancouver. When I read the entire story, she had difficulty remembering the story. However, when I read the story line by line, she could add comments and make edits. We also watched an example digital story, but Janet' eyesight caused her to have difficulty watching the video.

Session 5

I created her story script before session 5 with the edits and additions she made in session. I printed off her story script in 72-point Calibri font, but she still had difficulty reading her script. I read her script for her, and she made no edits. I also showed her some of the pictures that I found online for her story. I printed off the pictures, one photo per page, so she could see them with her eyesight. She liked the pictures I found so far. I brought the Yeti microphone to show Janet how to record her story. She seemed to have a sense of confidence because she now understood that her story would get recorded. She attempted recording her story today, but she was unable to record her

narration due to her eyesight. She said that she wanted to practice, and I could come back to record her narration.

Session 6

Recording Janet's narration was challenging. Her eyesight and dementia made reading difficult. Her husband told me that they had practiced 2 times the day before and 2 times in the morning. He whispered to me though that it did not go well. I suggested that she ask her husband, a friend, or family member to narrate her story. But Janet wanted to narrate her own story. I did my best to help her with her narration. I found that encouraging her with eye contact, nodding my head, and smiling kept her motivated to finish. At first, she tried to read her story line by line, but halfway through her story we switched to her repeating a few words after I read them. By the end she was laughing and her recording sounded better. Because Janet's recording was broken up with my words that she repeated, I spent several hours editing her narration in audacity before session 7. This session was a bit tiring for Janet, but she was satisfied that she recorded her own narration.

Session 7

Janet was excited to see me when I arrived, in fact she was waiting for me out in the hall. I told Janet and her husband that I had edited her narration for them to listen to. Janet was a bit confused at first and did not remember making the audio recording of her story in the previous session. Janet and her husband listened to her edited narration. They both thought her narration was very good. Finding pictures for Janet's story was time consuming because she no pictures of her own. I printed and brought several pictures from the storyboard I created for Janet's story. Janet and her husband helped to clarify which pictures to use and additional pictures I should find. For example, her husband gave comments about not using the CN rail picture because Janet's father worked for the great northern railway before it turned into the CP rail. She said here eyesight was not good enough to help with video editing in WeVideo, so Janet asked me to add pictures to her narration before out next session.

Session 8

I saw Janet in the common room, and she recognized me when I arrived. We went to her apartment to watch her digital story in WeVideo. She laughed while watching

her story, and she was very happy. We also listened to some of the royalty free music in WeVideo, and Janet chose some music. I told her that I could add some sound effects to her digital story like a seagull. She thought that was a good idea, and I told her I would finish the video editing before session 9.

Session 9

Janet and her husband watched her final digital story, and they enjoyed it. She was chuckling and smiling throughout. Her husband said that it was a great story. Both Janet and her husband seemed very happy with her digital story. I felt so delighted that they were happy. They had no edits. I published her digital story in WeVideo and gave her copies on her USB and DVDs. Janet wanted to complete the post-course interview questions and to sign the story release form. Janet's husband also decided to listen and comment on the post-course interview questions. I learned so much from working with Janet, and she was delightful to work with.

Themes

Based on the categories Robyn and I identified from Janet's post-interview transcript, I determined three themes. These themes illuminate my research question and focus of inquiry "what is the experience of digital storytelling for adults with early stage dementia?" The three themes determined are discussed below. I used excerpts from her pre-course interview and my field notes with reflections to further illuminate some of the themes identified.

Value of Legacy

The first theme that illuminated my focus of inquiry is "Value of Legacy". The codes that determined this theme are: preserved an important memory; memory or gift for their family; family got involved to create story (intergenerational opportunity); reminiscing, remembering the past, bringing back memories (good to remember the past, happy to reminisce); and challenging to recall some memories (could be painful memories).

For Janet, creating her legacy involved her family. Allen (2009) found that when creating a legacy was used as an intervention for people living in palliative care with their family members, family interactions were enhanced. Family members were directly

involved in Allen (2009) to create a lasting artifact as a legacy, but Janet chose to include her family in the creation of her digital story. During her pre-course interview Janet said that she likes to share stories with family including her husband and children. Here is an excerpt from her pre-course interview:

Hollis: Who do you share stories with? [question 12]

Janet: Well my husband, I think, with my husband.... And uh although the boys are, they really like to hear it. I think they'll, just family...To umm they like to hear what I'm when I go back to when I was a little girl and those types of stories. They love to hear those, I build them and I build them up and I build them up, you know.

Janet suggested that the process of creating her digital story allowed one of her sons to get involved. Her sons suggested to Janet that she write her story about their move across Canada from Winnipeg to Vancouver. Her oldest son helped her write her story because Janet could not remember many details from the trip. During her pre-course interview, Janet discussed how she wanted her family to get involved to help her write the story:

Janet: That's right, so I may get to so we'll talk about it and then we'll write my story. I think that's the best way to do it. It's a story for them to keep. That's what they want, Mum to write the story, yeah. My husband will help to, you know everybody will get in on the story that the boys want for future. They can give it to their family and so on...

Her husband even suggested that her their son getting involved to help write her story was the best part of the process. Here is an excerpt from her post-course interview:

Janet: I think umm, I think our oldest son gave you a bit of help you know you could feel that it was an interesting story for the family...yeah and you know we've got four sons but none of them, the others don't know anything about this. Just our oldest son getting into it...Yeah, but umm our oldest son said we should make a story of how we moved in here. How we moved into British Columbia...

Janet enjoyed reminiscing various memories associated with her story. Here is an excerpt from her post-interview transcript:

Hollis: What was your experience creating your digital story?
[Question 1]

Janet: Well I just [chuckle]...it was bringing back a lot of memories, things and happiness.

Hollis: What were the benefits of creating your digital story? [Question 3]

Janet: I am so that's hmm it's a memory that's what it is of us coming here that's how it ends up coming to Coquitlam or Burnaby... [laughter]

She said that her family was going to be very interested in the digital story she created. Here is an excerpt from her post-interview transcript:

Janet: And I think the boys are going to be really, well my oldest son and second son and especially but then the rest of them will have great interest and I can see the boys as, my son and his wife's two boys really enjoying it. Yeah so umm, I think I think it's gonna be a big time. [laughter]

Janet further described how the process of creating her digital story preserved an important memory for her family. This preserved memory allowed Janet and her husband to keep her digital story as a legacy for their family. A legacy is defined by Robb Lucy in his book *How Will You Be Remembered?: A Guide for Creating and Enjoying Your Legacies Now*, as something you can enjoy until the end of your life and leave behind to enhance lives when you are gone. Here are some excerpts from her post-interview transcript:

Janet: ...when I find what you've been doing, I am really quite excited and really it's something to us, so I'm, I'm really um feeling it's a very important umm remembrance for us. And you have created it. And that there [inaudible], and I am thankful to you for that.

Janet: Well I think so my husband because [chuckle] we're going to be able to, we'll keep this and the family can have this.

Generativity

The second theme that illuminated my focus of inquiry for Janet is "Generativity". The codes that were used to determine this theme are as follows: using past teaching skills and showing concern for Hollis (wants to help Hollis, eager).

Generativity is a sense of wanting to pass on to future generations. Erikson (1950) first described generativity in terms of guiding future generations through people passing on to their own children. In addition to people parenting their own children,

generativity also includes older adults passing on to their community by investing in the lives and work of others (Rubinstein, Girling, De Medeiros, Brazda, & Hannum; 2014). Rubinstein et al (2014) developed a framework that describes aspects of generativity through four foci and four conduits. The foci include people, groups, things, and activities. The conduits include historical, familial, individual, and relational spheres (Rubinstein Et al., 2014). Generativity often describes teacher knowledge. Generativity is “when teachers move from teaching skills to passing on their meaning, they become culturally generative” (Schoklitsch & Baumann, 2011). Generative teachers meet the educational needs of their students by integrating new knowledge with existing knowledge to consider the context and needs of their students (Ball, 2012).

Janet wanted to pass on her knowledge as a teacher to me through working on her digital story. During her pre-course interview, Janet discussed how her skills as a teacher taught her how to project her voice while telling stories to an audience. Here is an excerpt from her pre-course interview:

Janet: Some people will stand up to speak and you haven't a clue what they're saying. And it isn't because they speak French and I speak English, that's not it. It's that they don't speak out. When you're talking, your voice has to go there. It's not going to go there, so you have to go there and then everybody around can hear you if you're speaking out. Yes, I'm great for pushing that. Well the first I did, I was a teacher for quite a few years...

When Janet found out that I am a student working on this research for my Master's thesis, she felt motivated to do her best. She wanted to use her skills as a teacher to help me do my best on my thesis. Here is an excerpt from her post-course interview:

Janet: I wanted to know, when I found out it was a school project, I wanted to know that you had the best we could give you. Because I was a teacher, and I know what it was all about. And I wanted you up there, you've worked hard to get here, to do this, and I wanted to see that you get it written well and you can give it, you have to show this to people, you'll be able to do so

She also showed concern for me, and wanted to see me succeed. She offered to help me with any additional questions I might have. Because she used to be a teacher, she also wanted me to get a good grade. I explained to her that my research was not about getting graded, but more about learning about her experience. I was interested

that this process brought out her previous experience as a teacher. Here are some excerpts from her post-course interview:

Hollis: Is there anything else you would like to share?

Janet: I hope you get good marks and so on and attention for it.

Janet: I want to know that you've had good help...if you need any answers to any of things you think about or the questions you're making phone us and ask. Yep, you may as well keep to the top and get the best you can, great.

Relationship with Family Caregiver

The third theme that illuminated my focus of inquiry for Janet is "Relationship with Family Caregiver". The codes used to determine this theme are as follows: would create another digital story with help to write the story; couple dynamic (Janet wanted to create another story but her husband did not want to); confused about the process (got the present story confused with past digital storytelling courses she took); no challenges; process challenges (nervous, frustration); and positive, enjoyable experience.

Janet's husband is her primary caregiver because they live together in their apartment at their retirement residence. Her husband chose to be involved in the process to help Janet create her digital story. Even though my research did not specifically intend to include caregivers in the process, Janet's relationship with her husband played a role in her experience to create her digital story. There is also a large amount of research discussing the relationship between family caregivers and people living with dementia. CIRCA and the digital photograph diary are two methods of digital storytelling discussed in my literature review that incorporated family caregivers (Karlsson et al., 2014; Alm et al., 2007). The relationship between a child or spousal caregiver of an older adult is also defined as "how much the older person and the relationship with the older person is affectively valued by the caregiver" (Lawrence, Tennstedt, & Assmann, 1998, p. 150). A relational family caregiver who is a spouse often define their experiences as a caregiver by focusing on the continued spousal bond or connection (Lewis, Hepburn, Narayan, & Kirk, 2005). The personal relationship between a family caregiver and the person with dementia that they are caring for has many benefits for the caregiver including lower levels of depression, decreased sense of captivity, lower levels of caregiver burden and higher levels of caregiver competency (Lewis et al., 2005; Lawrence et al., 1998).

In Janet's digital story creation process, I described how her husband was involved and helped Janet create her digital story. During her post-course interview, her husband provided his insight about her experience. Janet expressed that she cares about her husband, and he is involved in different aspects of her life. Here is an excerpt from her pre-course interview:

Hollis: Tell me about your life right now. What do you care about?
(Question 2)

Janet: Mmm well I've got nice friends, and I like to umm and my husband will take part and help fill in anytime that my friends play bridge, and they need a person or go for some place for a ride or out for something. He'll either go in nice weather and drive or he goes to fill to in a spot. He will do all those things for me. He's a really good husband that guy. Yeah.

During her post-course interview, Janet often asked her husband for his insight. Here is an example of their couple dynamic during her post-course interview:

Hollis: Do you want to create more stories? Or, would you do this activity again? (Question 9)

Janet: [laughter] Well I can't say no because uh something might pop up but right now I don't know. Can you [her husband] think of anything that would make a good story for her [Hollis]?

Her husband responded by saying no to creating more stories. However, Janet wanted to create another digital story if she had help to write her story, but her husband did not agree. He might have disagreed because he remembered that Janet experienced some challenges during the process. Here is an excerpt from her post-course interview:

Janet: ...but who knows I may find another story. As long as somebody wants to write it. [laughter]

Janet said she did not experience any challenges. Here is an excerpt from her post-course interview:

Hollis: What were the challenges of creating your digital story?

Janet: I don't think so...

While thinking about the challenges she experienced, she became confused about the current process with the previous digital storytelling courses she took. She

thought she had go downstairs like she did for the previous courses, but I came up to her apartment to meet with her. Here is an excerpt from her post-course interview:

Hollis: What were the challenges of creating your digital story?
(Question 4)

Janet: I didn't mind well it started out we were down, I had to go down, that's where, you know and uh it didn't bother me getting up and going down there in the morning, and I got lazy toward the end and I didn't go back again anymore...

Her husband provided insight into some of the challenges, she experienced during the process. During her post-course interview, he described that she felt nervous at times because she wanted to help me with as Janet said, "what you should get." Her husband further described that she experienced some frustration during the middle of the process, but he said there was nothing I could have done to prevent her frustration.

Despite the challenges, both Janet and her husband agreed that the process was a positive and enjoyable experience. They both could not think of any changes that I could make to the process. Here is an excerpt from her post-course interview:

Hollis: Is there anything you would change?

Janet: What about you [her husband] can you think of anything that should be changed at all?

Her husband responded by saying that there was nothing to change. Her husband thanked me for working with Janet and for helping her create her digital story. Janet responded to his thank you by saying "oh my goodness, yes, yes."

4.2.2. Leonard

Introduction

I was referred to Leonard through the life enrichment manager at Thornebridge Gardens retirement residence. Leonard is 91 years old making him my oldest participant. The type of dementia that he was living with was undetermined. Leonard lives alone in an apartment in his retirement residence. Leonard enjoys telling stories to his friends at his residence which interested him in my study. He is very social and enjoys making new friends and telling them stories. When I arrived at his residence, I normally found him chatting with friends and telling them stories. During his pre-course

interview, he joked that he shares stories with “anybody that wants to listen [laughter].” Here is another excerpt from his pre-course interview:

Hollis: How would you describe yourself to yourself at this point in your life? (Question 7)

Leonard: Well trying to keep healthy and happy you know. Meet a lot of people and listen to them and tell them stories.

Staying healthy was very important to Leonard, and he mentioned his health several times throughout his pre-course interview. He did not specifically talk about his dementia during the process, but he often talked about his health. Here are some excerpts from his pre-course interview:

Hollis: What has been important to you over the past few years? [Question 1]

Leonard: My health, I guess. Well I was you know some hobbies and that. I dance a lot.

Hollis: Tell me about your life right now. What do you care about? (Question 2)

Leonard: Stay healthy.

Hollis: When you think about the future, what makes you feel uneasy/nervous/scared? [Question 8]

Leonard: I am just hoping to stay healthy, that’s all. Everything else is obtainable, you know, yeah. I mean you can’t do very much about your own health but your destiny you can plan it yourself.

Leonard had difficulty remembering me when I came to meet with him. I learned to introduce myself every time I met with him. He normally did not remember our meeting times, but I would look around the lobby of his retirement residence to find him, or I called his phone number. By the end of the process, I was excited because he remembered me. One day, I went to meet with my other participant who lived at the same retirement residence, and Leonard recognized me. He asked me how I was doing. Here are some excerpts from my field notes on Tues., Feb. 14, at 3:45 pm and Thurs., March 23, at 3 pm:

Hollis: I introduced myself again, and I sat down on the sofa next to him.

Hollis: I found Leonard in the kitchen chatting with some of his friends. Now he remembers me when he sees me, and when I asked him if he wants to go work on his story he said yes!

While talking with Leonard, he repeated some things several times. He often repeated the countries he travelled to and the languages he spoke. I wrote in my field notes on Fri., Feb. 3, at 2:15 pm that “He repeated the list of countries that he used to live in several times.”

Leonard scored a 21/30 on the MMSE. His score is within the estimated mild or early stage dementia scores of 21-25 (Perneckzy, Wagenpfeil, Komossa, Grimmer, Diehl, & Kurz, 2006). Leonard completed his high school degree. He did not have an email, and he had no access to a computer, smart phone, or tablet. He claimed to have used the internet a few times with his daughter. He self-identified as having no skill level using a computer or the internet. This was exciting because he had the opportunity to learn about a completely new skill. He had some experience writing in a journal.

Digital Story Creation Process

Table 4.5. Timeline showing the sessions and content for the creation of Leonard’s digital story.

Session	Content
1	Introductions
2	Discuss the information letter, sign the consent form, discuss the background information and interview questions
3	Discuss his story ideas I typed from session 2, ask him to look for pictures
4	Discuss the pictures in the photo album Leonard brought, watch an example digital story, write notes to create a new story based on the photos he brought
5	Help Leonard choose his pictures from his album and digitize them, discuss and edit his story script that I typed from session 4, create a storyboard
6	Edit his story script, discuss and edit his storyboard, record his narrative using his edited script
7	Listen to his edited narration, use his storyboard to add pictures to his digital story in WeVideo
8	Continue to use his storyboard to add pictures to his digital story in WeVideo
9	Find additional pictures for his story using Google Images
10	Find additional for pictures for his story using Google Images, choose music
11	Choose music and add music to his digital story
12	Add photos I took of Leonard to his digital story, publish his story in WeVideo, final interview questions, sign release form, give him USB and DVD copies of his digital story, complete the MMSE

Session 1

During our first session, the life enrichment manager at Leonard's retirement residence introduced me to Leonard. Leonard and I chatted to get to know each other. I was amazed at his rich life experiences that he briefly discussed. He was born in Poland but he moved to Italy because he was in the army. He travelled to several different countries while in the army. Then he lived in the Yukon producing explosives, and he went to the West coast to show the Natives Americans and people mining for gold in Alaska how to use explosives. Based on our initial conversation, I encouraged Leonard that he had many excellent stories to tell, and I asked him if he would be interested in my project. He was interested, and we agreed to chat more about it in our next session. We chatted for about 10 minutes because he wanted to go watch a fiddler play.

Session 2

When I arrived, Leonard was in the country kitchen chatting with two of his friends. I introduced myself to Leonard, and I told him that I was interested in talking with him more about stories today. He said okay, and we found a quiet place to chat at a table in the event room. He discussed being a dancer his whole life, and he loves dancing. We read over the information letter, and I answered Leonard's questions. He wanted to participate in my study and signed the consent form. I also asked him the pre-course interview questions. During his pre-course interview, his answers were brief. He did not tell any stories during the interview. After the interview, I asked him a question about being a dancer. He then told me his story about being a glider pilot. I learned that Leonard had many interesting stories to tell, but I needed to ask him good questions. I typed up the story Leonard told about flying his glider plane before session 3.

Session 3

I met with Leonard to look over the story notes about flying glider planes that I typed up from session 2. I asked him additional questions about his story, and I took notes. I typed up an edited version of his story before we met in session 4. Because Leonard was one of the first people that I worked with, I was still learning how to best help him create his story. When I asked him if he wanted to use this story about glider planes for his digital story, he was unsure. I learned to ask questions about his current

story ideas to help him create his story. Leonard and I also discussed how to gather pictures for his story about flying glider planes. He said he could ask his daughter for some pictures, and I said I could also look for some pictures and videos online.

Session 4

Before we met for our fourth session, Leonard had to cancel three sessions in a row. He cancelled the sessions for various reasons including his daughter visiting, a doctor's appointment, and not feeling well. I worried that he would fall behind in his progress. When he came to meet me for our fourth session, he forgot we wrote his story about glider planes. He brought his photo album when he came to meet me which was useful because he discussed the stories associated with each picture. His photo album was fantastic, and he wanted to tell a different story using pictures from the album. The album discussed his time in North Africa, Italy, and England during World War II. He said that he took and developed all the pictures in a tent using his own camera during World War II. Figure 4.1 shows some photos from Leonard's photo album that he used in digital story. Creating a new story would put us behind in our progress, but I was excited that Leonard wanted to tell this story. I also showed him an example digital story, so he would have a better idea of what we were creating. For my future participants, I learned to show them an example digital story in our first or second session. Watching an example digital story earlier in the process gave them a better idea of what we were creating. Leonard mentioned the importance of his time during World War II in his pre-course interview. If I had asked him to elaborate on this story during the interview, I could have helped him to write his story about World War II earlier in the process. I learned from this experience for when I worked with future participants

Figure 4.1. Photos from Leonard's World War II photo album.



Session 5

Before session 5, I typed up notes for his new story based on how he described the photos in his album. When I met Leonard, I asked him to get his photo album, so we could digitize his photos. He had some difficulties finding his album, so I went to help him. He enjoyed talking about his photos and choosing ones to use for his story. We started to create his storyboard by selecting photos to use for different parts of his story. We also edited and added to his story script. I incorporated his edits and additions into his story script before we met for session 6. He seemed to enjoy the process now, and I was surprised that he wanted to include a picture he made with cut-outs of his six girlfriends he had while in England after the war.

Session 6

Leonard and I read through his final script with the edits and additions from session 5. He made a few edits. After we made the edits, we used his script to record his story narration. We sat together on his sofa in his apartment where he was comfortable. Leonard held the microphone while I held my laptop that was connected to the microphone. I was surprised that Leonard read his story all the way through with only minor mistakes. We continued to discuss the pictures from his photo album and edit his storyboard. I edited his narration before session 7.

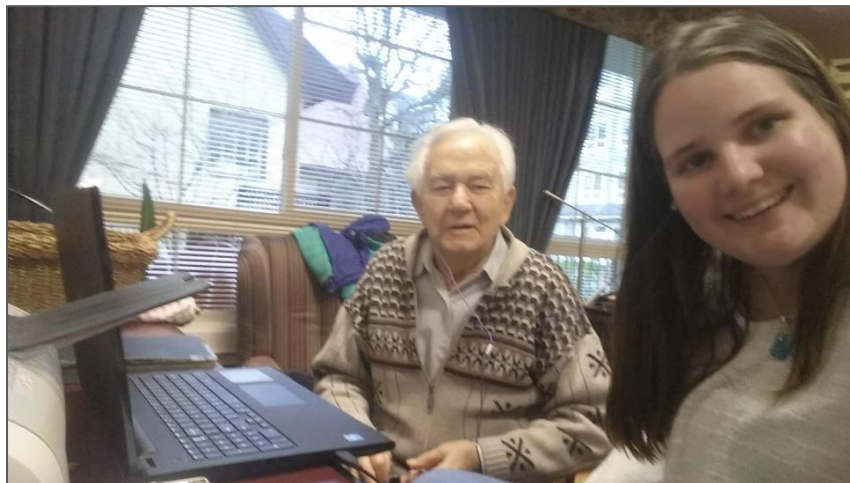
Session 7

When I met Leonard, we listened to his edited narration. We started to add pictures to his story using the storyboard we created. Because his story was based on the pictures in his photo album his storyboard was basically completed because he created his story by looking at an image and describing it. Leonard seemed a bit bored because we already knew the pictures to add. He was mainly just sitting and watching. After this session, I learned to ask him questions to verify which picture he wanted to use to keep him engaged. I thought that if I brought a mouse he could learn how to use WeVideo, but I learned in future sessions that he preferred to be the director while I controlled the mouse.

Session 8

We continued to add pictures to his digital story using his storyboard. Leonard was engaged during this session, and I started to learn how to include him in the process to keep him engaged. He did not want to use my laptop, but he enjoyed selecting the pictures. I was excited to see that Leonard had an opinion as to which picture should go first and last in his story. He took initiative, and he started to lead the process more. Figure 4.2 shows Leonard and I working together on his digital story.

Figure 4.2. Leonard and I working on his digital story using my laptop.



Session 9

I had to leave early today, so we looked for a few additional photos for his story using Google Images. Leonard seemed to enjoy our session, and I could tell that he was a bit sad when I had to leave early.

Session 10

When I arrived, I said hi to Leonard and asked him if wanted to go work on his story. He said sure. He seemed happy. This made me feel excited because he remembered me, and he wanted to work on his story. We went up to his apartment because he thought it would be better than the library in his retirement residence where we had been working. We found a few additional pictures for his story on Google, and we started to choose some music for his story. I continued to ask him questions about which pictures to add to keep him engaged. Leonard enjoyed directing the process.

Session 11

Leonard recalled songs that he wanted to include in his digital story, and he had fun listening to the songs and singing along. I found a YouTube video with the Russian music Leonard wanted. Even though we couldn't use this music in his story, he loved listening to the music. We sang along together to the music. It was a very fun moment in our process of working together. We added some public domain Italian and Russian music, but the quality of the Italian music did not match his story. I learned that taking time to enjoy the process was important even if we had to work together for additional sessions. At the time, I did not know that I could use songs that were not in the public domain if properly cited in my participant's stories. Before our final session I found some music in the public domain that was higher quality. Leonard was also taking more control of his digital story. He suggested we use the Polish word for the "the end" for ending of his digital story credits.

Session 12

During our final session, I was excited to see that we had formed a bond throughout this process. I suggested that I could add a picture of Leonard with his photo album to his digital story, and he agreed. We also added a picture of us working together. I showed him the transitions I added between his pictures as well as the different Italian music I found. He listened to his digital story, and he seemed very happy. He wanted to complete the post-course interview questions, MMSE, and to sign the story release form. At the completion of our final session, I wrote in my field notes from Tues., March 28 at 3 pm, "We hugged goodbye and it was an amazing experience working with Leonard."

Themes

Based on the categories Robyn and I identified from Leonard's post-interview transcript, I determined one theme. This theme illuminates my research question and focus of inquiry "what is the experience of digital storytelling for adults with early stage dementia?" The theme determined is discussed. I used excerpts from his pre-course interview and my field notes with reflections to further illuminate the themes identified for Leonard's experience.

Facilitated Reminiscence

The theme that illuminated my focus of inquiry is "Facilitated Reminiscence." The codes that determined this theme are: reminiscing, remembering the past, bring back memories (good to remember the past, happy to reminisce); challenging to recall some memories (could be painful memories); initiating another story; proud and equivocating on future participation.

As discussed in my literature review, reminiscence is a "process which occurs in stages, involving the recall of early life events and interaction between individuals" (Dempsey et al., 2012). Reminiscence is classified into three categories, and Leonard's experience is an example of simple reminiscence (Pinquart & Forstmeier, 2012). Simple reminiscence includes "mainly unstructured autobiographical storytelling with the goal of communicating and teaching or informing others, remembering positive past events, and enhancing positive feelings" (Pinquart & Forstmeier, 2012). Other forms of digital storytelling discussed in my literature review that facilitated reminiscence include the multimedia biography and digital photography diary (Crete-Nishihata et al., 2012; Karlsson et al., 2014). One benefit of the SFU Elder's Digital Storytelling Course is reminiscence and reflection upon life (Hausknecht et al., 2016b).

Leonard suggested that the process of creating his digital story allowed him to reminisce. Here is an excerpt from his post-course interview:

Leonard: ...well it was kind of good to reminisce again, you know, looking back on the past.

Throughout his post-course interview, Leonard focused on how creating his digital story allowed him to remember the past. He described his overall experience as a process of reminiscing. Here is an excerpt from his post-course interview:

Hollis: What was your experience creating your digital story?
[Question 1]

Leonard: Well it was looking in the past again, you know. It reminded me of a lot of things.

For Leonard, reminiscing was beneficial because it was an enjoyable experience and allowed him to remember positive memories. He said that looking into the past made him feel happy. Here is an excerpt from his post-course interview:

Hollis: Can you describe how you felt throughout this experience?
[Question 6]

Leonard: Well it was nice to look back into the past, you know. Yeah happy to see the past again.

One benefit of reminiscence is communication (Woods et al., 2018). For Leonard, reminiscing allowed to converse and interact with other residents in his retirement residence. As discussed in my literature review, other methods of digital storytelling that facilitated reminiscence including CIRCA and the digital photography diary facilitated conversation between the person living with dementia and their family and caregivers (Karlsson et al., 2014; Alm et al., 2007). In one nursing home, reminiscence promoted social interaction among residents through sharing stories in an interactive gallery of postcards with photos and memories written on them (Li, Lin, Kang, Hu, Hengeveld, Hummels, & Rauterberg, 2018). Reminiscing also benefitted Leonard by allowing him to connect and interact with other residents. He enjoyed reminiscing while describing his digital story to one of the residents at his retirement residence. Here is an excerpt from my field notes on Tues., March 14 at 3 pm:

Hollis: When we were almost finished adding the pictures to his digital story another resident came up and was interested in his story. Leonard was excited, and he described his photos to the other resident. The other resident was interested in his digital story, and she seemed like she wanted to also make a digital story. Leonard's self-confidence seemed to increase while talking to this resident. Another resident also came over, so there were two residents looking at Leonard's digital story. I couldn't help but feel proud and excited for Leonard that he was getting positive attention from the other residents who were curious about his digital story.

During his pre-course interview, he also stated that he likes to connect with new people by telling them stories. In his pre-course interview he stated:

Leonard: [I] meet a lot of people and listen to them and tell them stories.

Reminiscing while telling stories is something that was important to Leonard during his pre-course interview. He stated that the purpose of telling stories is to allow others to know your past. Here is an excerpt from his pre-course interview:

Hollis: What do you think is the reason (purpose) of telling stories?

Leonard: Well some people to know well your past like you know, where you've been, what you've done and what was the excitement and how many people you met.

Leonard used his photo album with the pictures he took and developed during World War II to reminisce about his past experiences. Figure 4.3 shows Leonard with his photo album.

Figure 4.3. Leonard holding his photo album with his pictures during and after World War II.



Leonard found reminiscing beneficial even when the process brought back a mixture of positive and negative memories. Here is an excerpt from his post-course interview:

Hollis: What were the benefits of creating your digital story?

Leonard: Yeah! It reminded me of all the good things and the bad things.

Hollis: Any other benefits?

Leonard: No, just looking back on the past.

The process also brought back memories of music he listened to. He had fun reminiscing and singing along while working on his digital story. Here is an excerpt from my field notes on Thurs., March 23 at 3 pm:

Hollis: ...I found a YouTube video with the Russian music Leonard wanted...he loved listening to the music, and we sang along together to the music. It was a very fun moment in our process of working together.

He described that looking in the past was also challenging for him in this excerpt from his post-course interview:

Hollis: What were the challenges of creating your digital story?

Leonard: Any challenges? Not really, you mean difficulties or? Well, I have to think back. Looking back in the past.

Reminiscence often includes a discussion of past events and experiences with prompts and triggers such as photographs, household and familiar items, smells, music, archived sound recordings, and questioning (Woods, Spector, Jones, Orrell, & Davies, 2005). For Leonard, watching his completed digital story also served as a trigger for his memory of additional stories. At the completion of Leonard's interview, he initiated another story about flying glider planes. He had just finished watching his completed digital story when he suggested another story. He did not remember that his original story during our process was about his experience flying glider planes. Here is an excerpt from his post-course interview:

Hollis: Is there anything else you would like to share? [Question 10]

Leonard: No. I would like to put in there I used to be a glider pilot from the age of 14. I used to fly my own gliders. I don't mean just the hand glider, the full aircraft without engine, you know.

Leonard has many meaningful stories to tell. He mentioned some of his other stories during his pre-course interview:

Hollis: Can you share a story that is meaningful to you?

Leonard: Is what? A meaningful story. Well I you know when I visited my relatives in France and Europe. I travelled and visited them and we go over the past and you know. I reminisce things and visit a lot of people that I knew in my younger days. Go to Hawaii a lot almost every year to get a tan. [laughter] travelling yeah, I like travelling.

Even though Leonard did not say he wanted to create another digital story, he did suggest his future participation. He suggested that he had more stories about when he moved to Canada. Here is an excerpt from his post-course interview:

Hollis: Do you want to create more stories? Or, would you do this activity again?

Leonard: Well I don't think there is much else to add. You it would have to be you know, the only stories I would have would be about Canada you know, yeah.

4.2.3. Max

Introduction

I was referred to Max through the recreation manager at AgeCare Harmony Court Estate. Max is 85 years old, and he has lived with a diagnosis of Alzheimer Disease for 5 years. Max lives with his wife in an apartment in the independent living side of Harmony Court. I initially met Max during my supervisor's Xbox Kinect game study that was conducted at Harmony Court. Max was very interested in any benefits that my research may have for people living with Alzheimer Disease.

Max's dementia was relatively stable as I worked with him. Some of my participants seemed to have fluctuations with "good" and "bad" days, but Max's cognitive function was stable throughout our sessions. However, this might be because I worked with Max for six sessions which is the shortest number of sessions that I worked with any of my participants. Max tried to keep active despite his dementia. In the pre-course interview he stated:

Hollis: What matters most to you now? What do you worry about now?
[Question 5]

Max: Well my family of course...I would say my ability for movement. You know so I like to keep on walking and moving around. Well and of course that I would uh second with that is that my uh

dementia would um be relatively stay stable so I won't become completely out.

Max wanted to keep a positive attitude about having Alzheimer Disease, but he acknowledged that his disease was causing deterioration. He wanted to live one day at a time. During his pre-course interview he stated:

Max: Well I would say I can see I am close to the end. So everything goes down, physically, mentally. How fast it's gonna go, I don't know and nobody knows. But I cannot look at anything anymore to say well oh this is gonna get better or so on. So, you, I think, you live really, what they would call it, moment to moment livin'...Also another thing, I don't think it should overwhelm you but on the other hand you want to also face reality. I mean you don't deny it, never helps.

While I was working with Max, his dementia caused him to repeat things multiple times during our conversations. He repeated aspects of his story several times during his pre-course interview. He repeated his age when Rotterdam was bombed in his story. This excerpt from his pre-course interview shows the repetition of being eight years old while he was telling his story:

Max: When I was only 8 or 10 and I was playing on the street, playing outside the front of the house and my Dad called me in and within a matter of 15 minutes I heard all this screaming and the whole inner city was in flames. That's the bombing in 1940. That's how they declared war, and we were the first targets so the whole inner city was wiped with flames and just on a date. So, I then I learned that nothing in life is certain, anything can happen. So, I had no idea, what I was only 8 years, but well I had heard that there was war, I think. But I didn't have any idea yet of politics or at depth, I was only 8 years old. But I was playing on the street and all at once I see this, I hear the sounds of the bombs and boom, boom, boom, boom. Those kind of things you never forget, you know.

When we created his script, I tried to reduce his repetitions by combining aspects of his story. His final story still included some repetition, and his wife mentioned that repetition is something Max struggles with. Here is an excerpt from my field notes describing his wife's reaction to his digital story on Thurs., April 27 at 2 pm:

Hollis: We went back to his apartment and we showed his wife his digital story. His wife was impressed with the effects in his digital story, but I could tell that she thought he repeated himself a bit in the story.

When Max forgot our meeting time, his wife helped to remind him. During one meeting, Max forgot to wear his shoes, and I reminded him to get him shoes. He mentioned that this is one of the symptoms of his dementia.

Max scored a 23/30 on his MMSE. His score is within the estimated mild or early stage dementia scores of 21-25 (Perneczky et al., 2006). Max is highly educated. He completed his four-year engineering degree at an engineering technical school, and he worked as an engineer until he retired.

Max's relationship with wife was an important aspect of his life. His wife assisted him with finding photographs and materials to use for his digital story. Figure 4.4 shows a picture of Max and his wife that he used in his digital story.

Figure 4.4. Max and his wife in Holland after they got married.



I called his wife to remind her of my meetings with Max. During the pre-course interview, Max self-identified a beginner level of skill using a computer and the internet. Max and his wife own a PC desktop computer, and he uses the internet a few times a month. His wife used their computer frequently. His wife also owned a smartphone, and Max used the phone once a month for phone calls. He did not have access to a tablet. He had some experience writing in a journal, but he said his wife was more experienced with storytelling because he was an engineer. During our initial sessions, Max was not confident with his storytelling skills as discussed in his pre-course interview:

Max: No, I'm not a storyteller...I think why we are a good match, my wife is very much more in all the literature and that's never been main. I came up and studied engineering, you know been on that end. But it worked out fine. Because I also, I have no abilities in that way. I'm not a good writer or I can't be a good painter, but that doesn't mean that I don't have any interest. So, I still like a good movie or read something that is very interesting or and do that kind. But it is not something that I pursue as hobbies.

Max's wife and I assured him that the purpose of my project was to help him learn how to create his story. I observed that Max had a natural ability for telling stories that he did not realize. When I first met him, he told me his story about being in the war with many details, and I was captivated by his story. His wife also told me that Max was a good storyteller. Here is an excerpt from my field notes on Tues., April 11 at 2 pm:

Hollis: I went back with Max to his room to meet his wife. She had some questions, but she seemed to be excited about the project. Max wanted her to help with the story he said she has lots of experience with storytelling. But we explained to Max that the purpose of my project is to teach him how to create a digital story, so no experience is needed. I arranged my next meeting with them and left. I felt excited to work with Max because he was very friendly and he seemed excited about my project.

Digital Story Creation Process

Table 4.6. Timeline showing the sessions and content for the creation of Max's digital story.

Session	Content
1	Introductions, give him the consent form and information letter to read over, watch an example digital story, meet his wife
2	Sign the consent form, discuss the background information and interview questions, discuss the photos he brought, digitize pictures
3	Discuss the pictures Max brought for his story, digitize pictures
4	Edit and discuss his story script that I typed from sessions 2 and 3, digitize his pictures
5	Record narrative using script, discuss the photos and book Max brought, discuss his storyboard, choose sound effects and additional pictures, digitize his pictures
6	Published his digital story in WeVideo, final interview questions, sign release form, give him USB and DVD copies of his digital story, complete the MMSE

Session 1

After I explained that my research involved storytelling, Max immediately shared one of his most vivid memories about being a child in Rotterdam during the bombings in World War II. I also showed him Leonard's digital story as an example digital story. Leonard's story about World War II reminded Max of more details from his own World War II story. Max was unique because most of my other participants thought about their story topic using the pre-course interview questions. However, Max naturally told his story before discussing the interview questions. Because he established his story in the first session, his digital story creation process was accelerated. He finished his digital story in six sessions which is the fewest number of sessions for any of my participants. I gave Max the information letter and consent form to read over with wife. After we finished meeting, Max brought me back to his apartment to meet his wife. His wife seemed excited that Max wanted to participate in my project. His wife is interested in storytelling, so she wanted to learn more about digital storytelling.

Session 2

When I arrived at Max's apartment, initially he had forgotten about our meeting. He still wanted to meet with me, and he had gathered some photos for us to look through. Max signed the consent form. I asked Max the pre-course interview questions. Max and I enjoyed talking with each other, and our interview was conversational. During his pre-course interview, he could not recall any meaningful stories to share. I mentioned the story that he shared when I met him in session one. He said that was an important story, and he shared his story about growing up in Rotterdam during World War II. I was surprised that Max initially said he could not recall any stories. I learned the importance of remembering and recalling story topics that the person I am working with shares. After Max's pre-course interview, he showed me the pictures he brought. I asked him to tell me more about them. I was very excited that he had pictures we could use in his digital story. He gathered them early in the process which also helped to accelerate his process. After he finished describing his photos, I digitized them. I felt much more comfortable working with Max because I had already gone through the process with two other participants. Before our third session, I transcribed his story that he told. I combined parts of his story to make it more congruent. I was surprised that after the second session we already had a script to work with.

Session 3

I was planning to read through and edit Max's script during our third session together. However, Max brought more photographs that he wanted to look through with me. Using his pictures, Max retold his story he described in sessions one and two. I edited his script using the additional details from session 3 before we met again in session 4. I told him that we could read over his script in our next session, and he joked that he will make sure it is truth.

Session 4

We read through Max's script and make edits today. I thought that he would only have minor edits and that we could also record his narration. However, we spent most of the time working together editing his script. I am happy that Max had so many edits and that he cared about his script. He did not record his narration today. He wanted me to combine his edits and reprint the story for him to make it easier for him to read. After we finished editing his script, we digitized some additional pictures that he collected. Before we met for our fifth session, I incorporated Max's edits into his script. Max was not comfortable using his computer, so I did not email his script to him to edit. I printed his script for him to edit when we met in person.

Session 5

Max and I met for 2 hours during our fifth session. We got a lot accomplished for his digital story during this session. Max brought additional pictures that I digitized. Max then read through his script and made a few minor edits. He then read his story, and I audio recorded his narration for him. His narration recording went smoothly and quickly. Next, I showed Max the storyboard I created using his pictures. I also found some additional pictures online to describe aspects of his story before this session. Max helped me to find additional pictures online that more accurately represented his story. Max had a clear idea of what pictures to use. One example is the picture I found of a bomber in World War II. He said this picture was not a bomber, so we spent time looking for another picture together. Another example is the supply truck that took him to safety during the night. He was not satisfied with any pictures that we found, so he drew a top view of the truck and the small slit of light that passed through the taped headlights. I re-created his drawings in PowerPoint, and we used them in his digital story. I was amazed that he remembered and cared deeply about which pictures to use in his digital story.

Once we found the pictures he wanted, we then looked for some sound effects to use in his digital story. We spent time listening to different sound effects for a bomb dropping and for the planes flying overhead because Max wanted to use realistic effects. Max wanted me to put his digital story together using WeVideo. We were a bit rushed because we wanted to finish during the sixth session. He wanted me to do most of the video editing using the images and sound effects that we collected before we met in session 6. Max had no preference for his music, so I chose something that fit his story.

Session 6

I edited his narration and completed the video editing using his storyboard before we met in session 6. During our final session, Max watched his digital story. He had some suggestions related to his script, but we had already changed his script to reflect these edits. He was satisfied with the images and music in his digital story, so I published his story for him in WeVideo. He wanted to complete the MMSE and post-course interview questions. I also gave him USB and DVD copies of his digital story. Throughout the process of working with Max, he thought I was more interested in the historical content of his story. I explained to him that I was interested in his experience during this process. I would have liked to include him more in the video editing process. We went back to his apartment and showed his wife his digital story. She applauded at the end. She said that she would be interested in creating a digital story. His wife was very happy with his digital story, and I observed that Max really appreciated her positive feedback. Max was excited because he could give a copy of his digital story to his future generations to keep, and it was a way of preserving his legacy.

Themes

Based on the categories Robyn and I identified from Max's post-interview transcript, I determined three themes. These themes illuminate my research question and focus of inquiry "what is the experience of digital storytelling for adults with early stage dementia?" The three themes determined are discussed. I used the pre-course interview questions and my field notes with reflections to further illuminate some of the themes identified for Max's experience.

Value of Legacy

The first theme that illuminated my focus of inquiry is “Value of Legacy”. The code that determined this theme is: a memory or gift for their family.

Max expressed the process of creating his digital story allowed him to create a memory from his life that he passed onto his family. He even suggested that this memory will be passed onto future generations of his family. A legacy is defined as something you can enjoy until the end of your life and leave behind to enhance lives when you are gone (Lucy, 2017, p. 11). As discussed in my literature review chapter, one benefit of the SFU Elder’s Digital Storytelling Course is creating a legacy (Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b). One benefit of the StoryCorp’s storytelling program for people living with dementia was also legacy creation (Savundranayagam et al, 2011). Max described how creating his digital story allowed him to preserve an important memory for his family as a legacy in this excerpt from his post-course interview:

Max: You’re really getting an expert telling something of your life which you can pass on and to my children again. And they will so, that’s the nice part of it. It’s excellent to, it can be distributed to the family, and they might keep it again and their children, somebody like that you know. So, if I have it some copies of it, then I have four children so I can give each a copy so they have something to show again. So, before you know it you’re well known, you can work in Hollywood [laughter].

In my field notes during my final session with Max on Thurs., April 27 at 2 pm, I wrote:

Hollis: Max was excited because he said he could give a copy of this story to his future generations to keep and it was a way of preserving his legacy.

This theme also relates to family being important to Max. During his pre-course interview, Max shared that his family was important. He expressed he cares about his family and hopes to never forget them. Here is an excerpt from his pre-course interview:

Hollis: What do you care about in your life right now? (question 2)

Max: What I care about? Well, I care about my wife of course. Well I have family you know umm that’s basically it. I have no particular attachment to a great deal of things you know because the changes, you know.

Hollis: What are some things you hope you never forget? (question 3)

Max: What I will never forget? You hope that uh that I my relation...with my wife and children. I think family is always central.

Learning about Technology

The second theme that illuminated my focus of inquiry for Max is “Learning about Technology” The codes that used to determine this theme are as follows: interesting process to see the digital story created; engaged in the process of making the digital story; no challenges; positive, enjoyable experience; relying on Hollis to write another story; doesn’t want to use computer; and process of working together was good

As I discussed in my literature review chapter, cognitive and physical decline contribute to the difficulties older adults experience when using computers and can create a barrier for them to learn how to use computers (Damodaran et al., 2013). One of the difficulties that people living with dementia experience when using technology are “limitations in the participants’ knowledge of the technology and its potential” (Nygård & Starkhammar, 2007). Through our digital storytelling process, Max enjoyed learning about the potential of the technology used to create his digital story. Even though dementia most often impairs the learning and memory cognitive domain, people living with early stage dementia are still capable of learning new skills or knowledge in some cases (Larson, 2015; Bier, Provencher, Gagnon, Van der Linden, Adam, & Desrosiers, 2008; Camic, Tischler, & Pearman, 2014). However, transfer of knowledge or skills to everyday contexts is limited for people living with dementia (Bier et al., 2008). Max enjoyed learning about the technology and process used to create his digital story rather than learning how to use the technology. I provided Max with the necessary support to create his digital story because people living with dementia often benefit from having additional support when using familiar and new technologies such as computers (Nygård & Starkhammar, 2007). As discussed in my literature review chapter, one benefit from the SFU Elder’s Digital Storytelling Course is life-long learning and learning something new (Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b).

Max enjoyed being involved in the process of creating his digital story. An important part of his experience was learning about how to create a digital story. Max discussed he was interested in the process used to create his digital story in this excerpt from his post-course interview:

Max: Oh learning the process of you know, or not quite learning. Seeing let's say the modern capabilities of making you know of creating a story with a computer. Yeah this I wouldn't see as a benefit as such because I don't learn anything from it, it's meant so that for me well I find it a very interesting process.

Max was engaged in the process of making his digital story. He believed that one of the benefits of his experience was being involved in the process. Max worked as an engineer, so he was very interested in the technical aspects of creating his digital story. Here is an excerpt from his post-course interview:

Hollis: What were the benefits of creating your digital story. [Question 3]

Max: Oh certainly learning the process of making or making it or showing or to show something the memorable experiences that you get an idea of the possibilities. You know that's what I get out of it. It's not that I know the whole process of course like you do but it gives me an idea you know how.

Hollis: So being kind of like the director or producer?

Max: Yeah. Being involved in it for me, the thing was the processing of the story.

Max enjoyed being involved in the process of creating his digital story, and he did not feel like he experienced any challenges. Max discussed that being involved in the process was an enjoyable experience in his post-course interview:

Max: But I found the, this was just as much work for you, this has been an interesting experience for me to see what how that little bit of what is involved and what you're aiming for and so on. What makes it for enjoyable. I don't see this as I have made a big commitment I have to sit down so tough [he was joking]. I really enjoyed this so hope you're satisfied with it.

Max was involved in creating his digital story, but his involvement was to an extent. Max did not want to create his digital story on his own, but he enjoyed learning about the process and being involved in the technical aspects. He said that he would rely on me to help him write his story if he made another digital story because he was not confident with his writing abilities. He stated in his post-course interview:

Max: For uh, I wouldn't write the stories, I'm not a writer.

I transcribed Max's story that he told me, but he still thought I was going to write his story. He felt like his involvement in writing his story was limited. Here is an excerpt from my field notes on Thurs., April 20 at 10 am while we were editing his script:

Hollis: He didn't seem to realize that I had transcribed his direct telling of his story. Because he kept talking about how I was going to write the story. I emphasized that this is Max's story and it should be told in his own words. I am only interested in the process of digital storytelling.

He did not learn how to make the video edits on my computer, but I provided the necessary support to make the video edits under his direction in WeVideo. During his post-course interview, he stated:

Hollis: So maybe you would like to maybe learn more about the details of using the computer?

Max: Yeah but I can that is again a whole thing in itself. And it changes all so much and so quickly.

Max suggested the support I provided throughout the process was sufficient when he expressed the process of working together was good. Max and I worked together to create his digital story which involved him in the process. Max stated in his post-course interview:

Hollis: About the process of working together?

Max: Oh, that's fine, sure that's great, good.

Facilitated Reminiscence

The final theme that illuminated my focus of inquiry for Max is "Facilitated Reminiscence" The codes used to determine this theme are as follows: reminiscing, remembering the past, brings back memories (good to remember the past, happy to reminisce); story's theme is difficult (war); and life experience as a child effects current life.

I discussed and defined reminiscence in my literature review and in Leonard's case study (Dempsey et al., 2012; Pinquart & Forstmeier, 2012). I also discussed other forms of digital storytelling that facilitated reminiscence and reflection upon life (Crete-Nishihata et al., 2012; Karlsson et al., 2014; Hausknecht et al., 2016b). Reminiscence is further defined as "the person is seen as reflecting on life, seeking to make sense and

find meaning in a life lived” (Woods et al., 2018). Reminiscing throughout the process allowed Max to reflect upon this memory from his childhood that gave meaning to his life.

Max’s digital story is based on one of his strongest memories from his youth. Verbal memories are often affected first, but emotional or traumatic memories are preserved until the later stages of the disease (James & Jackman, 2017). Figure 4.5 shows a picture of Max as a child in Rotterdam that he used in his digital story.

Figure 4.5. Max as a child in Rotterdam.



He grew up in Rotterdam during World War II. Max said that one of his experiences during our process brought him back to this memory. Here is an excerpt from his post-course interview:

Max: ...and something like this brings me back to a memory but you know for making this and so on it's a whole new...The whole world changes, that's hard to define like I said you grow from a very traditional way of what was certain in a time zone before the war there was, pre-war you had the what do you call it, when the economy wasn't that great so you it was were really some tough years between the first and second world war. But that's something in itself and that's something my parents experienced, you know so. And yeah from then on I found for me this not so much only the story for me has been very

meaningful that having been in that situation fortunately when I was 12 I was out of it.

Max's story dealt with the difficult theme of war. When I asked Max how he felt throughout this experience, I was referring to the process of creating his digital story. However, Max made sure to clarify that his experience during the war and creating his digital story were different. Max described the difficulty of writing a story about war in his post-course interview:

Hollis: Can you describe how you felt throughout this experience?
[Question 6]

Max: A new experience...very good, it's not of course of the story not when you write about the subjects.

The process of creating his digital story gave Max an opportunity to reflect on how his life experience as a child effects his current life. Max told his story, but he also took time to reflect on how his story effects his current life. Here is an excerpt from his post-course interview:

Max: From time and after my studies and work there have been a tremendous amount of changes and this is a continuous process...Having experienced that it stays with you so you and you sometimes have difficulty with this consumerism what there is now and things there all everybody wants to have everything and the best. Sure, we wanted to have basically the same thing and at this I am not saying were going the wrong direction. But I think there will be, we have come again set-ups in various areas we could very well have a war again. What's developing in the South America and so on and other areas, it's certainly not unique in that way. Unfortunately, we never seem to learn.

During our session on Tues., April 18 at 2 pm, Max reflected on how his story influences his current life by allowing him to be thankful:

Max: This is for me, I enjoy ...[inaudible]and think back about those things and see how fortunate you are...I've said that from then on I have been thankful for everything that I have received. And that's really, it changed your whole attitude.

4.2.4. Anne

Introduction

I was referred to Anne through the Alzheimer Society of B.C. She is 62 years old, and she has lived with a diagnosis of frontotemporal dementia for 17 years. She lives with her mother in an apartment. Anne was the first person that I worked with who had frontotemporal dementia. One thing I learned while working with her is that her dementia caused her to struggle to find the words she wanted to say. This excerpt from my field notes from our meeting on Monday, July 10 at 2 pm describes her difficulties communicating:

Hollis: I met Anne in the atrium area outside the doors of the Richmond Brighthouse Library. Anne said she was feeling tired, and she was having a hard time talking. I could tell that she was having a bad day. When she tried to speak she would freeze in the middle of her sentences and she would forget what she wanted to say. She became frustrated when she wasn't able to communicate her feelings. I encouraged her and said to not worry. This is a contrast to her normally friendly, cheerful and articulate self. We had a brief session because she was not feeling well, and we only looked through the outline that I created based on our conversation from our previous session...I felt sad when I saw the harsh reality of Anne's disease. That her brain was deteriorating evident through her struggle to communicate.

Anne seemed to experience "good" and "bad" days with her ability to communicate. On a good day, she would take some time to articulate her thoughts. She would hesitate as she was speaking and think of the words she wanted to say. Anne had learned to cope with her difficulty finding the words to say, and she accepted when she could not articulate her thoughts. Here is another excerpt from my field notes when Anne was having some hesitancy communicating, and what I learned from working with her on Thurs., June 22 at 2 pm:

Hollis: Anne is very friendly and is very fun and easy to talk with. I could tell that she was struggling more than the previous time I met her to speak and find the words. She would hesitate but then would find the words. Working with Anne is really redefining my view on people who are living with different types dementia. She still able to live a very functional life, and she can make an impact on the people around her.

Anne scored a 28/30 on her MMSE. Her MMSE score is above the estimated mild or early stage dementia scores of 21-25 (Perneck et al., 2006). According to Anne she took the MMSE several times at her doctor, so she was familiar with the test. Anne is highly educated because she previously worked as an emergency room nurse. These factors might have contributed to her high score. Anne is independent, and she often took transit or walked to meet with me to work on her digital story. Here is an excerpt from my field notes talking about her independence before I met her on Friday, June 16:

Hollis: She is also able to independently navigate the city. She suggested that she actually prefers to be mobile, so she did not want to meet in her home. She decided that it would be best if we met up at the cafeteria of the Vancouver Cancer Agency downtown Vancouver because...she is familiar with this place.

During the pre-course interview, Anne self-identified an intermediate level of skill using her computer and the internet. She owns an iMac and uses the internet every day. She communicated with me over email and through texting on her smart phone. She does not use a tablet. Her skill level with her computer and the internet initially surprised me because the three previous participants I had worked with had either none or very little experience with computers. Her experience with storytelling included writing in a journal after she was first diagnosed. Here is an excerpt from my field notes on Fri., June 16, describing my initial reaction to her use of technology:

Hollis: Initially I was surprised when Anne sent me an email personally saying that she was interested in my project. The fact that she can communicate through email suggests that her ability to use technology is at a higher level than any of my participants so far.

Digital Story Creation Process

Table 4.7. Timeline showing the sessions and content for the creation of Anne's digital story.

Session	Content
1	Introductions, give her the consent form and information letter to read over, watch an example digital story
2	Sign the consent form, discuss the background information and interview questions, complete the MMSE
3	Edit and discuss her story ideas I typed up from session 2, discuss the articles and links she sent me
4	Edit and discuss the outline for her story,
5	Discuss and edit her script, give her WeVideo log-in information, gather images and create storyboard (happened throughout the process)

Session	Content
6	Record narrative using the script
7	Listen to her edited audio recording, add pictures and edit in WeVideo
8	Music and sound effects, edit in WeVideo
9	Publish in WeVideo, final interview questions, sign release form, give her USB and DVD copies of her digital story

Session 1

During our first session, Anne naturally shared parts of her story with me even though we were meeting for the first time. The fact that my project is on storytelling caused her to share informally, so we could get to know each other better. Hearing about her life was fascinating. She was an advocate for people with dementia since 1999. She was diagnosed with frontotemporal dementia in 1999 at the age of 43. Anne started a support group at the Alzheimer's Society in Vancouver, and she was the first speaker with dementia at the Alzheimer Society of Canada's national meeting. She previously worked as an emergency room nurse. I was excited as I talked with her because her experience and insight will be very valuable as feedback for my project. I showed her another participant's digital story as an example. After watching the digital story and hearing more about my project, she was excited to create her own digital story. She seemed to have a very adventurous life with many stories. Before signing the consent form and information letter, Anne asked to take some time to read them over before our next session. She also asked to have a copy of the pre-course interview questions. She wanted to look at the questions ahead of time because her dementia causes her to draw a blank if she is just asked a question.

Session 2

During our second session, Anne signed the consent form and asked me questions that she had. She also completed the MMSE. I asked her the pre-course interview questions. I asked Anne if she had any meaningful stories to share. I was surprised that she was not sure how to answer. Because she had just finished telling me stories about her experience as an advocate for people living with dementia. I asked her to share more about her experience as an advocate and that helped her to remember additional stories. Before the third session, I typed Anne's story ideas from the pre-course interview. Anne seemed excited about the process, and she went home and a few hours later emailed me several articles and links to dementia resources.

Session 3

During our third session, Anne read over the notes for her story that I typed up. We used these notes as a starting place to continue creating her story. She wanted to create a story about advocacy that would benefit a large audience. She did not have much to add to the notes from our previous meeting, but she did help to clarify the notes. I asked her some questions about how she used her advocacy work to combat the stigma associated with dementia. Anne also brought a suitcase full of articles, photos and DVDs from her advocacy work. I digitized these materials. Figure 4.6 shows a picture of Anne when she graduated nursing school that she included in her digital story. These materials were extremely helpful, and they helped to accelerate our process of creating her digital story. Anne brought most of the media, we used to create her digital story. We just had to finish creating her script. Using the audio recording from our third session, I typed up an outline for Anne's story script.

Figure 4.6. Anne graduating from nursing school.



Session 4

In our fourth session, Anne was having a difficult day dealing with her dementia. We looked through and discussed the outline I created. Anne wanted me to email her the outline for her story, so she could change the wording and add onto it to create her script. I was excited that she wanted to take control of her story. Anne's ability to use technology and communicate over email helped to expedite her script writing.

Session 5

During session 5, we discussed and edited her script. I also gave her the WeVideo log-in information. Before session 5, Anne emailed me her script with the changes she had made. This surprised me because she was my first participant to do this. I was happy that Anne took ownership of her story and to be in her own words. She said that she had written things the way she wanted. We also worked on her storyboard, and I digitized more materials that Anne brought. Anne took the lead and made suggestions for where was best to use her pictures. Anne was having a good day, and we got a lot accomplished. Before session 6, I incorporated Anne's edits from session 5 into her script. I emailed Anne her script, and she made some additional edits to her story. Anne is an excellent editor. She said after our meeting that she had a friend with familial dementia who taught her how to edit.

Session 6

For session 6, we met at SFU Vancouver Harbor Center. I booked a room to record her narration, but the room was quite noisy due to the people in the room next door and construction. Anne felt frustrated while recording her script. The noise kept interrupting her while she was reading her script. We finished recording her narration, and she was satisfied. I felt frustrated for Anne that she came to SFU, and the conditions were not the best. She was understanding of the situation. I assured her that her narration would be okay, and we can always rerecord if needed.

Session 7

Before we met in session 7, I edited Anne's narration. During session 7, we listened to her edited audio recorded narration. Anne said that she was satisfied with the recording. We then started to upload her images to WeVideo and add them to her digital story. Anne took the role as the director, and she knew exactly which photos she wanted to add. She is in control of her story and knows what she wants more than some people I worked with previously. She said that WeVideo was like making a PowerPoint presentation.

Session 8

Before we met again for session 8, Anne wanted me to continue adding her pictures and videos according to her storyboard. When we met for session 8, Anne

brought a CD with the music she wanted to use. I found the same music on YouTube to use for her story. We continued to edit her video by adding more pictures. Anne seemed excited that her digital story was coming together.

Session 9

Before our final session, I added her music and credits to her digital story. When we met, Anne noticed that the text in one part of her story was not scrolling correctly. I fixed this and published her digital story. While her story was publishing, I asked her the post-course interview questions. I also gave her USB and DVD copies of her digital story. I was emotionally touched when Anne said that she was thankful to have this video to be able to still communicate when one day she will not be able to communicate. Working with Anne was delightful, and we enjoyed chatting. We hugged goodbye.

Themes

Based on the codes Robyn and I identified from Anne's post-interview transcript, I determined three themes. These themes illuminate my research questions and focus of inquiry "what is the experience of digital storytelling for adults with early stage dementia?" The three themes determined are discussed. I used excerpts from her pre-course interview and my field notes with reflections to further illuminate some of the themes identified for Anne's experience.

Engagement in the Process of Creation

The first theme that illuminated my focus of inquiry is "Engagement in the Process of Creation" The codes that determined this theme are as follows: digital storytelling is not a collective activity because it's a personal journey; comfortable process; fun process; positive, enjoyable experience; understood steps to create digital story; wouldn't change the process; would repeat the process; would recommend digital storytelling to others; and relying on Hollis to put the digital story together.

As discussed in my literature review, the Patient Voices Digital Storytelling Project for people living with dementia discussed themes centered around engagement of participants with their story, with doing, and with others (Stenhouse et al., 2013). Their themes of engagement with story and doing are similar to Anne's theme of engagement in the process of creation. Anne's engagement was also different from Stenhouse et al.

(2013) because her process did not involve other participants. Anne expressed that the process of creating her digital story was an individual experience. She thought the process is best used one-on-one outside of her support group setting due to the personal nature of each story. Stenhouse et al. (2013) involved participants working on their digital story in a group setting, but it was not a support group for people living with dementia. She acknowledged that certain support groups could use digital storytelling as a group activity for a collective story. Here is excerpt from her post-course interview:

Hollis: Is it a good idea to do this activity in support group meetings?
[Question 12]

Anne: I don't think so because well it depends what the theme is. Like umm I think it would be hard for everyone to do their individual story, but if it was a collective voice of how people thought about one different theme or you know that might be a good idea. Well just to add on to that. Not my support group as it is right now. I've been since you know since 2001 when I first was involved in starting the support group here in Vancouver. I've seen a lot of people. There's been a lot of different dynamics. So, I guess I want to qualify that by not the group I am in right now but maybe in other groups.

Different elements contributed to Anne's engagement during the digital storytelling process. She understood the process for creating her digital story. Understanding the process suggests she was engaged because she wanted to learn how it worked. Here is an excerpt from her post-course interview:

Anne: ...like each step we did moved onto to the next step. I could see that process happening, and umm it all went really smoothly.

Different elements that contributed to her engagement throughout the experience including feeling positive during the process through having fun. Anne mentioned comfort, fun, and positivity several times as she reflected on her experience. Here are some excerpts from her post-course interview:

Anne: Umm, I felt very comfortable...

Anne: Well it was a good experience in that umm it was fun gathering up the information and putting it together and seeing the finished product.

Anne: It was fun.

Anne: It was really a positive experience, thank you.

Because of her engagement throughout her experience, she discussed that she would not change the process. Here is an excerpt from her post-course interview:

Anne: No, I think it was really good.

Anne also said that she would repeat the process if she had an opportunity and that she would recommend this digital storytelling experience to others. Wanting to repeat something and recommending the experience suggests that she was engaged. Anne discussed these elements in her post-course interview as follows:

Anne: Yeah sure if I had a theme I could work on. Yep I'd like to do it again.

Anne: Oh yeah you know, everybody has a story to tell in their lives so umm and this is a good way of doing it if people wanted to get that story out then this process really worked well to do it.

Similar to Capstick et al. (2016) and Stenhouse et al. (2013), her engagement in the process relied on overcoming challenges through the relationship between the participant (Anne) and the researcher (Hollis). Anne relied on me to do the video editing for her digital story under her guidance. She appreciated my role helping her assemble the pieces of her digital story in WeVideo. Here is an excerpt from her post-course interview:

Anne: Because you were so good at putting it all together for me. You know I didn't have to do the computer work. Umm which I wouldn't have been able to do so that was good.

At first, I was a bit surprised that she did not want to do the computer work. Anne was very proficient at using email and editing her story in a Word document. Anne saw my role was to handle the computer work for her to make the process easier for Anne.

Generativity

The second theme that illuminated my focus of inquiry for Anne is "Generativity." The code used to determine this theme is as follows: happy to contribute to something meaningful.

As discussed in Janet's care study, generativity is a sense of wanting to pass on to future generations. Generativity also includes older adults passing on to their community by investing in the lives and work of others (Rubinstein et al., 2014). Anne

wanted to invest in my thesis research to pass on her knowledge. For Anne, working with me was meaningful to her because I am a student. She found value in helping me complete my thesis. At Anne's final story showing event, she told me and the group that initially she was hesitant to participate. But she liked the idea of contributing to a student's thesis. Although, Anne said she got way more out of the experience than I got out of it. Anne was wonderful to work with, and she taught me about working with people living different types of dementia. I feel very thankful for her contribution to my thesis and having the privilege to work with her. Anne's quote from her post-course interview discusses my role in her experience:

Anne: It makes me very happy to have been able to help a young person (you) with their education – especially with something as important as preparing their thesis.

My role was an important part of her digital storytelling experience because she sent me an email after her interview saying that she wanted to include that quote.

Dementia Awareness-Raising

The final theme that illuminated my focus of inquiry for Anne is "Dementia Awareness-Raising." The codes used to determine this theme are as follows: ability for others with dementia to learn from their story; digital story is object of pride; digital story gives a voice, preserves a legacy, overcame a disability; and organized past memories and artifacts into something tangible.

The World Health Organization (WHO) defines dementia awareness-raising as "people with dementia, their families and society in general, aiming to improve their understanding of dementia and to change public attitudes and practices" (World Health Organization, 2012, p. 92). Raising awareness about dementia has many benefits including improving lives of people living with dementia and allowing them to seek care sooner by reducing the stigma associated with dementia (World Health Organization, 2012). Awareness-raising about dementia is one strategy suggested by the WHO to reduce the burden of dementia throughout the world (World Health Organization, 2012). As discussed in my literature review, Capstick et al. (2016) found one benefit of creating digital stories was increased social citizenship. This was evident in the participants' creation of digital stories that are featured on websites and at film festivals (Capstick et al., 2016). The participants also attended events featuring their digital story and served

on a panel as experts for their work (Capstick et al., 2016). Increased social citizenship although not explicitly stated could promote awareness by increasing their community's understanding about dementia. Anne shared her digital story to increase understanding by educating people about dementia and to give them hope. She worked as an advocate for several years after getting diagnosed with early onset dementia. Her digital story features her advocacy and awareness-raising work, and the changes she inspired throughout the world.

For Anne, creating her digital story gave her a sense of pride for what she had accomplished in her life. Anne stated in her post-work interview:

Anne: ...seeing all those things that I probably could be very proud of in my life. Having it all there in in a video. That was a good thing.

For Anne creating her digital story also gave her an opportunity to organize her memories and artifacts into something tangible. Her finished digital story allowed her to see everything in one place. Her digital story also allowed others to benefit from hearing her story. Anne stated during her post-course interview:

Anne: Umm well I've never had everything, I've had these bits and pieces of information in a box and now it's all together on one video. And that's uh, I really like that bit. People can see it all together and umm that's good.

During one of my sessions working with Anne, she brought many materials that she collected during her advocacy and awareness-raising work for people living with dementia. I was excited to see that she had so many different artifacts including articles, videos, and photos to use in her digital story. On the same day that I digitized her materials, she discussed how her digital story could overcome the stigma associated with dementia. Her digital story could impact people's views on what it's like to live with dementia. This excerpt from my field notes from Mon., July 3 at 1:30 pm further explains this idea:

Hollis: Anne brought a small suitcase full of articles and photos from her advocacy work. I digitized her materials. After I finished digitizing her DVD, I went to the patio where she was sitting with her dad...I was very inspired to see that Anne who has dementia was visiting and taking care of her father who also has dementia. When I asked if digital storytelling would be beneficial for overcoming the stigma associated with dementia

she said '[digital storytelling] can have such a broad group of people watching it and you don't know. Umm so that's a good thing that a lot of people could be looking at digital storytelling especially your age group. And umm so your generation and if they talk to it about to other generations then that's a good thing yeah'.

Anne's digital story impacted her life by giving her a voice to share her story with others after her dementia progressed. Through this experience, Anne preserved her legacy to pass on and to overcome her disability. Her digital story will have an impact on other people when they watch her story to learn about Anne's life. Here is an excerpt from her post-course interview:

Anne: Well for me it is because I know that I will eventually probably lose my ability to speak, so then I won't be able to tell my story that well verbally. But there it is digitally.

For me this was one of the most impactful quotes from my research. In my field notes and reflection journal on Fri., Aug. 18 at 12 pm, I wrote:

Hollis: I was really emotionally touched when Anne said that she was thankful to have this video to be able to still communicate when one day she will be not able to communicate. Working with Anne was a delight, and we enjoyed chatting about the work and fun travelling Anne gets to do.

Anne also discussed how losing her ability to talk was something that made her nervous. Here is an excerpt from her pre-course interview:

Hollis: When you think about the future, what makes you feel uneasy/nervous/scared? [Question 8]

Anne: That would be that I would be unable to talk and unable to walk which would be the end point in my disease. And you know not necessarily come together but. And I know that my muscles are weaker, I'm having problems talking...

Anne's story also had an impact on other people living with dementia. Anne wanted people living with dementia and their caregivers to learn about she coped with dementia. Here is an excerpt from her post-course interview:

Anne: No, I don't think it's changed my life. Umm but well people see it well maybe it will. I am hoping I can change other people's lives and make it easier for them to deal with the diagnosis and their family members or loved ones that have it and umm and

to get for support and advocacy, support for people with early stage dementia.

During her pre-course interview, Anne defined stories as learning experiences. I was not surprised that she created a digital story that impacted people living with dementia. Here is an excerpt from her pre-course interview:

Hollis: What do you think is the reason (purpose) of telling stories?
[Question 13]

Anne: Yes, I think that they can be great learning experiences.

Hollis: Is there anything else you would like to share? [Question 14]

Anne: Yeah, I think learning experiences but also can help people feel better about themselves and others.

I also wrote about Anne's desire to tell a story that would have an impact on other people in my field notes on Mon., July 3 at 1:30 pm:

Hollis: She said that just listing her accomplishments would not be helpful for other people. She wanted to create a story about advocacy that would benefit a large audience.

4.2.5. Chris

Introduction

I was referred to Chris through the Alzheimer Society of B.C. He is 68 years old, and he has lived with a diagnosis of vascular dementia for 9 years. He lives independently in his home. Chris was the only person I worked with that lived on his own. His digital story explained how he coped with living with dementia. When I met Chris, I was surprised that he coped so well living on his own. Here is an excerpt from my field notes on Thurs., June 22 at 4 pm:

Hollis: He lives by himself and I was surprised about how independent he is. Talking to him for only one hour was already changing my perspective on what it's like for some people to live with dementia and that I should not stereo-type people. He seemed very excited about working with me.

Chris participates in many activities, and he wants to contribute to his community. Here is an excerpt from his pre-course interview:

H: Tell me about your life right now. What do you care about?
[Question 2]

C: Well, I am still, I am still capable of looking after myself. I make myself very useful by doing lots of volunteer work. And I seem to be, I am capable of contributing to whichever organization that I deal with and that in that capacity.

I was amazed that Chris volunteered in so many different roles around the city. During his pre-course interview he described his different volunteer roles:

Chris: Two days ago, they [Alzheimer Society] just sent me umm one of these documents, living alone. They wanted to update it...I have mentioned about my mentorship program with UBC...They invited me to come back...And this January umm another project that I got selected was, the representative for British Columbia for the Alzheimer Society of Canada....And then umm last two months ago we finished one of the projects with the city of Vancouver...It's a document that is about 30 pages on... how do you train the people at city hall to deal with people with dementia...So our last project is this umm the leadership group. The Alzheimer's society of BC created this program...They want to consult people with dementia before they create policies because a person who knows most is the person with the illness...And the one I am really happy about is the one I mentioned earlier about the Tourism Vancouver...like if tourists come in here they want to maximize their visit so we would advise them on where to go and what to do.

Chris is very meticulous and documents his experiences to help him remember parts of his life. Here is an example of how Chris documented lowering his A1C score for diabetes from my field notes excerpt on Wed., June 28 at 5 pm:

Hollis: When we first sat down to talk, Chris showed me his binder where he documented how he lowered his A1C count on his own. He said that he is a very meticulous person and he likes to document things so he can back up what he is saying. He had print outs and pictures of several books that he had read....

I also learned that his documentation allowed him to tell stories and educate people on health and dementia. Here are some excerpts from his pre-course interview:

Hollis: Do you like to tell stories? If yes, what kinds of stories do you like to tell? [Question 11]

Chris: No not really, but when the occasion comes I able to tell a rich story.

Hollis: Yeah, I can tell by the way you document things. In a way that's storytelling.

Hollis: What do you think is the reason (purpose) of telling stories?
[Question 13]

Chris: Sometimes, you can tell stories to make a point. Or sometimes there is something that I want to emphasize. Or what happened. Sometimes umm people says how do you deal with issues. Then I tell for example getting lost I I went to the [inaudible] Bay for Eagle watching one time. My friend sat in a corner, and I said I will go to McDonalds which is only 4 blocks away...I got lost, and I couldn't go back to where they were. So, I treat it in such a funny way that they don't dwell over it kind of thing. So those kind of stories tell you about hey this person has challenges kind of thing. So, stories to highlight the need for understanding kind of thing.

I observed that Chris used alternate words to communicate. If he could not remember a word, he used a different word or described the scenario. While trying to remember the word "dialogue", he used the phrase an "opening for people." He also used the word "video" before remembering "digital storytelling." Here is an excerpt from his post-course interview:

Chris: So that is interesting enough for me. So in a way you are you are the video, this digital storytelling create openings for people, a dialogue a better word for other people, so that's great.

Throughout the process, Chris remembered my name and recognized me. He was confused once on Canada Day for our first day of filming. Here is an excerpt from my field notes on Tues. July 4 at 8:30 am:

Hollis: Chris mentioned that when I went to film him on Sat. he was very excited because he thought I was one of his previous support group leaders. But then he realized it was me when I took out my camera.

Chris decided to not complete the MMSE because he said his doctor administers his MMSE every year. Here is an excerpt from my field notes on Wed., June 28 at 5 pm:

Hollis: ...Chris decided that he did not want to complete the MMSE with me because he does it with his doctor every year, and he said that this is personal information...

Chris completed a bachelor of arts in mass communications and English. He self-identified an intermediate level of skill using his computer and the internet. He owns a

PC desktop and uses the internet every day. He communicated with me over email frequently. He did not own a cell phone or tablet. His experience with storytelling included telling stories. He was very skilled at using his computer, and he edited his photos for his photography hobby on his computer. He expressed interest in learning about WeVideo. Here is an excerpt from my field notes on Thurs., July 6 at 8:45 am:

Hollis: Chris asked me how easy WeVideo was to use, and I told him that it is easy to learn. Chris said he wants to learn how to use WeVideo and do his own video editing.

Initially I was excited that he wanted to learn how to use WeVideo, and I wrote in my field notes on Thurs., July 11 at 11:30 am:

Hollis: Chris said he wanted to get access to WeVideo, and I told him that I would create an account for him. I feel excited that Chris is so eager to learn how to use WeVideo.

However, when we started working together, Chris felt more comfortable as the director. He decided what he wanted to include in his digital story, and I helped him execute his vision in WeVideo.

Digital Story Creation Process

Table 4.8. Timeline showing the sessions and content for the creation of Chris's digital story.

Session	Content
1	Introductions, give him the consent form and information letter to read over, watch an example digital story, discuss his story ideas
2	Sign the consent form, discuss the background information and interview questions, discuss his story ideas, discuss his filming schedule
3	Filming at Canada Place
4	Filming at Capilano Suspension bridge, Cleveland Dam, Kirin dim sum restaurant, Marine Building, Vancouver art gallery, Chinatown including Hasting's Sunrise Market; discuss his story outline; discuss his filming schedule and locations
5	Filming at his walking group downtown Vancouver, Holy Rosary Cathedral church, Harbor Center lookout, Queen Elizabeth park including the Bloedel Floral Conservatory with birds and the rose garden, Steveston including the Cannery; discuss his story script and video clips via email
6	Filming at the Alzheimer Society of BC office and leadership meeting, Granville island, and Aquabus; gather pictures
7	Filming at the Tourism Vancouver Office near Canada Place, give him USB with video clips to look over
8	Discuss the video clips he wants to use

Session	Content
9	Discuss his segment outline and use it to help him write his script, digitize some photos and artifacts
10	Filming at his house, look over the images Chris collected
11	Discuss and select music, find a twinkling stars animation, use his script to record his narrative
12	Listen to his edited narration, re-record narration segment, introduction to WeVideo, search for a twinkling stars animation
13	Edit in WeVideo (add pictures, videos, music)
14	Edit in WeVideo
15	Edit in WeVideo
16	Publish in WeVideo, post-course interview questions, sign release form, give him USB and DVD copies of his story

Session 1

Chris requested that we meet outside the Canada Place food court because he is more comfortable talking in a relaxed environment. We introduced ourselves, and he told me about several projects that he is involved in. He was excited about my project, and I gave him the information letter and consent form to read. He was the first person to tell me that he was excited that I contacted him. We watched an example digital story, and he immediately told me that he wants to create something different. He wanted to create a digital story about living with dementia, and he wanted to use video clips from his daily life. He has a free pass to different tourist attractions in Vancouver because he volunteers at Tourism Vancouver, so I would follow him to these places and film him. He said then he would create a voice over for these video clips. He is very enthusiastic and has so many good ideas. I was excited to work with him.

Session 2

Chris read through the information letter and consent form. I answered his questions, and we discussed the pre-course interview questions. He requested that I email him the interview questions before our meeting, so he was prepared to answer them. He also discussed another idea for his story about health, but he decided to use his original idea. We incorporated some of his practices for healthy living into his digital story. I feel like Chris is really reversing many ideas that I had about a person living with dementia. I felt amazed that Chris is so independent and functions on his own and has a very positive attitude. Chris discussed some locations where he wanted to film for his digital story. The first location was on Canada Day while he was volunteering at Canada

Place. After our meeting, he emailed me a tentative schedule of all the places he wanted to film for his digital story.

Session 3

When I arrived at Canada Place, I walked around looking for the tent where Chris was volunteering. I was nervous at first because I did not have experience with filming. I borrowed a video camera from the SFU education department. I practiced filming before I met with Chris. I found Chris handing out Canada 150 flags. He gave me some tips about where and how to shoot the video with the information tent sign in the background as he was handing out flags. I felt like Chris knew more about filming than I did. I tried to get shots from different angles. It was very fun, and Chris seemed to really enjoy it. I went home and watched the shots. After filming him I felt more confident because the videos looked good. Before we met for session 4, Chris sent me an email with more suggestions for filming locations. I was excited to help and support him create the digital story he wanted.

Session 4

During session four, Chris and I travelled to several locations around Vancouver to film. We met at 8:30 am and finished at around 2:30 pm. At first, I felt a bit nervous because I was not experienced with filming, but Chris knew what he wanted. He directed me to shoot various videos. Figure 4.7 shows a photograph that Chris took of me filming him on Capilano Suspension Bridge. Despite going to many locations, I was surprised that Chris had lots of energy. We ate dim sum for lunch and discussed the outline I created for his story based on an email he sent me. Chris wanted me to audio record an excerpt for his story before he forgot it. We also discussed his filming schedule and additional locations.

Figure 4.7. Filming session at Capilano Suspension Bridge.



Session 5

Chris emailed me before our meeting to tell me which locations he wanted to film. We went to several locations across Vancouver on transit. We worked together from 8:45 am to 3 pm. He was very specific about the shots he wanted—he told me where to stand, what to shoot, etc. I am excited that Chris is taking ownership of his story. Chris had lots of energy, and he took a power nap while we were on the bus. Before session 6, Chris sent me several emails discussing ideas for his script outline and video clips.

Session 6

At the Alzheimer Society of BC, we staged a leadership meeting for his video. We then went to film some shots at Granville Island. He was very excited about filming him leaving on the Aquabus for the ending of his digital story. He gave me a USB with some photos he gathered for his digital story. Chris is a photographer, so he used his personal photos for his digital story. Figure 4.8 shows some of Chris's personal photos that he included in his digital story.

Figure 4.8. Chris's personal photos that he included in his digital story.



Session 7

Today Chris wanted me to film him volunteering at the Vancouver Tourism Office. I gave Chris a USB with some of his video clips because he wanted to look through them. I told Chris that he had many video clips, so we should start focusing on his story script.

Session 8

Chris and I saw each other on the Skytrain, so we decided to have an impromptu meeting. We discussed the video clips to use for his digital story. He told me that some of the videos were great, and they were clearer than he expected. I was excited that Chris liked several of the video clips.

Session 9

I went to Chris's home to work on his script. He is comfortable meeting in his home. Chris emailed me an outline of what he wanted to include in his digital story. I asked him questions to elaborate on each point. Chris was not feeling his best today, and he seemed to be distracted and having a harder time finding the words to say. He ended up not having a shortage to say and talked for about 40 minutes total. He said that it would be better to have more for his story then we can cut it down. I audio recorded the session and typed what he said after the session to help him write his story script. He also showed me some photos and artifacts to include in his digital story.

Session 10

Today was our final filming session. Chris wanted me to film him doing various activities at his home. We also looked at some of the photos Chris collected on his USB for his digital story. Chris said he had not been feeling well the past few days because he sprayed Febreze in his house, and he is allergic to it. I noticed that Chris was lower in energy than normal, and he was struggling more than usual to find the words when talking. After our session, Chris said he saw his digital story coming together. He was excited about this. We spent several sessions working together, so we developed a friendship throughout the process. Figure 4.9 shows a picture of Chris and I taking a break and enjoying Halo Halo together. He also told me that he wanted to record his narration at home where he felt the most comfortable.

Figure 4.9. Chris and I enjoying Halo Halo together.



Session 11

Chris wanted to use a twinkling stars animation in his digital story. We spent some time figuring out the best way to include this in his digital story. I saw Christmas lights on one of his chairs that he had covered in a black garbage bag. He wanted me to film the Christmas lights up close to simulate stars twinkling in the sky. I was amazed at his creativity! I told him that we could find a twinkling stars animation online if he preferred because his Christmas lights were colored. He agreed. We also recorded his narration. He recorded several takes for his segments. He listened and rerecorded to improve. To help him make his narration sound more natural I asked him a question and maintained eye contact as he read his script. He selected some of the music he wanted

to use, and I loaded the music onto my USB. Chris is so creative and has amazing ideas for his digital story. I am his assistant helping him execute these ideas. His digital story is taking additional sessions because he has so many ideas.

Session 12

I edited his narration before we met in session 12. We listened to his edited narration, and we rerecorded the final segment due to the construction noises in the background. Chris was curious to learn how WeVideo works, so I gave him a brief introduction to the program. I was amazed that Chris cares about the details, and how he knows exactly what he wants to include in his digital story. We spent time looking for a suitable twinkling stars animation, but we could not find what he wanted.

Session 13

Chris was in his garden chatting with some friends and picking figs from his tree when I arrived. I felt like Chris's fig tree allowed him to remain connected to his friends and contribute to his community through sharing what he grows in his garden. We went inside, and Chris had prepared a huge plate of figs for us to snack on during our meeting. I was so amazed. Chris rearranged the furniture, so we could both look at my laptop on a small table. We started editing his video by adding his pictures, music, and videos. Chris was the leader, and he knew exactly what he wanted. I followed his direction. The internet was working slowly. The videos took a long time to upload, so we worked on the first and final segment of his video. Chris was very happy with our progress and seemed to have fun working on his video.

Session 14

We continued to edit his digital story in WeVideo. Unlike other participants, Chris wanted to direct me during the entire video editing process. I did not work on the video editing outside of our sessions together. I was excited that Chris wanted to take control by directing the video editing process, but this also meant that we needed to meet for additional sessions. We found a suitable twinkling stars animation to use, but he asked to change the background to black. He wanted to add small details to his digital story, but these details took additional sessions to complete. Filming so many locations also increased the number of sessions needed to complete his digital story. He watched his digital story at the end of our session, and he said he was getting goose bumps while

watching his story. This made me so happy and excited because at first Chris was hesitant about my project, but now he was so excited.

Session 15

We continued editing his digital story in WeVideo. He was a bit frazzled because he had printed his updated script for his new video clips and music selections, but he left it at the Alzheimer Society office when he went there for a meeting. We added and changed his music selections. He also wanted to add a picture of us working together to his digital story. Before met for our final session, Chris asked me to email him the interview questions to look over.

Session 16

Chris watched his final digital story, and he made a few comments for edits. Part way through watching his digital story he got excited and said, “we are basically professionals.” I laughed internally because I felt far from being a professional, but this made me feel so happy that Chris enjoy his experience. He commented on the music ending abruptly after the Aquabus, but I assured him that I did my best to smooth it out. He was overall very happy with his digital story, and I published his digital story in WeVideo. I asked him the final interview questions and gave him USB and DVD copies of his digital story. I forgot to print his release form, so I met with him an additional time where he read over the release form and signed it. Even though Chris’s process was time consuming, I learned so much from him and was happy that he was so satisfied with his digital story. After our final meeting, his digital story underwent two additional revisions with minor edits that Chris wanted. He also contacted me to meet an additional time after our final session because he wanted to add onto his post-course interview.

Themes

Based on the categories Robyn and I identified from Chris’s post-interview transcript, I determined three themes. These themes illuminate my research question and focus of inquiry “what is the experience of digital storytelling for adults with early stage dementia?” The three themes determined are discussed. I used excerpts from his pre-course interview and my field notes with reflections to further illuminate some of the themes identified for Chris’s experience.

Value of Legacy

The first theme that illuminated my focus of inquiry is “Value of Legacy.” The codes that determined this theme are as follows: memory or gift for their family; digital storytelling provides a way to record thoughts and a way to be remembered before the disease progresses; would recommend digital storytelling to others; and digital storytelling is not a collective activity because it’s a personal journey.

As discussed in my literature review, a legacy is defined as something you can enjoy until the end of your life and leave behind to enhance lives when you are gone (Lucy, 2017), and storytelling and digital storytelling provide opportunities to create a legacy (Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b; Savundranayagam et al, 2011). Chris discussed how his digital story provided him with a memory that he can share and leave with his grandsons. This memory allowed him to leave a legacy for his grandsons to remember him. Here is an excerpt from his post-course interview:

Hollis: Is there anything else you would like to share? [Question 10]

Chris: This one I can share and leave to my grandsons. And they say here I was 10 years after my diagnosis...I like to think I have captured a slice of my existence...where I am still active I am having fun kind of thing.

I discussed Chris wanting to leave his digital story as a legacy for his grandsons in my field notes on Mon., Aug. 18 at 7:30 pm:

Hollis: I felt emotional when he said that would allow him to preserve a memory for his future grandchildren’s children.

Chris recommended digital storytelling to others because it provides a way to be remembered. He also discussed that digital storytelling provides a way to record your thoughts before the disease progresses. Here are some excerpts from his post-course interview:

Hollis: Is there anything else you would like to share? [Question 10]

Chris: I recommend that people who feel like they want a something for they can be remembered by like now.

Hollis: Would you recommend this activity to others? Why? Or, Why not? [Question 11]

Chris: Oh, definitely because especially with people with dementia you don't know how progressive. Some of them could be progressing fast, some of them could be slower. So, the sooner they do something to record their thoughts, their ideas or their wishes...it's better to do it that way so whatever happens uh tomorrow then they have already written down what they wish uhh how they wish to be remembered or something like that.

Chris also recommended that creating a legacy is a personal journey and not a collective activity. During his post-course interview, he stated:

Chris: So if you capture a one on one and the person most likely they will open up and you will capture the essence of what they really wanted to be. If you are in a group situation uh umm there is always that sense of oh he's saying something, I can do better and then you don't get the real story.

Building Trust

The second theme that illuminated my focus of inquiry for Chris is "Building Trust" The codes used to determine this theme are as follows: reason for feeling hesitant to share his story at first (stereotyping); process challenges (making a coherent story, privacy, trust); felt safe to share story because they trusted Hollis and felt comfortable talking with Hollis; video editing (creation) process challenges (time limits); video editing process (improvising, helped, interesting); authentic experience; wouldn't change the process; and fun process.

One of my goals to maintain credibility discussed in my methods chapter was to build trust with my participants through prolonged engagement and persistent observation (Moen, 2006). Some ways to build trust between in a participant-researcher relationship include reciprocity throughout the process, "empathy, credibility, rapport, and breaking down power relationships, to increase researcher trustworthiness by demonstrating their probity and commitment to those with whom they are doing research" (Emmel, et al., 2007). In the participant-researcher relationship between Chris and me, we first built trust through me sharing about the use of my research findings. At the beginning of the process, Chris hesitated to share his story. He did not want people to feel sorry for him or to share too many personal details. He also hesitated because he was unsure if other people would believe his story. Chris discussed this challenge during his post-course interview:

Hollis: What was your experience creating your digital story?
[Question 1]

Chris: Well hesitant to share it because I am sometimes some of the feelings in the story could be too intimate too personal. And sometimes you have that hesitation oh people will say something. Umm and sometimes you feel like oh you don't want to give the impression that it's a sad story. You don't want people to feel sorry for you. And that was not my that was very far from my intention...And some hesitancy that oh the people will not believe my version of what I'm doing. So that's one of the things that make a little apprehensive...But other than that I decided, hey, might as well go with it kind of thing.

During the process, Chris experienced some additional challenges with making a coherent story, privacy, and trust. Here are some excerpts from his post-course interview:

Chris: And of course, the challenge of how do we make it relevant or how do you sort of. What can I do to make the story umm to tell the story a little bit more easier to understand, you know those little things.

Hollis: What were the challenges of creating your digital story?

Chris: Sharing my experience, sharing my personal, my family life. That's a bit difficult kind of thing. Because that's more like a private thing. But other than that.

Despite the challenges, Chris felt safe sharing his story because he trusted me and felt comfortable talking with me because we built rapport with each other during the process. He believed that the trust built and his comfort level working with me was very important. During his post-course interview, he discussed how we built trust with each other. Here is an excerpt from his post-course interview:

Chris: I think once it is very important to get that sort of comfort level. Once you get that kind of rapport uh then I think then it's easier umm what I want. How with the videographer tell that side of the story...Once you trusted somebody with your story then you sort of say okay this person is on my side kind of thing. They are not going to do anything that would sort of put a not derogatory more like the negative side of you kind of thing. So once the trust level is initiated I think that is very important.

Throughout the process, Chris and I enjoyed working and talking with each other. I built a relationship with Chris through reciprocity by participating in some of the

activities that he enjoys with him. Here are some excerpts from my field notes on Tues., July 4 at 8:30 am and Thurs., July 20 at 1:15 pm:

Hollis: Overall everything went very smoothly and Chris even commented that the stars were aligned in our favor. Chris sent me an email that evening saying that he enjoyed the day. He seemed to enjoy having a friend to talk to and travel to these places with...

Hollis: We walked 4 blocks from his house, and he brought me to a little restaurant. He knew the woman at the restaurant and ordered our drinks in Filipino. We sat as friends chatting about food and Philippines and we took a selfie to remember the moment. I definitely have established a friendship with Chris, and he introduces me as "my friend, a student from SFU who selected me to make a story." I feel like he feels special to be part of my project which is very cool. We then went next door to the government office where he volunteers during election times. Finally, we went to save on foods where he bought some steaks to freeze for his family coming because he is the oldest son and he wants to take care of his family.

Chris said he was comfortable talking with me because he trusted me to help him tell his story the way he wanted. Here are some excerpts from his post-course interview:

Chris: I'm so comfortable talking with you because I know there are some that are privileged information and those were not put in there so that's the important thing.

Chris: There's perils in that one in the sense that if you don't know the person and now you have shared your life it might somewhere else kind of thing. But sometimes for the sake of saying okay this is what I want to tell more or less you trust the person.

In the beginning of the process, Chris was hesitant about the video editing process. He expected me to have a professional video editor, but I assured him that I was capable to help him. Here is an excerpt from my field notes on Tues., July 4 at 8:30 am:

Hollis: He also asked me if I had a video editor, and I told him that I am the video editor haha and that I have a video editing program.

Throughout the video editing process, I built my credibility with Chris when he saw my video editing skills demonstrated. Chris discussed how he was surprised that the video editing process allowed him to create a coherent story. We shot several videos

that he wanted for his digital story. The time constraint for his digital story length was one challenge that we overcame. Here is an excerpt from his post-course interview:

Chris: Plus, we took so many videos and I was saying how do we fit this in [laughter] and yet you were able to sort of splice, cut things and make it...more like a cohesive kind of storyline. And I'm quite amazed really [laughter]. I look at it 7:53 minutes and I go uh wow. And I say is this too long and yet to me it's not long enough kind of thing [laughter]. But then of course umm ah with the time limitation there are so many things we can do, but we were able to tell a story which I think is complete in itself.

When we were initially creating his digital story, Chris felt like we were improvising. He was not sure how everything was going to fit together, but he found the editing process interesting. Here is an excerpt from his post-course interview:

Chris: To me because I haven't done those kind of things before. So as you will recall the scripts are more like, we were improvising and all those things. We don't have any script, we go by what you asked me and by instinct, okay let's do this. This might prove interesting kind of thing. And then of course the cutting of the video, I think helped a lot kind of thing.

Chris was satisfied that we overcame the challenge to not tell a story that makes people feel sorry for him. He believed that we portrayed his authentic story. Here is an excerpt from his post-course interview:

Hollis: Can you describe how you felt throughout this experience?
[Question 6]

Chris: It was the challenge of saying how can I share this without feeling you know that kind of sappy you know that kind of I don't want to make it sound like tearful or cloying you know that kind of thing. And be able to share and experience without them feeling sorry for myself. I think we able to do that kind of, I think we solved that issue there. I didn't see anything that would make me feel like I am trying to dramatize it that kind of thing.

Overall, Chris was satisfied with how we worked together and overcame the challenges. He did not want to change the process. Here is an excerpt from his post-course interview:

Chris: Well I think we did, we worked well. I don't see how we could change it.

Throughout the process, Chris enjoyed having the freedom to create his digital story. He made decisions about what he wanted to include in his digital story. Here is an excerpt from my field notes on Tues., July 4 at 8:30 am:

Hollis: He also told me that he was enjoying this experience because he had freedom to choose what he wanted in his story. This was different from when he worked with an experienced journalist who made a story for Chris.

At the beginning of the process, Chris expressed some concerns because I looked young and did not have a professional camera. Throughout the process, we learned to trust each other as I built credibility through demonstrating my skills. Here is an excerpt from my field notes on Thurs., July 6 at 8:45 am:

Hollis: I am excited that Chris is enjoying this process because my supervisor told me about an email Chris sent because he was not sure about the project in the beginning because I looked very young and did not have a professional camera. Normally I need some time to prove myself. Chris has even made a connection with his support group leader to refer me to others in his support group that might be interested in creating a digital story.

Chris enjoyed overcoming the challenges with creating his digital story. When we started adding his videos and photos to his story in WeVideo, Chris said he was having fun. Here is an excerpt from my field notes on Fri., Aug. 11 at 7 pm:

Hollis: Once we finished for the evening he said, 'Thank you Hollis, I'm really enjoying myself, I'm really having fun!' This made me feel so excited that he was having fun and enjoying himself which made my project feel so meaningful.

He stated several times during his post-course interview that he had fun during the process. Here are some excerpts from his post-course interview:

Hollis: Were there any benefits for you personally? Like from the process or...

Chris: I had fun! [laughter] I had so much fun creating the video and interacting...and the things that were doing.

Hollis: Can you describe how you felt throughout this experience?
[Question 6]

Chris: I had a lot of fun [laughter]. What can I say [laughter].

Hollis: Did this storytelling activity change your life? How? [Question 8]

Chris: I had fun and of course umm putting a slice of your hand, a slice of your life into the hands of somebody.

Hollis: Is there anything else you would like to share? [Question 10]

Chris: I don't know what can I say, I had fun doing this.

Dementia Awareness-Raising

The final theme that illuminated my focus of inquiry for Chris is "Dementia Awareness-Raising." The codes that were used to determine this theme are as follows: sharing story with others; their digital story connected with others (strangers); digital storytelling creates a dialogue; story influences, shares a perspective, and relates to people with and without dementia; shared his digital story to promote public awareness; ability for others with dementia to learn from their story; reason/motivation for creating digital story – vehicle for change, empowerment; their digital story is sending the message of hope; power of digital storytelling; and amazement.

As discussed in Anne's case study, the WHO defines dementia awareness-raising as "people with dementia, their families and society in general, aiming to improve their understanding of dementia and to change public attitudes and practices" (World Health Organization, 2012, p. 92). A lack of understanding about dementia results in fear and stigmatization of people living with dementia (WHO, 2012). One of the benefits of raising-awareness about dementia is reducing the stigma associated with dementia (World Health Organization, 2012). Chris wanted to communicate his digital story to the public and people living with dementia to inspire change by raising awareness about how he copes and lives with dementia as an active member of his community. By raising awareness through his digital story, he wanted to combat the stigma associated with dementia.

Chris discussed that his digital story was something to share with others beyond his family. He stated in his post-course interview:

Chris: And I think that's something to share, nice to share with anybody actually.

Through sharing his digital story with others, he was surprised that his digital story connected with his community including people he never met. Chris posted his

digital story on his Facebook profile. He contacted me to meet up again to add these comments about the “power of digital storytelling” to his post-course interview after our final session. Here are some excerpts from his additional comments after he shared his video on Facebook:

Chris: Yeah, I am so surprised at uh the reaction on the video. As you will recall, we made the video on the premise that it’s a legacy to be left to my family, so I expect a few people who will see it kind of thing...I am so surprised, I am really so bowled over by the number of hits kind of thing...

Chris: So, it was so fun and then it’s also very interesting how to me umm because somehow the video ended up telling the story outside of my family and somehow it connected, and I am so glad that it connected with with strangers. So, the way you cut the video, I think helped a lot on the way people perceived it kind of thing.

Chris: The way it turned out is some people started to get a connection like they were touched by the video...

Chris communicated his digital story with the public to promote awareness. When I spoke with him after he shared his digital story on Facebook, he was excited by how many people had viewed his digital story. Here is an excerpt from his additions to his post-course interview:

Chris: I posted it on Facebook and some strangers decided I will share this. And then that somehow started the ball rolling. There is a person in Duncan I have not met before that decided to send me a message saying, ‘can I share this?’ And I said well by all means because this is about dementia anything that would spread the word would help the awareness. And guess how many people he got from sharing it? Sixty-five, and I go oh I don’t believe it...so I was expecting if I get 50 that’s excellent. It’s now almost 400. So that is something.

Chris’s digital story allowed him to communicate his story by creating a dialogue with his viewers. Here is an excerpt from his post-course interview:

Chris: So, in a way you are you are the video, this digital storytelling create openings for people, a dialogue a better word for other people, so that’s great.

Digital storytelling also allowed Chris to communicate his story to other people living with dementia. Chris discussed one of the benefits of creating his digital story was

the ability for other people living with dementia to learn from his story. Here is an excerpt from his post-course interview:

Hollis: What were the benefits of creating your digital story? [Question 3]

Chris: ...what immediately comes to my mind would be...if people look at it and especially people with dementia, they might think that hey I can do that to... Like this guy did something. It looks like he had a different outlook and it seems to have helped him.

His digital story related to a broad range of people in the public with and without dementia. Through his digital story he wanted to inspire change in the lives of people living with dementia. He hoped to inspire change through changing how people deal with dementia or even changing their perspective. Here is an excerpt from his post-course interview:

Hollis: How has the process of creating your own digital story affected your life? [Question 2]

Chris: Now I have put it down something people can look at and hopefully some people can relate to this story and maybe pick up something from it. And the idea that may be able to influence other people to either do something whether change the way they do things or maybe take another perspective on how they're dealing with it. Then I think that it important enough for me.

Chris was motivated to communicate his digital story because he wanted to use it as a vehicle for change for how people perceive dementia. He wanted to influence the stereotype that people living with dementia are without hope and depressed to hopefully reduce the stigma associated with dementia. Figure 4.10 shows some pictures that Chris included in his digital story of him enjoying rafting and taking photographs.

Figure 4.10. Chris enjoying rafting and taking photographs.



Here is an excerpt from his post-course interview:

Hollis: What was your experience creating your digital story?
[Question 1]

Chris: The reason I wanted to do it is more like let's take a look at the other side of... the people with Alzheimer [dementia]. Because most of the time you see images of people who are... a little bit of a downer. Most of the pictures are people looking depressed and kind of a hopeless... And then if I share my story because I did so many radical change that are even my doctor say how did you do it?

He also wanted to inspire change through communicating the message of hope in his digital story. Based on the response he got when he shared his digital story, he believed that digital storytelling allowed people living with dementia to share a message. Here is an excerpt from his post-course interview:

Chris: And I like to think...that from the way the video was produced they're getting the message of hope. The message of hey this person is doing something... So that kind of reception make me a little bit more saying hey this idea of the video storytelling could be something that people can use not only for their family but a way of sending a message if they have a message or say involving other people.

Chris believed that digital storytelling was a powerful way for him to communicate his story with a large audience. He was amazed by the response he got from people who viewed his digital story. I was excited for him that he received a positive response from sharing his video. Here is an excerpt from his additions to his post-course interview:

Chris: So that is the power of the video. Thank you! So that's... how powerful it was because there will be a few people who will look at it and even bother saying like or whatever, but these people actually liked it so if there are sixty-five people who liked it, what that tells me is there is more than sixty-five people who viewed it. So that is interesting enough for me...Well, that's amazing, so to me hey this is something, so.

Chris updated me several months after his post-course interview, and his digital story had more than 600 views. The Alzheimer Society of Canada also posted his video on their website in my profile as part of their awareness campaign to prevent the stigma associated with dementia called "I Live with Dementia" (Alzheimer Society, 2018).

4.2.6. Ian

Introduction

I was referred to Ian through one of his friends who took a continuing education digital storytelling class at SFU. I was a research assistant for this class, and she connected me with Ian's sister to describe my project. Ian lived at Normanna care facility. He is 73 years old, and he had lived a diagnosis of Lewy body dementia for 4 years. He lives alone in his care facility. Ian was the first person I met who lived with Lewy body dementia. His dementia caused him to experience hallucinations and Parkinson's disease symptoms. He described his disease during his pre-course interview:

Hollis: Tell me about your life right now. What do you care about?
[Question 2]

Ian: Well I try to keep my life from being chaotic. This dementia really interferes with my activities. So, I'm trying to keep my life together, but it's been hard. So, my symptoms are getting worse. I joke with my friends you know this this Lewy Body gives tremors and now it's harder and harder to control those. I try to discover things to make my life easier. I do keep up with my yoga and exercise. The exercise seems to help. Otherwise I don't know what condition I'd be in. I do try to get out. One thing that is not good is if I'm feeling agitated or if my body gets overheated then I have to attend to that.

Ian further described his disease and discussed that his memory was still functional. Here is an excerpt from his pre-course interview:

Hollis: What are some things you hope you never forget? [Question 3]

Ian: I'm not losing much information. My memory is actually quite good. I tried to stop slowing down...I'm still pretty functional...I joke with my friends. I tell them this Lewy Body condition has 10 symptoms, I have 12 of them. So, I keep it simple and maintain hope and be honest with my friends.

I observed that his memory was normally good. In my field notes on Tues., Sept. 26 at 9:45 am and Mon., Oct. 2 at 10 am I wrote:

Hollis: Ian seems like a very intelligent person caught inside his deteriorating body.

Hollis: I am also realizing that all of the dementia types are so different, and the struggles that Ian deals with are unique compared to some of my other participants... Because his body is failing at the same time as his dementia is progressing due to his Parkinson's disease. He is still very articulate though, and he surprised me by things that he does remember.

According to the nurses, sometimes he wakes up in the morning experiencing hallucinations. Here is an excerpt from my field notes on Fri., Sept. 29 at 9:30 am:

Hollis: I went to Ian's room and the nurses were finishing getting him ready for the day and feeding him his breakfast. One of the nurses told me that early in the morning he has bad hallucinations, and he doesn't even recognize her even though he sees her every day. She said he was doing better now, and I could go and talk with him. I introduced myself again and said that I was the Master's student from Simon Fraser University. He said that he remembered me.

While I was working with him one day, he became confused. He thought he saw sheep in his room. I wrote in my field notes on Mon., Nov. 21 at 10:15 am:

Hollis: He was a bit confused because he thought he was having a party. And then he asked who let the sheep out, and he said that it was just his imagination.

Ian became confused sometimes because he would think we were writing his story about his medical condition. Here is an excerpt from my field notes on Thurs., Oct. 5 at 10 am:

Hollis: Sometimes while we were working on editing his story, Ian became confused and thought the story was about a medical condition. But then we would get back on track.

I first met Ian in August, but I waited until September before I worked with him. We were waiting for his care home to sign and approve their support letter for my ethics amendment. When I first met Ian, he could walk with assistance. Within the next 1.5 months, his physical abilities deteriorated, and he needed to use a wheelchair. Ian and his family were excited when we finally received ethics approval.

Ian scored a 19/30 on his MMSE. His MMSE score is below the estimated mild or early stage dementia scores of 21-25 (Pernecky et al., 2006). He completed the MMSE during our final session, so his score might have been higher at the beginning. He had Parkinson's, so he was not able to complete the drawing or paper folding portion of the MMSE.

Ian is highly educated and completed his Master's degree in archaeology. While working with him, I was surprised that he was so intelligent. He used elaborate words and discussed history or books that I was not familiar with. While working with him, I learned that he used to compete in Scrabble tournaments. Here are excerpts from my field notes on Fri., Sept. 29 at 9:30 am and Mon., Oct. 2 at 10 am:

Hollis: Ian also said the word 'hubris' which I didn't know, so he spelled it for me and explained the word. He also said I could look it up in the dictionary to learn more. I was amazed at how intelligent Ian is.

Hollis: As I was typing his story, I realized that his title "Down and Out in London and Paris" is a famous book title. I didn't even realize that Ian is very intelligent.

During his pre-course interview, Ian self-identified an intermediate level of skill using his computer and the internet. He owns an PC laptop and claimed to use the internet daily. However, his friend said that he did not use his laptop due to the progression of his disease, so Ian might have been referring to his previous experience. He did not own a cell phone or tablet. His experience with storytelling included telling stories. When I was in his room, I saw the he had an old laptop. He also understood that I was typing his story using a word processing software. Here are some excerpts from my field notes on Tues., Sept. 26 at 9:45 am and Thurs., Oct. 26 at 10:15 am:

Hollis: I looked around his room and I saw an old large laptop sitting on his desk under some papers, his bed, and an old TV on top of his bookcase. A poster that talked about scrabble was taped to his bookcase, and his scrabble game was in his bookcase.

His bookcase was also full of boxes of some of his notes from anthropology.

Hollis: Ian asked me what I used to type up his story. I said Word, and he said he preferred Word Perfect. I was surprised that he knew what this is, I guess he previously used Word Perfect.

Ian was the only participant that I worked with who was living in a care home. When I contacted his sister, she told me that she was Ian's power to attorney. She read and signed Ian's consent form. Ian read and signed the assent form.

Digital Story Creation Process

Table 4.9. Timeline showing the sessions and content for the creation of Ian's digital story.

Session	Content
1	Introductions, read over the assent form, sign the assent form, discuss the background information and interview questions
2	Discuss his story ideas
3	Discuss an additional story idea, watch an example digital story
4	Discuss and edit his new script
5	Digitize and discuss photos and artifacts, meet his sister
6	Discuss and edit his story script
7	Discuss and edit his printed story script
8	Discuss and edit his printed story script
9	Discuss and edit his story script, attempt to record his narration
10	Discuss and edit his final script, record his narration with the help of his friend, listen to his narration
11	Listen to his edited narration, discuss and create his storyboard, add pictures and edit in WeVideo
12	Watch and publish his edited digital story in WeVideo, final interview questions, sign the release form that was signed by his proxy, complete the MMSE, give him a DVD copy of his story, discuss giving additional DVD copies and USB with his digital story to his sister

Session 1

Ian's friend met me at his care home to facilitate our introduction. I had met Ian more than a month prior to see if he was interested in participating in my project. Ian was sitting in his new wheelchair with a support for his head. He smiled brightly when I told him that I heard he had a lot of good stories to tell. We read over the assent form, and I answered his questions. He decided to sign the assent form and seemed excited about participating in my project. Signing was a bit difficult for him because he had difficulty holding the pen and reading where he should sign. After a few minutes, he signed the

assent form. We then discussed the pre-course interview questions. I immediately learned that Ian loved telling stories, and he was a natural storyteller. He told a few short stories during his pre-course interview, but we did not use these for his digital story. One of the short stories he told was a funny story from when he was in elementary school about a flying landing on his desk. We took a short break during his interview, so he could rest before he finished the questions. Because Ian spoke in a very quiet raspy voice, I handwrote his answers to the interview questions because my audio recorder could not pick up his voice. Talking with him was very pleasant, and I am excited to hear more of his stories.

Session 2

We discussed some of his many different ideas for stories. He smiled and chuckled when I talked about his story from elementary school when the fly flew onto his desk. Ian said that is a “famous Ian story.” I felt a bit unsure of what to do next, so I told him that we were trying to choose a story to use and expand upon. I asked him to tell me more about his days as an archaeologist, but he told me that this story could be criticized. So, he didn’t think this was a good story for my project. He said golfing might be a better story because it was funny. Since I already had written notes for his golfing story, I asked him to tell me more about his job in horse racing as a chart keeper. He expanded upon his story about horse racing. His voice was very quiet, but he slowed his speech pace and waited for me to catch up as I was writing. Some parts of his horse racing story were difficult to understand because I didn’t know about the field of horse racing. He said I was getting a crash course in horse racing. He seemed to be getting tired, so I thanked him for his time and made a time to meet him the following week. I enjoyed meeting with Ian, and I was excited about further developing his story.

Session 3

Ian’s friend met with him the day before session 3, and his friend emailed me saying that Ian wanted to change his story idea to his trip to Paris. I had already written his script based on what he told me in session 2 about horse racing, but we instead worked on writing his story about his travel abroad trip to Paris. Ian seemed very sharp this morning, and I was having a much easier time understanding him with his quiet voice. I asked him if he could tell me about his trip to Paris. He smiled and said, “I guess we’re diving right in.” I wrote down what he said as he described his trip, and then I

asked him some clarifying questions. Ian wanted to include several details about his family history, but I explained to him a digital story is generally about 5 minutes long. We also watched an example digital story. He asked me if it was made using only photos and sound. I said yes and he seemed to be amazed. I was excited that he had that insight into the process. Before leaving, Ian said 'I'll do some brainstorming' to think about some additional ideas for his story

Session 4

I went to meet Ian again before this session, but he was sleeping. The nurse said I could come back to meet with him another day. During session 4, we edited and discussed his new script that I typed from my notes on his trip to Paris as an exchange student. I told him that I typed up his story based on what he said, so we needed to read through it to make sure it was accurate. We went through his story line by line, and Ian enjoyed editing his script. I was very impressed with his editing skills. He said that he likes to write things that are concise. We did not finish editing his script, but we made a lot of progress. We also got to know each other better in this session through finding out we both speak Spanish.

Session 5

Ian's sister came to visit from Northern BC, and she brought his photos and artifacts to use for his digital story. She was very excited that I was working with Ian, and she told me that Ian enjoyed working with me. Ian enjoyed reminiscing while looking at his photos and the incredible drawings he created. Figure 4.11 shows some of Ian's drawings that he included in his digital story.

Figure 4.11. Ian's drawings and artwork.



Session 6

I met with Ian to continue editing his story about Paris. I learned that it was easier to print his story rather than editing it directly on my laptop. I told him I would bring a printed copy of story for our next session. He seemed to forget that we had already edited parts of his story, so we re-edited portions.

Session 7

During session 7, we discussed and edited his printed story script. Ian asked for a pencil, and he enjoyed making edits on his script. I was amazed because previously Ian had difficulty even signing his name. Figure 4.12 shows Ian editing his script. Even though I could not read the scribbles he made, I would ask him what he was editing. I wrote his edits on my copy of his script. He insisted on including the fact that he visited his grandfather in England. I was not sure how including his grandfather in his story would fit. I realized that this was his story, so he should include what he wanted. I told him that I found a picture of Hotel Le Canada online, and he was delighted and smiled.

When he was in Paris, he took a day trip to visit Normandy where he saw Hotel Le Canada. I showed him the image. He seemed very excited, and told me to tell his sister.

Figure 4.12. Ian editing his script.



Session 8

We continued to discuss and edit his script. I felt like we did not get much accomplished during this session, but Ian seemed to enjoy making edits. I patiently sat and waited while he read and made edits. He seemed to get stuck though and would just stare at the page, so I would read some parts to help him. I am not sure if his eyesight is fully okay. He pointed out some typos and corrected them and circled them. He seemed to think there were misspellings but everything was spelled correctly. I did not tell him this because he enjoyed making the edits. Ian was a little confused today, and he said that wanted to include some his hallucinations in his story. We spent several sessions editing his script which increased the overall number of sessions we met.

Session 9

Ian and I could not meet for more than 2 weeks between sessions 8 and 9. I went to a conference, and another day he was sleeping when I came to visit him. We were

supposed to finish editing his script, but Ian still thought there were some redundancies. He was doing well today and was very bright. When I sat down to chat with him, he said, "It's a good challenge for me and brought me a little enthusiasm." I was very excited to hear this. We also attempted to record his narration. Ian had difficulty reading his script, and his voice was extremely quiet. After a few attempts, I suggested that maybe we could invite his friend to narrate his story for him in our next session. He seemed hesitant at first, but he agreed after a while that his close friend could help. I told him that we could listen to the narration, and he could decide if it is okay.

Session 10

Before we met in session 10, I contacted his sister and friend about narrating his story. His sister also read over his script and made some clarifying edits. His friend said he was honored to narrate Ian's script. Ian, his friend, and I met to audio record Ian's narration. Ian was very alert today, and he seemed to be thinking more clearly than most of our previous meetings. I read his final script that his sister edited, and Ian made a few additional edits. Ian even remembered the name of his Great Uncle and the cafeteria at his university in Paris. He also reminisced and told other stories related to his Paris trip. He was overall satisfied with the edits his sister made because she eliminated the redundancies. His friend narrated his story, and Ian listened and made suggestions. We listened to the audio recorded narration, and Ian seemed very happy. Ian recorded his title and ending quote in his own voice to include in his narration. We listened to the narration and Ian was so delighted. This was the first time I saw him laugh, and his face was beaming with smiles. I was so happy to see Ian excited about his story. Ian said, "I'm very happy, at times I was not sure this was such a good idea." Ian also said this "gets him in the creative mode." I was also excited because now we could move forward more quickly to finish the process.

Session 11

We listened to his edited narration, and he was very happy with smiles and laughter. We also discussed and created his storyboard based on the pictures and artifacts his sister gave me and some online pictures I found. He looked at the pictures from his sister about Paris, and he told me where in Paris the pictures were taken. He wanted me to finish the video editing in WeVideo and come back to show him to get his feedback.

Session 12

Before session 12, Ian skipped two sessions in a row because he was not feeling well. When we met for session 12, we watched and published his final digital story in WeVideo. Ian did not have any edits, and he was so delighted with digital story that watching it brought him to tears. I felt very emotional watching Ian's reaction. The story seemed to really come to life for him. I felt so honored to be part of this process to help Ian create his digital story. Ian completed the final interview questions and the MMSE. He also wanted to sign the release form that was signed by his proxy. I gave him a DVD copy of his digital story, and I told him I was going to bring additional copies of his digital story on DVDs and USB to his birthday party for his sister. I had already been invited to his party, and I was so excited that he was going to share his digital story with his family and friends. Working with Ian really impacted me, and I was sad to see Ian's health declining. Ian is so bright and intelligent. I feel humbled and honored to have gotten this opportunity to work with Ian.

Themes

Based on the categories Robyn and I identified from Ian's post-interview transcript, I determined two themes. These themes illuminate my research question and focus of inquiry "what is the experience of digital storytelling for adults with early stage dementia?" The two themes determined are discussed. I used the pre-course interview excerpts and my field notes with reflections to further illuminate some of the themes identified for Ian's experience.

Meaningful and Transformative Experience

The first theme that illuminated my focus of inquiry is "Meaningful and Transformative Experience." The codes that determined this theme are as follows: his digital story captured a piece of his life, digital storytelling gave meaning to his life, his digital story gave his pictures meaning, would recommend digital storytelling to others because digital storytelling gave meaning to and allowed him to assess his life, interested in his sister creating a digital story, and digital storytelling changed his life.

Ian's experience was unique from the themes identified in the digital storytelling literature I reviewed. The literature discussed meaningful themes and benefits related to empowered participants (Hausknecht et al., 2016a; Hausknecht et al., 2016b),

experiencing a sense of purpose (Stenhouse et al., 2013), and improved well-being (Capstick et al., 2016). Ian's experience went beyond being meaningful because he found that his experience was transformative. Ian said that creating his digital story allowed him to capture a piece of his life. He described digital storytelling as bringing the magic of life. Figure 4.13 shows some of Ian's photos including his trip to Paris that he included in his digital story.

Figure 4.13. Photos of Ian and his trip to Paris that he included in his digital story.



His quote summarized many of my feelings throughout working with my participants. I saw how digital storytelling allowed them to capture the magic of their life. Here is an excerpt from his post-course interview:

Hollis: What was your experience creating your digital story?
[Question 1]

Ian: I have a life. It was difficult. I would say it's worth doing. It brings the magic of life. It's just a photograph but it's a real life. And it's a real picture of life...

Because his digital story captured a piece of his life, his digital story gave meaning to his life. During his post-course interview Ian said:

Ian: It [digital storytelling] gave a different meaning to my life.

His digital story also gave meaning to his pictures. Ian said this was one of the benefits of creating his digital story. Here is an excerpt from his post-course interview:

Hollis: What were the benefits of creating your digital story? [Question 3]

Ian: Well for me it's kind of...it keeps a little more meaning to the pictures.

Ian recommended digital storytelling to others because he believed that digital storytelling gave life meaning and allowed him to assess his life. Here is an excerpt from his post-course interview:

Hollis: Would you recommend this activity to others? Why? Or, Why not? [Question 11]

Ian: Yep. The same reason. It gives a different meaning to my life and if someone else is doing their own. Well I think it's wise to assess your life especially in these days when you're working life is longer. I'd never be the same person that I was when I found anthropology and archaeology.

He also wanted to recommend digital storytelling to his sister. Here is an excerpt from his post-course interview:

Ian: My sister would probably be interested in doing it. You know we're almost the same age. It would be interesting to see the comparison, anyway.

During his pre-course interview, Ian discussed how his family and sister are important to him. Here is an excerpt from his pre-course interview:

Hollis: What has been important to you over the past few years? [Question 1]

Ian: My sister lives out of town. We're both pretty busy, my brother and sister, so the family is important. I would say family and friends.

Ian was my only participant that said creating his digital story changed his life. I was humbled and amazed when he said this. I believe that because his digital story provided additional meaning to his life, he believed that creating his digital story changed his life. Although, Ian did not directly state the reasons that his digital story changed his life. Thinking about how his life was changed might have been too challenging for Ian. Here are some excerpts from his post-course interview:

Hollis: Did this storytelling activity change your life? How? [Question 8]

Ian: Yeah.

Hollis: Is there anything else you would like to share? (Question 10)

Ian: Like I said, it changed my life.

During his pre-course interview, Ian recognized the importance of storytelling. He believed that a well told story provides unique information especially in the context of his experience as an anthropologist. Here is an excerpt from his pre-course interview:

Hollis: What do you think is the reason (purpose) of telling stories?
[Question 13]

Ian: I think it's, tells you about, if it's properly organized. You get information, no one else has. There's an anthropologist, and he learned the language and got involved. He explained the ghost, stories about ancestors.

Engagement in the Process of Creation

The second theme that illuminated my focus of inquiry for Ian is "Engagement in the Process of Creation." The codes used to determine this theme are as follows: process challenges-writing story, organizing information; changes in the material used; glad to create digital story; and the process encouraged him to want to create additional digital stories.

As discussed in my literature review, the Patient Voices Digital Storytelling Project for people living with dementia discussed themes centered around engagement of participants with their story, with doing, and with others (Stenhouse et al., 2013). Their themes of engagement with story and doing are similar to Ian's theme of engagement in the process of creation. Stenhouse et al. (2013) also discussed several challenges associated with their themes of engagement. Ian said he experienced some challenges including writing his story script and organizing the information. He recognized that this is a common challenge for producing a video. Here is an excerpt from his post-course interview:

Hollis: What were the challenges of creating your digital story?
[Question 4]

Ian: Oh yeah plenty. Organizing the information in a multi-media like that. And...you know it's writing and getting it down on paper and video to actually produce any video.

Ian said that some of the material he used could be changed. He also recognized that with any film there are changes that can be made, but making these changes may be difficult. Here is an excerpt from his post-course interview:

Hollis: Is there anything you would change? [Question 5]

Ian: Umm probably I can't say right now. This film, I think it's hard to see this made. Always changes, including more of this, different material.

During our first session, Ian was aware that he wanted to include details in his digital story. In his pre-course interview he stated:

Ian: One thing I would like to see is to capture the background like if there are flies on your desk. So, you have classroom noises...That's my point about having the background noises, the characters, people.

I also wrote in my field notes on Tues., Sept 26 that Ian recognized the importance of including details in his digital story. Here is an excerpt from my field notes on Tues., Sept. 26 at 9:45 am:

Hollis: I was surprised that he mentioned at the end that he wanted me to incorporate the sounds of birds chirping on a golf course into his digital story. This made me think that he really understood what we were going to create and I was surprised he had this insight.

Even though there were some challenges, the process encouraged Ian to want to create additional digital stories. Here are some excerpts from his post-course interview:

Hollis: What were the benefits of creating your digital story? [Question 3]

Ian: Oh ,I think it encouraged me to make these films. I have more ideas, yeah more ideas. It encouraged me to make more of them. You know 3 or 4. I could make more of them. I'll let you know if I come up with something. I understand, and I have some pictures.

Hollis: Can you describe how you felt throughout this experience? [Question 6]

Ian: Makes me feel like doing another one. On my life, my experiences. Not necessarily mine. You know an interesting story. You (Hollis) know the basics of mine. I'd like to do another one.

He felt glad that he created his digital story, despite the challenges. Here is an excerpt from his post-course interview:

Hollis: Can you describe how you felt throughout this experience?
[Question 6]

Ian: I'm glad it was done.

4.3. Summary

I summarized the themes that illuminated each participant's experience to create their digital story in Table 4.10. There was some variability across the cases depending upon each participant's unique experience creating their digital story. Four themes were unique to each participant's experience including "Relationship with Family Caregiver," "Learning about Technology," "Building Trust," and "Meaningful and Transformative Experience." Five themes illuminated the experience of more than one participant including "Value of Legacy," "Generativity," "Facilitated Reminiscence," "Engagement in the Process of Creation," and "Dementia Awareness-Raising." The theme "Value of Legacy" was identified across the case studies for Janet, Max, and Chris. The theme "Generativity" was identified across the case studies for Janet and Anne. The theme "Facilitated Reminiscence" was identified across the case studies for Leonard and Max. The theme "Engagement in the Process of Creation" was identified across the case studies for Anne and Ian. The theme "Dementia Awareness-Raising" was identified across the case studies for Anne and Chris. The relationship of these five most prevalent themes across participants and to the literature are further discussed in Chapter 5 - Discussion and Conclusion.

Table 4.10. The themes found for each participant that illuminate my focus of inquiry.

Person	Theme 1	Theme 2	Theme 3
Janet	<i>Value of Legacy</i>	<i>Generativity</i>	<i>Relationship with Family Caregiver</i>
Leonard	<i>Facilitated Reminiscence</i>	<i>N/A</i>	<i>N/A</i>
Max	<i>Value of Legacy</i>	<i>Learning about Technology</i>	<i>Facilitated Reminiscence</i>
Anne	<i>Engagement in the Process of Creation</i>	<i>Generativity</i>	<i>Dementia Awareness-Raising</i>
Chris	<i>Value of Legacy</i>	<i>Building Trust</i>	<i>Dementia Awareness-Raising</i>
Ian	<i>Meaningful and Transformative Experience</i>	<i>Engagement in the Process of Creation</i>	<i>N/A</i>

Table 4.2 showed a general timeline describing the process used to create my participant's digital stories. This general timeline was adapted from the SFU digital storytelling course curriculum (Hausknecht et al., 2016a). The practical process that I followed to create each digital story extends the outline of daily tasks that Stenhouse et al. (2013) discussed for their digital story workshop. The variability I found in my general timeline when used to create each participant's digital stories highlights the importance of flexibility and adaption for each person living with dementia to create their digital story. The number of sessions for my participants ranged from 6 to 16 sessions with an average of 11 sessions. The duration of each session was intended to last for about 45 minutes. My sessions ranged from 15 minutes to 6.25 hours with an overall average of 1.5 hours per session. The longest sessions were travelling around Vancouver filming the locations for Chris's digital story. An average of 11 sessions and 1.5 hours per session is similar to the SFU digital storytelling course developed by Hausknecht et al. (2016a) which takes 10 sessions to complete with 2 hours per session. However, the time needed and number of sessions do not reflect the time I spent outside our sessions typing notes for their scripts and editing their digital stories. The number of sessions for my digital storytelling process is significantly more than the four-day workshop that Stenhouse et al. (2013) described, but likely less than the eighteen-month participatory process that Capstick et al. (2016) used.

Chapter 5. Discussion and Conclusion

5.1. Introduction

Dementia is a worldwide public health priority (World Health Organization, 2012), and the number of people living with dementia is continuing to increase (Alzheimer's Society Canada, 2012). People living with dementia experience many challenges including social isolation, reduced well-being, breakdown of communication, and sensory functional changes (Alm et al., 2007). Reminiscence is often used as an intervention for people living with dementia, and reminiscence therapy was first introduced into dementia care by Kiernat (1979). Storytelling is also often used as an intervention for people living with dementia which includes creating a life story for the person living with dementia (Beard, 2011; McKeown et al., 2010). More recently, digital storytelling incorporating reminiscence has been used in various forms as an intervention for people living with dementia (Stenhouse et al., 2013; Capstick et al., 2016; Davis et al., 2010; Crete-Nishihata et al., 2012; Alm et al., 2007).

Personhood and person-centered care is an area of growing emphasis in the care for people living with dementia. One focus of personhood for people living with dementia is understanding their subjective experience of living with dementia and looking at the world from the person's perspective (Brooker, 2003). Benefits of creating life stories for people living with dementia include preserving a sense of identity, maintaining dignity, and enhancing person-centered care (Heggestad & Slettebø, 2015; McKeown et al., 2010). Several benefits of digital storytelling for people living with dementia include areas such as engagement, well-being, social citizenship, and communication found using methods such as observation, scales, pulse measurement and interviewing their caregivers (Capstick et al., 2016; Davis et al., 2010; Stenhouse et al., 2013; Crete-Nishihata et al., 2012). The StoryCorp oral history project emphasized personhood and interviewed the storytellers who were people living with dementia to understand their experience (Savundranayagam et al, 2011). Chapter 4 - Findings sought to illuminate the experience of digital storytelling from the perspective of the storytellers – the people living with dementia. Chapter 5 - Discussion and Conclusion discusses the major findings of my research in relation to my research question, "What is

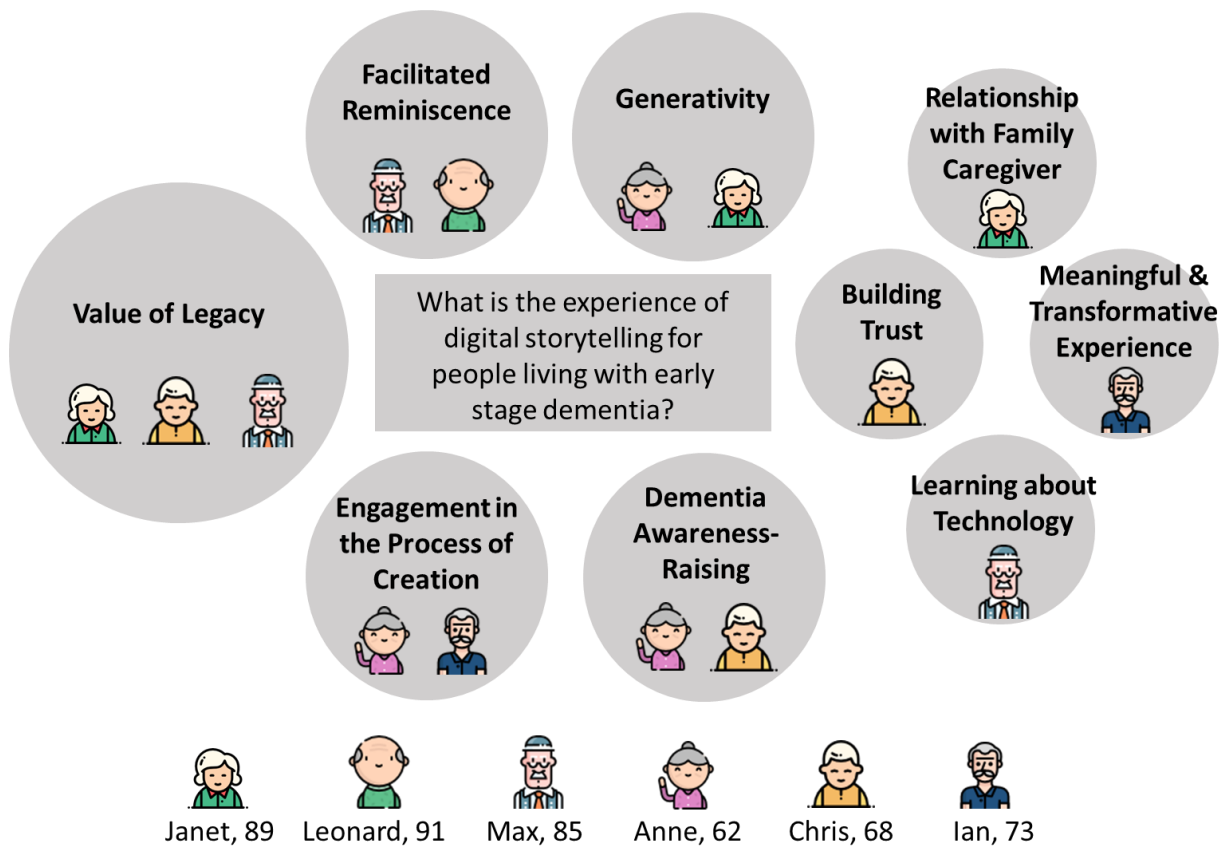
the experience of digital storytelling for adults with early stage dementia?” Chapter 5 also includes a discussion of future work, reflexivity, and the limitations of my research.

5.2. Major Findings of my Research

The major findings of my research include the themes illuminated for each case study and the process for digital story creation for people living with dementia. My observations were also a key part of this process, and sometimes I observed more than a participant expressed. I focused on the interviews I conducted with each participant because I wanted to understand their experience from their own perspective, but I did triangulate my themes with my observations. Across my six participants, nine themes illuminated their experience creating their digital stories shown in Figure 5.1. The theme “Value of Legacy” illuminated the experience of three of my participants. The themes “Facilitated Reminiscence,” “Generativity,” “Engagement in the Process of Creation,” and “Dementia Awareness-Raising” illuminated the experience of digital storytelling across two case studies for different participants. The remaining four themes “Relationship with Family Caregiver,” “Building Trust,” “Meaningful and Transformative Experience,” and “Learning about Technology” illuminated the experience unique to each participant’s experience. These themes are discussed in relation to the literature and across case studies. My relationship with each participant was an important part of their experience. In addition to the process, the finished digital story product was a meaningful part of their experience. Each participant enjoyed seeing their ideas and artifacts being constructed into a tangible digital story that they could keep after we finished our creation process.

5.2.1. Themes

Figure 5.1. Themes illuminating participant's experience creating their digital stories. The cartoon people icons used in this figure were made by Monkik and Freepik (n.d.).



Key Theme #1: Value of Legacy

The value of legacy was identified as a theme across the case studies for Janet, Max, and Chris as shown in Figure 5.1. As discussed in my literature review and findings chapters, a legacy is defined as something you can enjoy until the end of your life and leave behind to enhance lives when you are gone (Lucy, 2017, p. 11). Storytelling and digital storytelling provide opportunities to create a legacy (Savundranayagam et al, 2011; Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b). For Janet, Max, and

Chris creating their digital story as a legacy was important because they wanted to preserve this memory for their family and future descendants. Max described his experience as “You’re really getting an expert telling something of your life which you can pass on and to my children again.” According to Hausknecht et al.(2016b), creating a legacy was beneficial for “participants who really wanted to share what they had learned in life, while others wanted pieces of history for family, and others simply wanted the story preserved” (p. 14).

When a person living with dementia creates an artifact to provide a way to be remembered, this process can enhance their personhood and sense of self (Wallace, Wright, McCarthy, Green, Thomas, & Olivier, 2013). Allen (2009) found that when creating a legacy was used an intervention for people living in palliative care with their family members, family interactions were enhanced. For Janet, her family was involved in the process of creating her legacy. She asked her husband to help her throughout the process, and her son helped write her story script. For Max, his wife was involved to help him create his legacy by helping him find pictures for his story. For Chris, creating his legacy was an individual journey. Chris also emphasized that this process allowed him to preserve his legacy before his dementia progressed. Chris said, “people with dementia...Some of them could be progressing fast, some of them could be slower. So, the sooner they do something to record their thoughts, their ideas or their wishes...it’s better to do it that way so whatever happens uh tomorrow then they have already written down what they wish how... to be remembered...”

Hausknecht et al.(2016b) found that “Creating Legacy” was one of the themes identified to describe participants’ experience in their digital storytelling course. My digital storytelling process was based on Hausknecht et al.’s (2016b) digital storytelling course curriculum. Three of my participants experienced a similar theme the “Value of Legacy” which was the most common across my case studies. The StoryCorp’s Memory Loss Initiative found that storytelling allows people living with dementia to preserve their legacy for future generations (Savundranayagam et al, 2011). However, the theme “Value of Legacy” extends current literature on digital storytelling for people living with dementia (Stenhouse et al., 2013; Capstick et al., 2016; Davis et al., 2010; Crete-Nishihata et al., 2012; Alm et al., 2007) because for three of my participants digital storytelling also provided an opportunity to create a valuable legacy.

Key Theme #2: Generativity

Generativity was identified as a theme across the case studies for Janet and Anne as shown in Figure 5.1. As discussed in Janet and Anne's case studies, generativity is a sense of wanting to pass on to future generations. Generativity also includes older adults passing on to their community by investing in the lives and work of others (Rubinstein et al., 2014). Both Janet and Anne wanted to help me succeed because I was a student working on my thesis. Anne said, "It makes me very happy to have been able to help a young person (you) with their education - especially with something as important as preparing their thesis." Generativity often describes teacher knowledge (Schoklitsch & Baumann, 2011). Janet expressed generativity through wanting to pass on her knowledge from her background as a teacher to me through working on her digital story. Anne also wanted to invest in my thesis research by passing on her knowledge as an advocate for people living with dementia. Even though many older adults want to pass on to future generations or to their community (Rubinstein et al., 2014), the digital storytelling literature I reviewed for people living with dementia (Stenhouse et al., 2013; Capstick et al., 2016; Davis et al., 2010; Crete-Nishihata et al., 2012; Alm et al., 2007) did not describe participant's experience as being generative. The theme "Generativity" could extend current literature on digital storytelling for people living with dementia by providing a unique insight that described two of my participant's experience.

Key Theme #3: Facilitated Reminiscence

Facilitated reminiscence was identified as a theme across the case studies for Leonard and Max. As defined in my literature review and their case studies, reminiscence is a "process which occurs in stages, involving the recall of early life events and interaction between individuals" (Dempsey et al., 2012). I also reviewed other forms of digital storytelling that facilitated reminiscence and reflection upon life (Crete-Nishihata et al., 2012; Karlsson et al., 2014; Hausknecht et al., 2016b). For Leonard, reminiscing was the only theme identified for his case study that illuminated his experience creating his digital story. Leonard said, "Well it was kind of good to reminisce again, you know, looking back on the past." One benefit of reminiscence is communication (Woods et al., 2018). As discussed in Leonard's case study, reminiscing allowed him to converse and interact with other residents in his retirement residence by sharing stories.

As discussed in Max's case study, reminiscence also allowed him to reflect on his life which is one aspect of reminiscence described by Woods et al. (2018). For Max, reminiscing throughout the process also allowed him to reflect on how his memory from his childhood gave meaning to his life. The themes for both Leonard's and Max's digital stories were World War II. Leonard fought in the war, and Max grew up as a child during the war. Prompts and triggers for reminiscence often include photographs (Woods et al., 2005), and both Leonard and Max reminisced through discussing their personal pictures from their life. For Leonard, watching his completed digital story also brought back memories of additional stories. Max watched Leonard's completed digital story as an example digital story. Watching Leonard's digital story, allowed Max to reminisce about his own story from World War II as a child in Rotterdam.

Hausknecht et al.(2016b) discussed that "Reminiscence and Reflecting Upon Life" was a theme identified in all the focus group interviews describing participant's experience in their digital storytelling course. My digital storytelling process was based on their digital storytelling course curriculum, and two of my participants living with dementia experienced a similar theme "Facilitated Reminiscence." My findings for Leonard and Max's case studies support current literature that discusses digital storytelling facilitates reminiscence for people living with dementia (Crete-Nishihata et al., 2012; Karlsson et al., 2014). Even though Leonard and Max's experience with reminiscence was mostly positive, reminiscence is not universally a positive process for people living with dementia which should be considered when implementing digital storytelling (Coleman, 1986). Reminiscence was not identified as a theme across all my case studies, but reminiscence was likely part of other participants' experiences. To create their digital story, each participant recalled life events which is defined as reminiscence (Dempsey et al., 2012).

Key Theme #4: Engagement in the Process of Creation

The fourth theme identified across two cases is engagement in the process of creation. This theme was identified for Anne and Ian's case studies as shown in Figure 5.1. As discussed in my literature review and their case studies, the Patient Voices Digital Storytelling Project for people living with dementia discussed themes centered around engagement of participants with their story, with doing, and with others (Stenhouse et al., 2013). Anne enjoyed seeing the pieces of her digital story come

together into her final video, and she expressed that she really enjoyed the process and had fun. Ian was glad he created his digital story, and he enjoyed seeing his digital story come together with the details he wanted. Ian talked about some details for his digital story in his pre-course interview, "One thing I would like to see is to capture the background like if there are flies on your desk. So, you have classroom noises... That's my point about having the background noises, the characters, people."

Stenhouse et al. (2013) and Capstick et al. (2016) discussed that the relationship between the participants living with dementia and researcher were essential to overcome challenges throughout the process to create their digital stories. Stenhouse et al. (2013) discussed that during the Patient Voices Digital Storytelling Project, nursing student facilitators worked closely with the participants to help them create their digital stories. Crucial to the success of their workshop was the relationship between the facilitators and the participants (Stenhouse et al., 2013). When people with dementia experienced difficulties during the digital storytelling process, which included telling their stories and using technology, the constant supervision from and relationship with the facilitators enabled the participants to complete their stories (Stenhouse et al., 2013). Capstick et al. (2016) described that in their participatory video project, they also relied on the relationship between the participants living with dementia and the researchers. The benefits experienced during their story creation process were dependent upon the relationships that the researchers formed with the participants living in a long-term care facility (Capstick, 2016). Similar to Stenhouse et al. (2013) and Capstick et al. (2016), Anne and Ian's engagement in the process relied on overcoming challenges through the relationship they formed with the researcher (Hollis). Anne relied on me to complete her video editing and assemble the pieces of her digital story under her direction. Ian experienced some challenges editing his script, assembling his media and editing his video, but under his direction we worked together to complete his digital story.

"Engagement in the Process of Creation" was not a theme for my other four participant's experiences. However, Janet, Leonard, Max and Chris did discuss their relationship with me (the researcher) during their post-course interview. For example, Chris and I built trust with each other as part of our relationship as a participant and researcher (Emmel, et al., 2007). One of Chris's themes was "Building Trust." Janet's theme of "Generativity" expressed that she wanted to pass on her knowledge as a teacher on to me a student through our relationship working on her digital story.

Leonard enjoyed reminiscing with me throughout his experience. For example, during session 11 Leonard asked me to find one of his favorite songs on YouTube to use in his digital story. He enjoyed singing along to this song with me. Max enjoyed learning about how a digital story was created, but I provided the necessary support to make the video edits under his direction in WeVideo. Each participant relied on me to make edits to their digital story in WeVideo under their direction. This could suggest that similar to Stenhouse et al. (2013) and Capstick et al. (2016), relationship with the researcher was important to my all of my participant's experiences creating their digital stories.

Key Theme #5: Dementia Awareness-Raising

The final theme that was identified across cases that illuminated my focus of inquiry was "Dementia Awareness-Raising" for Anne and Chris's case studies. As discussed in their case studies, the WHO defines dementia awareness-raising as "people with dementia, their families and society in general, aiming to improve their understanding of dementia and to change public attitudes and practices" (World Health Organization, 2012, p. 92). Both Anne and Chris's backgrounds as advocates for people living with dementia for various organizations inspired their digital story themes. Anne wanted to share her digital story to increase understanding about dementia by educating people and giving them hope. Her digital story features her advocacy and awareness-raising work. Anne stated, "I am hoping I can change other people's lives and make it easier for them to deal with the diagnosis and their family members or loved ones that have it and...to get for support and advocacy, support for people with early stage dementia."

Chris wanted to combat the stigma associated with dementia through sharing his digital story. Chris stated, "Some people started to get a connection like they were touched by the video, and I posted it on Facebook and some strangers decided I will share this...digital storytelling creates openings for people, a dialogue a better word for other people, so that's great." The WHO states that one of the benefits of raising-awareness about dementia is reducing the stigma associated with dementia (World Health Organization, 2012). Chris shared his digital story with a large public audience, and his digital story discussed how he copes and lives well with dementia.

Interestingly, current literature on digital storytelling for people living with dementia (Stenhouse et al., 2013; Capstick et al., 2016; Davis et al., 2010; Crete-

Nishihata et al., 2012; Alm et al., 2007) do not discuss using digital stories for raising awareness. Capstick et al. (2016) discussed increased social citizenship that included featuring their digital stories on websites and at film festivals. In Capstick et al.'s (2016) project, participants attended events featuring their digital story and served on a panel as experts for their work. Although not explicitly stated by Capstick et al. (2016), their digital stories could promote awareness by increasing the community's understanding about dementia. The stories created using the TimeSlips storytelling method help did help to promote public awareness by demonstrating that people living with dementia can participate in creative storytelling (Basting, 2006).

Because Anne and Chris had experience with awareness-raising and were advocates for people living with dementia, their experience creating their digital story was likely influenced by their background. Anne and Ian's experience was unique to their background, but the theme "Dementia Awareness-Raising" extends the current literature on digital storytelling for people living with dementia. However, all the digital stories that were created could be used for advocacy if they were shared with a public audience. All the digital stories provide a picture of what it's like to live with dementia or a background of the many life experiences that each person participated in before and after being diagnosed with dementia. I was excited that digital storytelling for people living with dementia could have a broader impact by raising awareness which is a strategy suggested by the WHO to reduce the burden of dementia throughout the world (World Health Organization, 2012).

Additional Themes: Learning about Technology, Relationship with Family Caregiver, Building Trust, and Meaningful and Transformative Experience

As shown in Figure 5.1, the final four themes that illuminated individual participant's experience are "Learning about Technology", "Meaningful and Transformative Experience", "Relationship with Family Caregiver", and "Building Trust." For Max, "Learning about Technology" was an important theme to describe his experience creating his digital story. As discussed in my literature review and Max's case study, he did not learn how to use a computer and complete the video edits. Max's experience aligned with Damodaran et al.'s (2013) explanation that cognitive and physical decline contribute to the difficulties older adults experience when using computers. One of the main difficulties that people living with dementia experience is a lack of understanding and knowledge about the technology (Nygård & Starkhammar,

2007). Max enjoyed learning about the capabilities of the technology used to create his digital story. Dementia most often impairs the learning and memory cognitive domain (Larson, 2015), but people living with early stage dementia are still capable of learning new skills or knowledge in some cases (Bier et al., 2008; Camic et al., 2014). However, transfer of knowledge or skills to everyday contexts is limited (Bier et al., 2008). Max enjoyed learning about the process used to create his digital story, but likely his transfer of knowledge about creating his digital story is limited. One benefit of the SFU Elder's Digital Storytelling Course that my process is based on is life-long learning and learning something new (Hausknecht & Kaufman, 2018; Hausknecht et al., 2016b). For Max, he appreciated learning about the technology and process, but he did not experience the same benefits of life-long learning discussed by Hausknecht & Kaufman (2018) and Hausknecht et al. (2016b).

For Janet, "Relationship with Family Caregiver" was an important theme that illuminated her experience. As discussed in her case study, Janet's husband is her primary caregiver, and he was involved in her digital story creation process. The relationship between a spousal caregiver and the older adult they are caring for is often defined by how valued the caregiver feels by their partner (Lawrence et al., 1998). A relational family caregiver who is a spouse often defines their experience as a caregiver by focusing on the continued spousal bond or connection (Lewis et al., 2005). Two digital storytelling methods CIRCA and the digital photograph diary discussed in my literature review incorporated family caregivers into their research (Karlsson et al., 2014; Alm et al., 2007). My research did not directly intend to include caregivers in the process, but Janet seemed to enjoy the support she received from her husband.

For Chris, "Building Trust" was an important theme that illuminated his experience. Chris's theme that illuminated his experience reflected one of my goals to maintain the credibility of my research. I discussed in my methods chapter that I wanted to build trust with my participants through prolonged engagement and persistent observation (Moen, 2006). Building trust allowed Chris to feel comfortable sharing his story and to see the purpose of participating in my research project. The importance of building a relationship with participants discussed by Stenhouse et al. (2013) and Capstick et al. (2016) likely included building trust with their participants.

For Ian, his experience creating his digital story was a “Meaningful and Transformative Experience.” He was the only participant that expressed creating his digital story changed his life. He said, “It [digital storytelling] changed my life...it gave a different meaning to my life.” Ian’s experience was unique from the themes identified in the digital storytelling literature I reviewed. The literature discussed meaningful themes and benefits related to empowered participants (Hausknecht et al., 2016a; Hausknecht et al., 2016b), experiencing a sense of purpose (Stenhouse et al., 2013), and improved well-being (Capstick et al., 2016). Ian’s experience was transformative. Ian said that creating his digital story allowed him to capture a piece of his life. He described digital storytelling as bringing the magic of life. Ian stated, “I have a life. It was difficult. I would say it’s worth doing. It brings the magic of life. It’s just a photograph but it’s a real life. And it’s a real picture of life...”

5.3. Future Work

Future work related to digital storytelling for people living with dementia could explore and analyze their story themes and media used in relation to participants’ age and type of dementia. Capstick et al. (2016) discussed the reminiscence bump and found that all 10 of their participants created digital stories with themes from memories from their life during ages 5 to 30 years old. Future research could explore why the story themes for some of my participants included stories outside the reminiscence bump from present life and mid-life. Generativity in addition to being a theme illuminating two of my participant’s experience could also be explored as an overarching concept for the entire process of co-creating digital stories with people living with dementia. The digital story multimedia that participant’s chose to use in their digital stories could be explored using a framework similar to Hausknecht et al.’s (2018) analysis of the SFU Elder’s Digital Storytelling Course digital stories.

Further research could also explore an audience’s experience of watching participant’s digital stories. All my participants chose to share their digital stories with an audience after they completed their digital stories. Janet and Leonard shared their completed digital stories with residents from their retirement residence at a digital storytelling showcase hosted by their retirement residence. Max, Anne, and Chris shared their digital stories at with each other, Max’s wife and the volunteer coordinator at Max’s retirement residence. Figure 5.2 shows me with three of my participants at their digital

story sharing event. Chris also chose to share his digital story more broadly including on Facebook and on the Alzheimer Society of Canada's I Live with Dementia website. Ian shared his digital story with his friends and family at his birthday party at his care home. Further research could explore if their digital stories to raise the viewer's awareness about dementia. Max's retirement residence even suggested to use their digital stories as an education day for the other residents to learn about dementia and to promote conversation about the topic.

Figure 5.2. Digital story sharing event.



Further research could also explore if the digital stories created by the person living with early stage dementia could be used to facilitate reminiscence in the later stages of the disease for that person. Their digital stories could potentially facilitate reminiscence for other people living with dementia. For example, Max watched Leonard's digital story, and Leonard's story reminded Max of his own World War II story. Further research could also explore if there any benefits of including family caregivers in the process. If family caregivers were included in the digital storytelling process, the personal relationship between the caregiver and family member living with dementia could be explored. The personal relationship between a family caregiver and the person with dementia that they are caring for has many benefits for the caregiver including lower levels of depression, decreased sense of captivity, lower levels of caregiver burden and higher levels of caregiver competency (Lewis et al., 2005; Lawrence et al., 1998). My

themes were not specifically related to happiness and well-being, but this was an aspect of my participant's experience. After Ian watched listened to his final narration, he was beaming and smiling from ear to ear. Several of my participants repeatedly said they were having so much fun. Well-being would be an interesting concept to explore in relation to my participant's experience's.

5.4. Limitations of my Research

There were several limitations of my research. My findings are limited to the unique experience of each participant and do not directly translate the experience that other people living with dementia would have when creating their digital story. Another limitation is the applicability of the process I used to other settings due to lengthy time needed to complete each digital story. Chris's story took the longest amount of time because he wanted to collect videos and complete all the video editing together. Figure 5.3 shows me filming Chris in Queen Elizabeth Park in Vancouver for one of the videos used in his digital story. Chris and I spent a total of 35 hours working together.

Figure 5.3. Filming Chris in Queen Elizabeth Park.



Another limitation is that the whoever works with the person living with dementia would need to have some video editing skills. I am a trained course facilitator for the SFU Elder's Digital Storytelling Course developed by Hausknecht et al. (2016a). Leading these digital storytelling courses gave me experience with teaching the process of digital

story creation before working with my participants. Working with people living with dementia and helping them create their digital stories was a learning experience despite my initial digital storytelling skills. I learned how to adapt the digital story process based on what I learned from each participant. Most importantly, I wanted each person to tell a meaningful story that they wanted to tell, and I learned to support them in this process.

There are several strengths and limitations associated with using a qualitative research paradigm. Qualitative research allowed me to understand the experience of each person living with dementia to create their stories. Atieno (2009) discusses that qualitative research is a strength when “the purpose is to learn from the participants in a setting or a process the way they experience it, the meanings they put on it, and how they interpret what they experience” (p. 16). Qualitative research also gave me the flexibility to update my digital story process after working with each person and to provide each person the freedom to create their digital on the topic they wanted (Anderson, 2010). Another strength is that each person living with dementia could describe and express their experience (Anderson, 2010). There are some limitations of qualitative research described by Anderson (2010). My role as a researcher was essential to the process, so the quality of my research is influenced by my skills and biases (Anderson, 2010). To produce their digital stories my role was essential as we co-created their digital story. Other limitations of qualitative research include the amount of time needed to analyze the data and my involvement could have influenced my participant’s responses (Anderson, 2010). A final limitation of qualitative research is that my research findings cannot be generalized to a larger population because my findings are unique to each participant’s experience (Atieno, 2009).

5.5. Reflexivity

When I started this study, I was excited to work with people living with dementia. For many years, I had volunteered with my dog “Sky” who I trained to be a certified therapy dog. I enjoyed visiting care homes with Sky and talking with the residents who often lived with dementia. My experience and background gave me a natural rapport and the ability to build trust with my participants quickly. I did not realize how much I would learn about dementia and each person’s experience living with dementia while conducting this research. Each person I worked with taught me something about the disease. Initially, I had the misunderstanding that dementia is mainly characterized by

memory loss. This is often true, but each type of dementia presents different challenges. For example, I learned from Anne that frontotemporal dementia caused her to have difficulty with her speech. Ian's Lewy body dementia caused hallucinations. My role in the process was unique in that I combined my roles as an educator/researcher with my health researcher role. I mainly observed and adapted to the challenges that dementia caused for each participant living with dementia. I used my role as an educator to co-create their digital story.

This is my first qualitative research project which is a contrast to my background in biomedical engineering. In engineering, statistical significance and quantitative data are the norm. I was excited to learn about another approach to research. I realized that engineering often lacks an understanding of the significance of a person's experience. Numbers only paint part of the picture, and that there is power in the word's expressed by participants that illuminate their experience.

I also learned that there are several challenges of working with people living with dementia. Often, they would forget that we were going to meet, or they would even forget who I was when I go meet with them. Sometimes they would have a bad day and not be able to meet even though I would travel to meet with them. Another challenge is that would sometimes forget what story we were working on, so it was helpful to bring a printed copy of their story. Before conducting this research, my experience with digital storytelling was facilitating large groups of 8-10 older adults. I enjoyed having the time to work with each person individually to allow them to create the digital story that they wanted. Each digital story reflected the individual personality of my participants. I had fun working with each person, and I enjoyed watching most of my participants go from being uncertain if they could create a digital story to watching their final digital story with them.

5.6. Conclusion

Throughout this process I learned that each person living with dementia that I worked with had a unique story that was meaningful to him or her. Anne expressed this in her final interview, "...everybody has a story to tell in their lives...this is a good way of doing it..." Through patience, flexibility, and time, each person I worked with was successful in creating their digital story. Each of their experiences were illuminated by

several themes shown in Figure 5.1 including “Value of Legacy,” “Facilitated Reminiscence,” “Generativity,” “Engagement in the Process of Creation,” “Dementia Awareness-Raising,” “Relationship with Family Caregiver,” “Building Trust,” “Meaningful and Transformative Experience,” and “Learning about Technology.” Ball (2012) discusses how a personal voice in research can cross the gap between knowing and doing to make a difference. Dementia is a public health priority according to the WHO (World Health Organization, 2012). My hope is that my research demonstrated the importance of exploring alternate interventions for people living with dementia and how creating digital stories is one way to enhance the lives of people living with dementia. I’m concluding with the words spoken by Anne and Ian after they watched their digital stories. Anne said, *“I know that I will eventually probably lose my ability to speak, so then I won’t be able to tell my story that well verbally. But there it is digitally.”* Ian said, *“It brings the magic of life.”* Figure 5.4 shows Ian and I after he shared his digital story with his family and friends at his birthday party in his care home. My hope is this process of digital storytelling had an impact on their lives and the lives of others.

Figure 5.4. Ian and I after he shared his digital story with his family and friends.



References

- Allen, R. S. (2009). The Legacy Project intervention to enhance meaningful family interactions: Case examples. *Clinical Gerontologist*, 32(2), 164-176.
- Alm, N., Dye, R., Gowans, G., Campbell, J., Astell, A., & Ellis, M. (2007). A communication support system for older people with dementia. *IEEE Computer Society*, (5), 35-41.
- Alzheimer's Society Canada: A New Way of Looking at the Impact of Dementia in Canada. (2012). Retrieved February 29, 2016 from Alzheimer's Society Canada: http://www.alzheimer.ca/cornwall/~media/Files/national/Media-releases/asc_factsheet_new_data_09272012_en.pdf
- Alzheimer Society of Canada: Hollis. (2018). Retrieved May 22, 2018, from the Alzheimer Society Canada: <https://ilivewithdementia.ca/hollis/>
- Anderson, C. (2010). Presenting and evaluating qualitative research. *American journal of pharmaceutical education*, 74(8), 141.
- Atieno, O. P. (2009). An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century*, 13(1), 13-38.
- Ball, A. F. (2012). To know is not enough: Knowledge, power, and the zone of generativity. *Educational Researcher*, 41(8), 283-293.
- Basting, A. D. (2006). Creative storytelling and self-expression among people with dementia. *Thinking about dementia: Culture, loss, and the anthropology of senility*, 180-194.
- Basting, A. D. (2003). Reading the Story behind the Story: Context and Content in Stories by People with Dementia. *Generations: Journal of the American Society on Aging*, 27(3), 25-29.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report*, 13(4), 544-559.
- Beard, R. L. (2011). Art therapies and dementia care: A systematic review. *Dementia*, 11(5), 633.
- Bier, N., Provencher, V., Gagnon, L., Van der Linden, M., Adam, S., & Desrosiers, J. (2008). New learning in dementia: Transfer and spontaneous use of learning in everyday life functioning. Two case studies. *Neuropsychological Rehabilitation*, 18(2), 204-235.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

- Brooker, D. (2003). What is person-centred care in dementia?. *Reviews in clinical gerontology*, 13(3), 215-222.
- Burgess, J. (2006). Hearing ordinary voices: Cultural studies, vernacular creativity and digital storytelling. *Continuum*, 20(2), 201-214.
- Camic, P. M., Tischler, V., & Pearman, C. H. (2014). Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers. *Aging & Mental Health*, 18(2), 161-168.
- Capstick A, Ludwin K, Chatwin J and Walters ER (2016) Participatory video and well-being in long-term care. *Journal of Dementia Care*, 24 (1): 26–29.
- Coghlan, D., & Brydon-Miller, M. (Eds.). (2014). *The SAGE encyclopedia of action research*. Sage.
- Coleman, P. G. (1986). *Ageing and reminiscence processes: Social and clinical implications*. John Wiley & Sons.
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., & Brodaty, H. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24(06), 856-870.
- Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). Boston, MA: Pearson.
- Crete-Nishihata, M., Baecker, R. M., Massimi, M., Ptak, D., Campigotto, R., Kaufman, L. D., & Black, S. E. (2012). Reconstructing the past: personal memory technologies are not just personal and not just for memory. *Human-Computer Interaction*, 27(1-2), 92-123.
- Damodaran, L., Olphert, W., & Phipps, S. (2013). Keeping silver surfers on the crest of a wave—older people's ICT learning and support needs. *Working with Older People*, 17(1), 32-36.
- Davis, B. H., Spake, M., & Gray, T. (2010). When the picture talks: creating monogram booklets for spouses and friends. *Acta Alzheimerica et Dementiae*, 11(2), 33-38.
- Dempsey, L., Murphy, K., Cooney, A., Casey, D., O'Shea, E., Devane, D., & Hunter, A. (2012). Reminiscence in dementia: A concept analysis. *Dementia*, 0(0), 1-17.
- Emmel, N., Hughes, K., Greenhalgh, J., & Sales, A. (2007). Accessing socially excluded people—Trust and the gatekeeper in the researcher-participant relationship. *Sociological Research Online*, 12(2), 1-13.
- Erikson, E. H. (1950). *Childhood and society*, New York (WW Norton) 1950.

- Farlow, M. (2015). Clinical features and diagnosis of dementia with Lewy bodies. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)
- Fels, D. I., & Astell, A. J. (2011). Storytelling as a model of conversation for people with dementia and caregivers. *American journal of Alzheimer's disease and other dementias*, 26(7), 535-541.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research*, 12(3), 189-198.
- Fritsch, T., Kwak, J., Grant, S., Lang, J., Montgomery, R. R., & Basting, A. D. (2009). Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *The Gerontologist*, 49(1), 117-127.
- Gonzalez, Jesus, Teresa Mayordomo, Marta Torres, Alicia Sales, and Juan C. Meléndez. "Reminiscence and dementia: a therapeutic intervention." (2015). *International psychogeriatrics*. 27(10), 1731-1737.
- Haron, H., Sabri, S. M., & Jamil, N. (2014). Exploring Technology Use in Reminiscence for Elderly Knowledge Recall. *Australian Journal of Basic and Applied Sciences*, 8(5), 469- 477.
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual studies*, 17(1), 13- 26.
- Hausknecht, S., Vanchu-Orosco, M., & Kaufman, D. (2016a). Sharing Life Stories: Design and Evaluation of a Digital Storytelling Workshop for Older Adults. In *International Conference on Computer Supported Education* (pp. 497-512). Springer, Cham.
- Hausknecht, S., Kaufman, D., & Vanchu-Orosco, M. (2016b). Digitizing the wisdom of our elders: Connecting life learning through digital storytelling. Manuscript in preparation.
- Hausknecht, S., Kaufman, D. (2018, June). Increasing digital literacy skills of older adults through a digital storytelling project-based learning course. In *EdMedia: World Conference on Educational Media and Technology*. Association for the Advancement of Computing in Education (AACE).
- Hausknecht, S. (2018). The role of new media in communicating and shaping older adult stories. In: Zhou J., Salvendy G. (eds) *Human Aspects of IT for the Aged Population. Applications, Services and Contexts*. ITAP 2018. Springer, Cham.
- Heggestad, A. K. T., & Slettebø, Å. (2015). How individuals with dementia in nursing homes maintain their dignity through life storytelling—a case study. *Journal of clinical nursing*, 24(15-16), 2323-2330.

- Heo, M. (2009). Digital storytelling: An empirical study of the impact of digital storytelling on pre-service teachers' self-efficacy and dispositions towards educational technology. *Journal of Educational Multimedia and Hypermedia*, 18(4), 405-428.
- Holm, A., Lepp, M., & Ringsberg, K. (2005). Dementia: Involving patients in storytelling – a caring intervention. A pilot study. *Journal of Clinical Nursing*, 14(2), 256-263.
- Holloway, I., & Biley, F. C. (2011). Being a qualitative researcher. *Qualitative Health Research*, 21(7), 968-975.
- Huldtgren, A., Mertl, F., Vormann, A., & Geiger, C. (2017). Reminiscence of People With Dementia Mediated by Multimedia Artifacts. *Interacting with Computers*, 29(5), 679-696.
- Hydén, L. C., Martin, W., Kontos, P., & Ward, R. (2013). Storytelling in dementia: Embodiment as a resource. *Dementia*, 12(3), 359-367.
- Hydén, L. C. (2017). *Entangled Narratives: Collaborative Storytelling and the Re-Imagining of Dementia*. Oxford University Press.
- James, I. A., & Jackman, L. (2017). *Understanding behaviour in dementia that challenges: a guide to assessment and treatment*. Jessica Kingsley Publishers.
- Karlsson, E., Axelsson, K., Zingmark, K., Fahlander, K., & Sävenstedt, S. (2014). "Carpe Diem": Supporting Conversations Between Individuals With Dementia and Their Family Members. *Journal of gerontological nursing*. 40(4), 38-46.
- Kiernat, J. M. (1979). The use of life review activity with confused nursing home residents. *The American journal of occupational therapy: official publication of the American Occupational Therapy Association*, 33(5), 306-310.
- Klaebe, H. G., Foth, M., Burgess, J. E., & Bilandzic, M. (2007). Digital storytelling and history lines: Community engagement in a master-planned development. In *Proceedings of the 13th international conference on virtual systems and multimedia: Exchange and experience in space and place, VSMM 2007*. Australasian Cooperative Research Centre for Interaction Design Pty, Limited.
- Lambert, J. (2012). *Digital storytelling: Capturing lives, creating community*. Routledge.
- Larson, E. (2015). Evaluation of cognitive impairment and dementia. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)
- Lawrence, R. H., Tennstedt, S. L., & Assmann, S. F. (1998). Quality of the caregiver–care recipient relationship: Does it offset negative consequences of caregiving for family caregivers?. *Psychology and Aging*, 13(1), 150.
- Lee, S. and Miller, B. (2015). Frontotemporal dementia: Clinical features and diagnosis. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)

- Lewis, M. L., Hepburn, K., Narayan, S., & Kirk, L. N. (2005). Relationship matters in dementia caregiving. *American journal of Alzheimer's disease and other dementias*, 20(6), 341- 347.
- Li, C., Lin, X., Kang, K., Hu, J., Hengeveld, B., Hummels, C., & Rauterberg, M. (2018). Interactive Gallery: Enhance social interaction for elders by story sharing. In *Advances in Digital Cultural Heritage* (pp. 104-116). Springer, Cham.
- Lucy, R. (2017). How will you be remembered?: a guide for creating and enjoying your legacies now. Delta, British Columbia, Canada: Engage Communications Inc.
- Madden, M. (2010). Older adults and social media: Social networking use among those ages 50 and older nearly doubled over the past year. *Pew Internet & American Life Project*.
- Maykut, P., & Morehouse, R. (1994). *Beginning qualitative research: a philosophic and practical approach*.
- McAdams, D. P. (2008). Life Story. *The Encyclopedia of Adulthood and Aging*.
- McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing*, 5(2), 148-158.
- Meulenbroek, O., Vernooij-Dassen, M. J. F. J., Kessels, R. P. C., Graff, M. J. L., Sjögren, M. J. C., Schalk, B. W. M., ... & Rikkert, M. O. (2010). Informed consent in dementia research. Legislation, theoretical concepts and how to assess capacity to consent. *Geriatric Medicine*, 1(1), 58-63.
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard* (2014+), 30(7), 46.
- Mitchell, A. J. (2017). The Mini-Mental State Examination (MMSE): update on its diagnostic accuracy and clinical utility for cognitive disorders. In *Cognitive Screening Instruments* (pp. 37-48). Springer International Publishing.
- Moen, T. (2006). Reflections on the narrative research approach. *International Journal of Qualitative Methods*, 5(4), 56-69.
- Molloy, D. W., Alemayehu, E., & Roberts, R. (1991). Reliability of a standardized mini-mental state examination compared with the traditional mini-mental state examination. *Am J Psychiatry*, 148(1), 102-105.
- Monkik & Freepik. (n.d.). Icons in Figure 5.1 made by Monkik <https://www.flaticon.com/authors/monkik> and by Freepik from <http://www.freepik.com> from www.flaticon.com is licensed by CC 3.0 BY (<http://creativecommons.org/licenses/by/3.0/>)

- Morris, J. C. (1993). The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*.
- Nygård, L., & Starkhammar, S. (2007). The use of everyday technology by people with dementia living alone: Mapping out the difficulties. *Aging & Mental Health*, 11(2), 144-155.
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., ... & Beattie, L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia*, 6(1), 121-142.
- Page, S., & Keady, J. (2010). Sharing stories: A meta-ethnographic analysis of 12 autobiographies written by people with dementia between 1989 and 2007. *Ageing and Society*, 30(3), 511-526.
- Perneczky, R., Wagenpfeil, S., Komossa, K., Grimmer, T., Diehl, J., & Kurz, A. (2006). Mapping scores onto stages: mini-mental state examination and clinical dementia rating. *The American Journal of Geriatric Psychiatry*, 14(2), 139-144.
- Pinquart, M., & Forstmeier, S. (2012). Effects of reminiscence interventions on psychosocial outcomes: A meta-analysis. *Aging & mental health*, 16(5), 541-558.
- Phinney, A., Chaudhury, H., & O'connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*, 11(4), 384-393.
- Pringle, A., & Somerville, S. (2013). Computer-assisted reminiscence therapy: developing practice. *Mental Health Practice*, 17(4), 34-37.
- Purves, B. A., Phinney, A., Hulko, W., Puurveen, G., & Astell, A. J. (2015). Developing CIRCA-BC and Exploring the Role of the Computer as a Third Participant in Conversation. *American journal of Alzheimer's disease and other dementias*, 30(1), 101- 107.
- Robin, B. (2008). Digital Storytelling: A Powerful Technology Tool for the 21st Century Classroom. *Theory Into Practice*, 47(3), 220-228.
- Rodnitzsky, R. (2015). Cognitive impairment and dementia in Parkinson disease. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)
- Rubinstein, R. L., Girling, L. M., De Medeiros, K., Brazda, M., & Hannum, S. (2014). Extending the framework of generativity theory through research: A qualitative study. *The Gerontologist*, 55(4), 548-559.
- Rule, L. (2010). DIGITAL STORYTELLING: Never Has Storytelling Been So Easy or So Powerful. *Knowledge Quest*, 38(4), 56-57.

- Savundranayagam, M. Y., Dilley, L. J., & Basting, A. (2011). StoryCorps' memory loss initiative: enhancing personhood for storytellers with memory loss. *Dementia*, 10(3), 415-433.
- Sawhney, N. (2009, June). Voices beyond walls: the role of digital storytelling for empowering marginalized youth in refugee camps. In *Proceedings of the 8th International Conference on Interaction Design and Children* (pp. 302-305). ACM.
- Schoklitsch, A., & Baumann, U. (2011). Measuring generativity in older adults: The development of new scales. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 24(1), 31.
- Stages of Alzheimer's disease. (2014, October). Retrieved April 13, 2016, from <http://www.alzheimer.ca/en/bc/About-dementia/Alzheimer-s-disease/Stages-of-Alzheimer-s-disease>
- Stake, R. E. (1995). *The art of case study research*. Sage.
- Stenhouse, R., Tait, J., Hardy, P., & Sumner, T. (2013). Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia. *Journal of psychiatric and mental health nursing*, 20(2), 134-141.
- Wallace, J., Wright, P., McCarthy, J., Green, D., Thomas, J., & Olivier, P. (2013). A design-led inquiry into personhood in dementia. *CHI '13 Extended Abstracts on Human Factors in Computing Systems*, 2883-2884.
- Wolk, D., and Dickerson, B. (2016). Clinical features and diagnosis of Alzheimer disease. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)
- Woods, B., Spector, A., Jones, C., Orrell, M., & Davies, S. (2005). Reminiscence therapy for dementia. *Cochrane Database Systematic Review*, 2.
- Woods, B., O'Philbin, L., Farrell, E. M., Spector, A. E. & Orrell, M. (2018). Reminiscence therapy for dementia. *Cochrane Database of Systematic Review*, 3.
- World Health Organization. (2012). *Dementia: a public health priority*. World Health Organization.
- Wright, C. (2015). Etiology, clinical manifestations, and diagnosis of vascular dementia. In: UpToDate, Post TW (Ed), UpToDate, Waltham, MA. (Accessed on March 24, 2016.)

Appendix A. Initial Project Goals

The initial goals/aims for our project used to create the post-course interview questions:

For people with dementia and caregivers:

- ☐ To provide people living with dementia the means to create and leave a digital legacy for their family and friends
- ☐ To potentially benefit people with dementia and their family caregiver. Research has noted benefits such as improved well-being, increased confidence, communication, connection with others, and feeling a sense of purpose.
- ☐ To provided possible emotional benefits during the process of digital storytelling such as joy, inspiration, and hope for the person with dementia and family caregiver

For families and loved ones:

- ☐ To provide families with a means to preserve memories with their love one with dementia
- ☐ To share stories with loved ones to foster and nurture relationships
- ☐ To provide a meaningful activity that the caregiver and person with dementia can engage in together

For the Alzheimer's Society:

- ☐ To collaboratively develop a storytelling program that is user friendly and appealing to the people with dementia and caregivers
- ☐ To provide the Alzheimer's Society with an activity to be implemented in their caregiver support groups
- ☐ To provide the Alzheimer's Society with digital stories that can be included on their website

Appendix B. MMSE

Blank copy of the MMSE, for information only:

Standardized Mini-Mental State Examination (SMMSE)	
DIRECTIONS FOR ADMINISTRATION OF THE SMMSE	
<p>1. Before the questionnaire is administered, try to get the person to sit down facing you. Assess the person's ability to hear and understand very simple conversation, e.g. What is your name? If the person uses hearing or visual aids, provide these before starting.</p> <p>2. Introduce yourself and try to get the person's confidence. Before you begin, get the person's permission to ask questions, e.g. Would it be all right to ask you some questions about your memory? This helps to avoid catastrophic reactions.</p> <p>3. Ask each question a maximum of three times. If the subject does not respond, score 0.</p> <p>4. If the person answers incorrectly, score 0. Accept that answer and do not ask the question again, hint, or provide any physical clues such as head shaking, etc.</p> <p>5. The following equipment is required to administer the instrument: A watch, a pencil and some blank paper. A piece of paper with CLOSE YOUR EYES written in large letters and two five-sided figures intersecting to make a four-sided figure is also required (on reverse)</p> <p>6. If the person answers What did you say?, do not explain or engage in conversation. Merely repeat the same directions a maximum of three times.</p> <p>7. If the person interrupts (e.g. What is this for?), just reply: I will explain in a few minutes, when we are finished. Now if we could proceed please... we are almost finished.</p>	
I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can.	
1. (Allow 10 seconds for each reply)	
a) What year is this? (accept exact answer only)	/ 1
b) What season is this? (during the last week of the old season or first week of a new season, accept either)	/ 1
c) What month is this? (on the first day of a new month or the last day of the previous month, accept either)	/ 1
d) What is today's date? (accept previous or next date)	/ 1
e) What day of the week is this? (accept exact answer only)	/ 1
2. (Allow 10 seconds for each reply)	
a) What country are we in? (accept exact answer only)	/ 1
b) What province are we in? (accept exact answer only)	/ 1
c) What city/town are we in? (accept exact answer only)	/ 1
d) (In clinic) What is the name of this hospital/building? (accept exact name of hospital or institution only)	/ 1
(In home) What is the street address of this house? (accept street name and house number or equivalent in rural areas)	/ 1
e) (In clinic) What floor of the building are we on? (accept exact answer only)	/ 1
(In home) What room are we in? (accept exact answer only)	/ 1
3. Say: I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. (say slowly at approximately one-second intervals)	
Ball Car Man	
For repeated use: Bell, jar, fan; Bill, tar, can; Bull, bar, pan	
Please repeat the three items for me. (score one point for each correct reply on the first attempt)	
Allow 20 seconds for reply; if the person did not repeat all three, repeat until they are learned or up to a maximum of five times. (but only score first attempt)	
4. Spell the word WORLD. (you may help the person to spell the word correctly) Say: Now spell it backwards please	
(allow 30 seconds; if the subject cannot spell world even with assistance, score 0) Refer to reverse for scoring instructions	
5. Say: Now what were the three objects I asked you to remember?	
(score one point for each correct answer regardless of order; allow 10 seconds)	
6. Show wristwatch. Ask: What is this called?	
(score one point for correct response; accept "wristwatch" or "watch"; do not accept "clock" or "time", etc.; allow 10 seconds)	
7. Show pencil. Ask: What is this called?	
(score one point for correct response; accept "pencil" only; score 0 for pen; allow 10 seconds for reply)	
8. Say: I would like you to repeat a phrase after me: No ifs, ands, or buts.	
(allow 10 seconds for response. Score one point for a correct repetition. Must be exact, e.g. no ifs or buts, score 0)	
9. Say: Read the words on this page and then do what it says.	
Then, hand the person the sheet with CLOSE YOUR EYES on it. If the subject just reads and does not close eyes, you may repeat: Read the words on this page and then do what it says, (a maximum of three times. This is covered in #3 directions section above). Allow 10 seconds, score one point only if the subject closes eyes. The subject does not have to read aloud.	
10. Hand the person a pencil and paper. Say: Write a complete sentence on that piece of paper. Allow 30 seconds.	
Score one point. The sentence must make sense. Ignore spelling errors.	
11. Place design, pencil, eraser and paper in front of the person. Say: Copy this design please. Allow multiple tries. Wait until the person is finished and hands it back. Score one point for a correctly copied diagram. The person must have drawn a four-sided figure between two five-sided figures. Maximum time: One minute.	
12. Ask the person if he is right or left handed. Take a piece of paper, hold it up in front of the person and say the following: Take this paper in your right/left hand (whichever is non-dominant), fold the paper in half once with both hands and put the paper down on the floor.	
Allow 30 seconds. Score one point for each instruction executed correctly.	
Takes paper in correct hand.....	
Folds it in half.....	
Puts it on the floor.....	
TOTAL TEST SCORE: / 30	
ADJUSTED SCORE: /	

This questionnaire should not be modified or reproduced without the written consent of Dr. D. William Molloy, Molloy DW, Alamyeh E, Roberts R. Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental state Examination. American Journal of Psychiatry, Vol. 14, 1991a, pp.102-105.

Appendix C. Release Form

Each participant chose to sign this release form which gave permission to include their photos in this research:

2016s0547



Digital Storytelling and Dementia Project Release Form

Please fill in and sign this form if you are willing to give us permission to use the images, photographs, documents, written materials, voice and sound recordings, and any other materials you have provided to go with your digital story. This release form is separate from the consent form that you signed before participating in this study. You are in no way obligated to sign this form to participate in this study.

Participant's Name: _____

Project Title: Digital Storytelling and Dementia

Research Team: Elly Park, Hollis Owens, Ron Beleno, Lili Liu, David Kaufman, Arlene Astell

I agree that my voice recordings and the images submitted, and taken during the project as well as my writings, documents, and photographs may be distributed by agents, employees or representatives of Simon Fraser University (hereinafter called "the University") without limitation through presentations, exhibitions, websites, print and internet publishing. Once the recordings and images are published, the researchers will not be able to remove them from the public domain.

I understand that I am granting all rights to these documents and images without compensation to the University for educational, noncommercial use.

However, by signing this release you do not waive any rights to legal recourse for harm you may incur as a participant in the research.

Project Title: Digital Storytelling and Dementia

Date: _____ By: _____
Signature

Telephone Printed Name

Email Street Address

City Province Postal Code