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Developing Design Elements for a Parkinson's Disease Informative Website: A Social

Marketing Approach

by

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A thesis proposal submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
with a concentration in Media Studies
The Zimmerman School of Advertising and Mass Communications
College of Arts & Sciences
University of South Florida

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Date of Approval:
June 17, 2020

Keywords: Grounded theory approach, information seeking, website design, health
communication

Acknowledgments

I dedicate this thesis to the incredible individuals I have had the privilege of meeting and interviewing for this project. Thank you for sharing your stories, thank you for helping me and trusting me to take what you gave me and make it something that will hopefully help people in the future. Thank you to my committee for their guidance, and particularly my chair, Dr. Janelle Applequist, for mentoring me through the thesis process and master's program. Thank you to my family, friends and boyfriend, your constant love and support has been invaluable. This process is a daunting one, it can be overwhelming, but it is worth it. Every second spent, every word read – creating something that can make a difference, it is always worth it.

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Abstract

Parkinson's disease is a neurodegenerative disease with no known cause or cure. No two cases are identical, meaning that every individual will present different symptoms and will have a different progression of the disease. Me Over PD is an initiative created to aid newly diagnosed PD patients and care partners in navigating the complexities surrounding the disease and live a more informed life with PD. Considering Me Over PD, the present research works to understand the experiences of PD patients and care partners upon diagnosis and after, and gauge what elements and information would be most beneficial to these individuals in creating an educational website. Study 1 used a grounded theory approach to guide the research, wherefrom the findings informed the use of Social Marketing Theory (SMT) in Study 2. The literature review contextualizes the use of semi-structured interviews and both theories respectively.

From Study 1 themes of misdiagnoses, lack of information upon diagnosis, information seeking via the internet, and social support emerged, which informed the need to create a PD website resource to provide them with the necessary information. From Study 2 categories emerged outlining specific types of favorable information, barriers of usage, the internet as the preferred resource, reiterating the findings from Study 1, and the wish to be informed about a PD website via the doctor. PD is a topic that has not been researched extensively, particularly regarding the early experiences of affected individuals. The present study aims to contribute new knowledge pertaining to the experiences of PD patients and care partners and inform what elements and information would be most agreeable for those individuals in creating an educational website for PD. By creating awareness of the needs of PD patients and care partners,

healthcare providers and the health communication community can take steps towards better understanding and catering to this demographic. Though more extensive research on the topic is needed, the present understanding and catering to this demographic. Though more extensive research on the topic is needed, the present research works as a building block for a better understanding of PD affected individuals and how best Me Over PD can develop a PD educational website for them.

Chapter One

Introduction

According to the U.S. Department of Health & Human Services, approximately 50,000 people are diagnosed with Parkinson's disease (PD). This number continues to increase as the U.S. population ages, with no preventative measures or improvement in the treatment of and cure for PD (National Institutes of Health, 2010).

Dr. James Parkinson first described PD in 1817 as a "shaking palsy." It is a chronic, progressive neurodegenerative disease characterized by both motor and non-motor features (DeMaagd, 2015). Though every case of Parkinson's varies from person to person, one constant of the diagnosis is increasing symptomatic degeneration and uncertainty surrounding its progression and treatment. Parkinson's disease can have severe impacts on patients, as well as their caregivers, through its progressive degenerative effects on both mobility and muscle control. "The motor symptoms of PD are attributed to the loss of striatal dopaminergic neurons, although the presence of non-motor symptoms supports neuronal loss in non-dopaminergic areas as well" (DeMaagd, 2015).

Advances have been made regarding treatment, primarily related to choices of medication and lifestyle regimens. However, there is still a lack of centrality for the information that patients and care partners need, meaning there is no one source of information that individuals living with PD seek out. An initial diagnosis should offer relief in terms of available resources that can ameliorate feelings of concern, distress, and doubt while offering solutions that encourage a more informed life with Parkinson's disease.

Me Over PD is an initiative established to create various forms of access through media and hardcopy for newly diagnosed patients to become more informed about all spheres PD, immediately. A larger study in progress aimed to garner a deeper understanding of patient and care partners experiences with PD, through their diagnosis, how they have coped with it and what was missing at the initial diagnosis, among other components (Appendix C).

A Grounded Theory approach guided the study in progress (Study 1) which brought the emergence of themes that became the basis for Study 2. The initial approach enabled the organic exploration of experiences and opinions of participants through the use of semi-structured interviews, which led to the overwhelming evidence for the need to create an online resource that could aid in giving newly diagnosed patients and their care partners the resources that many participants claimed that they did not receive upon their initial diagnosis. The results from Study 1 informed the use of Social Marketing Theory (SMT) in that it would inform what components would make a website, as a resource, the most useful. As SMT has not yet been used in the context of PD, this study aims to use SMT's framework in a way that can benefit newly diagnosed patients and care partners and shed light what elements and information would be beneficial to include in an educational website, barriers of usage, what medium of receiving information would be preferred and where they would want to learn 3about the website.

The current study will aim to answer the following questions, as they specifically relate to the creation of an ideal PD website and what that would entail:

1. How can theory help to inform the design of an educational website for newly-diagnosed PD patients and care partners?
2. What elements should be considered in the creation of an educational website for newly-diagnosed PD patients and care partners?

3. What types of information is most important to include in an educational website for

   newly-diagnosed PD patients and care partners?

Chapter Two

Literature Review

Lack of Information about Parkinson's disease

As patients and care partners regularly see various physicians, their ability to convey an understanding of the uncertainty they experience and being able to explicate what to expect with PD, is integral to both patients' and care partners' ability to better cope with their diagnosis. Pinder (1990) proposes that specialized training and educating physicians on the subject of PD will make the patient and care partners' coming to terms with the diagnosis more bearable. As PD is a complex and individualized disease, positive coping strategies that serve all patients and care partners are not readily available.

Physician insights are integral to a patient and care partner's understanding. Van der Eijk's (2011) used focus groups of patients and care partners to identify what is missing in patient-care, found that one of the primary faults in the healthcare system, with regard to movement disorders, was that patients did not have the tools to find professionals that met their exact PD needs. The study aimed to aid healthcare professionals in providing individualized medical help for PD patients through further research. Due to the complexity of PD, there is difficulty related to finding specialized physicians, among other things, which is a critical reason that an initiative such as Me Over PD is so vital to patients and care partners.

Another physician-related component vital to patients and care partners being more informed about PD is the communication between care partners and physicians. McLaughlin (2010) investigated caregivers' experience through the health system with PD, finding that

"carers commented on the lack of continued and coordinated care plans for relatives, resulting in symptoms being mismanaged and care opportunities for relatives and carers missed" (McLaughlin, 2010). The lack of coordinated care constitutes concern as it results in various complications both physically and emotionally for patients and care partners. A coordinated, central site for information and care would be beneficial in avoiding improper and lacking care and treatment.

As a result of the lack of communication between patients, care partners, and physicians, and physicians' general lack of knowledge about the disease, patients and care partners are essentially not able to "live well." Lee's (1994) research assessed the lack of knowledge of patients and caregivers. The study found that as PD is a disease that comes with various difficulties both physically and mentally, proper knowledge of lifestyle management and ways to overcome or "live with" such difficulties is integral to improving a patients quality of life, as well as aiding the care partners in providing the day-to-day care needed (Lee, 1994). A central campaign provides a hub of information for all stakeholders involved with PD, would be beneficial in ensuring a better life for the patient, and a less stressful task of care for the caregiver.

Another barrier for information gathering is that of limitations in media usage and how that affects patients' ability to seek out PD information. As the shared decision-making approach conveys a patient's active engagement with his/her treatment, an analysis examining the strategies of information-seeking used by patients shed light on patients' perceived access to information (Lubi, 2014). Participants who actively use various media sources were more likely to seek out information online and find information readily available than the participants who are less active media users (Lubi, 2014). Though information concerning disease progression

was not explicitly stated, such factors and age could contribute to a patients' inability to/lack of want to use media both in general and for information-seeking purposes. Furthermore, a campaign and platform that would cater to individuals who are both media savvy and those who are not, would allow for a larger group of patients and care partners to participate in active information-seeking.

However, coping styles and uncertainty about PD serves as another reason for the creation of the Me Over PD campaign. Sanders-Dewey (2001) found that emotion-focused coping was associated with a higher level of distress in patients, whereas emotion-focused coping, as well as uncertainty, warranted more distress for care partners. Emotional distress over the PD, specific to the patient, manifests predominantly in the patient as a care partner can only empathize; however, this does not affect their uncertainty about the illness. Overall uncertainty about PD affects all parties involved and calls for better education about the disease and ways to manage symptoms and overall well-being.

Uncertainty surrounding PD can have severe consequences for patients. One study found that of a sample of 120 patient participants, 68% scored above the cut-off score for depression (Ahn, 2017). The determining factor for this mental illness was attributed to fatigue and uncertainty, further illuminating the importance of ameliorating uncertainty, so that it does not lead to other negative health-related consequences.

Many factors come into play concerning the uncertainty experienced by patients and care partners, whether it be a lack of information or a general lack of communication. Proper conveying of information is essential to have a more wholesome understanding of the disease and how to live with it.

Grounded Theory Approach

Glaser and Strauss who founded Grounded Theory (GT) in 1967, described the theory as "how the discovery of theory from data – systematically obtained and analyzed in social research – can be furthered" (Glaser & Straus, 2009, p.1), a main strategy of theirs being the general method of comparative analysis. Tracy (2019) describes the constant comparison as "The inductive process of generating an interrelated set of conceptual categories to explain a phenomenon, a theory, is made possible by the use of …constant comparison" (Tracy, 2019, p.72). Induction is considered the key for the Grounded Theory approach development, which entails the researcher transitioning from the data to empirical generalization, and thereafter, possibly, theory development (Heath, 2004).

Furthermore, Tracy (2019) emphasizes another aspect of the Grounded Theory approach as being of great importance, which is theoretical sampling. This essentially means narrowing in on a sample through various criteria that will best inform a given topic of research. As a researcher chooses a topic of study and develops research questions, by creating criteria for a study's sample it allows the researcher to narrow in what qualifications will be most important in extracting information to best answer the research questions and allow for consistent data to emerge that results in new phenomena.

In addition, by constantly comparing the data collected from a sample of individuals that fit the framework of what is being studied and the topic, the Grounded Theory approach allows for categories and themes to emerge naturally, guided by what or whom is being studied. Using constant comparison allows for the empirical data to be conceptualized in categories that can form generalizations about a topic (Tracy, 2019, p.73). The process of coding is divided into three separate phases which are open, axial and selective coding. First is open coding wherein

the researcher looks at the raw data and aims to show and explain what is happening, thereafter axial coding aims to narrow down the categories or codes created from open coding, and lastly, selective coding then aims to make meaning of the major categories found during axial coding. Through these phases the researcher aims to generate new conceptualizations of the studied phenomena (Walker, 2006).

The Grounded Theory approach differs from Grounded Theory, in that it is not a process used for the development and creation of theory, but rather the focus on how new phenomena can be discovered through the natural emergence of themes and categories through the analyzing data. The foundation of the Grounded Theory approach is the development of themes through rigorous analysis of empirical data (Charmaz, 2015). The approach uses the same concepts of theoretical sampling, induction reasoning and constant comparative method in order to reach new phenomena, however, instead of theory, the findings' novelty are the purpose of using the approach.

Grounded Theory Approach & Parkinson's disease

Furthermore, the GT approach has been used when approaching various healthcare issues and experiences, specifically in the case of Parkinson's disease, as the disease is so individual to each patient and care partner. Using an approach that allows for the natural emergence of themes is essential in understanding the individual experience.

Abendroth (2012) used semi-structured interviews focusing on Parkinson's disease, specifically looking at "the process of healthcare decision-making and to illustrate the experiences of caring for persons with Parkinson's disease. The interview questions centered on family caregiving experiences and on how these caregivers made long-term care decisions on behalf of their loved ones" (Abendroth, 2012, p.445). Results showed that increased strain on the

caregiver, with the progression of the disease, was a significant risk factor for institutionalization. Other factors included progression in symptoms that could lead to severe injury, managing health changes, among other things. With increased duties as a caregiver, when a patient's disease progresses, Abendroth (2012) found caregivers more likely to choose institutionalization for their loved ones. The noteworthiness of this study becomes clear in that the factors that result in the choice to institutionalize could be lessened if proper tools were available for both the patient and care partner. Bringing about the necessary resources for a patient to halt or slow progression would potentially result in a lesser burden for the care partner. Furthermore, having more resources and information could allow for better coping, even when faced with a progressively difficult situation.

Better communication between care partners and healthcare providers, family-centered interventions and care partner assessments, may be useful tools to prevent early institutionalization of a patient. The study showed how care partners are affected has implications on several fronts — using a Grounded Theory approach, asking broadened questions about their care and decision making, results in novel findings of triggers and factors coming into play, resulting in institutionalization, which henceforth could be considered. Furthermore, the Grounded Theory approach worked as an agent for bringing about themes that researchers may not have considered before. Allowing the factors of distress and overall experiences bring about themes and essentially identifying what must be done differently so that premature institutionalization can be avoided is vital to understanding and living a more informed life with Parkinson's disease for all parties involved.

Conversely, a Grounded Theory approach was used when looking at self-care exercised by patients with PD, a topic of study that is extremely limited, as most studies are concerned

with the choices that care partners and physicians have to make for them (Soleimani, 2015). Findings showed a 'fear of becoming crippled' as a critical concern for patients, identifying 'independent self-care' as the most useful approach to counteracting the fear. In understanding these concerns and specific needs such as, 'spiritual care' and 'seeking treatment' through the scope of the Grounded Theory approach, was beneficial in that it allowed the acquirement of information specific to each patient living with Parkinson's disease, that may not have been evident if the research had been guided through a more narrow theoretical scope, not focused on the natural themes emerging from the interviews.

Furthering the topic of 'choice' for a patient, another study looked at the positive and negative outcomes associated with a PD progression-resistance program. O'Brien (2009) used a Grounded Theory approach interviewing Parkinson's patients who participated in the 10-week resistance program. Themes emerged describing "(i) motivators for participation in the PRST programme were broader than physical outcomes, (ii) the outcomes were broader than just physical outcomes, (iii) the indicators of success for participants varied, and (iv) the participants' experience of a disease-specific exercise programme was positive" (O'Brien, 2009).

Using a qualitative Grounded Theory approach identified themes that are not necessarily quantifiable, but acknowledge individual experiences and motivators, specific to each participant. These themes, in a broadened view, could shed light on how other individuals with Parkinson's might also feel about such a program.

Resistance to the progression of PD is essential, whether it be opinions on a resistance program or an exercise program as with Eriksson's (2013) research. His study examined the meaning of exercise to Parkinson's patients involved with an exercise program. A Grounded Theory approach was used, resulting in the emergence of themes, as for example "keep moving

to retain the healthy self." Key reasons for continuous exercise were wishes to halt the progression of PD, maintaining confidence and life goals, among others. These emerging themes, identified through the use of a Grounded Theory approach, are key components to promoting physical exercise for Parkinson's patients, as the responses and reasonings are qualitative, bringing about broader ideas that could aid in making other PD patients participate.

Interviews conducted on PD patients and near familial relatives found in looking at perceptions of communication, "managing identity together," was a prominent theme that emerged. This sheds light on ideas of independence, or lack thereof, self-sufficiency, and sense of self, as it relates to living with Parkinson's disease (Roger, 2010). The emergence of such categories facilitates an organic rise of certain themes, as a result of the specific experiences of the participants.

However, Grounded Theory approach can also work as a way of understanding the lived experience of PD patients. Another study looked at late-stage Parkinson's patients through longitudinally conducted interviews, Williams found the emergence of "bridging" came about. Specific to this category were three subcategories: 1) building on the past, 2) bridging the present, and 3) broaching the future. These subcategories addressed the stages that participants went through as they adjusted to their diagnosis and what it means to live with PD. This study sheds light on transitional themes of participant experiences that emerged as a result of a Grounded Theory approach allowing categories to emerge from raw data, without a predetermined framework.

Grounded Theory Approach & Neurodegenerative diseases

Other neurodegenerative diseases have used a Grounded Theory approach. Wilson (1989) explored caregivers of elderly relatives who have Alzheimer's, focusing on their experiences as

caregivers. Themes of coping emerged, as it related to having to make negative choices for and about their relatives, for example, institutionalization versus keeping the patient at home. This category was broken down into three stages of coping: taking it on, going through it, and turning it over. These three stages capture the various feelings taken on by caregivers when faced with negative choices about a relative with Alzheimer's. Through the use of a Grounded Theory approach, Wilson was able to extract an umbrella category, which then illuminated three subcategories of coping.

Wuest (1994) explored another facet of coping in her study, focusing on the "becoming strangers" facet of coping with a family member with Alzheimer's. By using a Grounded Theory approach, patients and caregivers were interviewed to gauge the reciprocal process of "dawning, holding on and letting go" (Wuest, 1994). Themes of familial struggles emerged as caregivers navigated the complexities of commitment to the person they once knew and the detachment from the person that they have become. A Grounded Theory approach was essential to such a study as no theoretical framework would necessarily have allowed for the natural emergence of themes from both caregivers and patients.

From the research above, Orona's (1990) study looked at the construction of one's social identity, formed and maintained, and how such an identity becomes lost through Alzheimer's disease, through the eyes of family members. Themes emerged of the family members' strategies of holding on to the patient's former self and the subjective aspects of such experiences. Orona's Grounded Theory approach allowed for the concept of identity loss and wanting to "hold on" loss perceived by family members to surface.

The Grounded Theory approach has been the framework in the context of Multiple Sclerosis. Looking at the occupational nature of being a caregiver to an individual with multiple

sclerosis, Heward (2006) examined how the disease can affect family life. Results found that partner's occupations were influenced by multiple sclerosis, bringing about themes of new opportunities inspired by the disease, constraints brought about as a result of the disease, and a yearning for the life they had before multiple sclerosis. These categories of the occupational impact of multiple sclerosis on care partners shed light on the difficulties faced by allowing the natural emergence of themes through a non-guiding framework.

Social Marketing Theory

Zaltman and Kotler (1971) introduced the Social Marketing Theory (SMT) as a way of using marketing concepts in order to influence social problems or initiatives. They proved how marketing analysis, planning, and control could aid in facilitating social change in society. These changes are facilitated through the four P's of marketing: product, price, place, and promotion, which, when all analyzed, about a specific social cause/change, behaviorally speaking, will be beneficial in progressing such change. Each component signifies an essential element to a successful behavior change. The product itself is the behavior or benefit that researchers aim to steer individuals toward. The price is potential barriers to behavior change, such as price, transportation cost, or general resentment of the proposed or potential behavior change/benefit. Thirdly is the promotional aspect, how do they engage, meaning, how is it presented in a way that encourages interest. Lastly is the place, referring to the place that an individual would go for the product, for example the internet, depending on what people would be most likely to use/would want to use.

"According to Dearing and Kreuter (2010), designers must be listeners, in order to facilitate a consumer-oriented approach, in which researchers seek to understand the needs and interests of potential adopters, who are substantially engaged in developing, adapting, and

improving an innovation based on their unique experiences (p. S105). Involving the target population in the design of innovation, such as a product or service, ensures that the innovation is needed and will be more likely to diffuse quickly and sustain longer" (Sundstrom, 2014, p.88). In essence, the core concept of social marketing theory is the ability to understand the needs of consumers as it relates to a particular topic/issue or behavior, and reflect that in a product that aligns in terms of all marketing aspects, including the price, place and promotional aspects, as they inform the way by which the product is to be set up so that it creates the overall wanted behavior.

In looking at social marketing theory, an important use of the theory is designing campaigns and interventions. As Manikam (2016) describes, many theories that social marketers use may not accurately reflect the exact nature of the behavioral issue, which is where social marketing theory can fill a critical gap. The study explained that the theory used to guide a campaign or intervention must explicitly reflect insight and core behavioral drivers in order to be successful. Social marketing theory plays an integral role in this, as the theory, with its four P's, evaluates and identifies key factors in the social marketing process that will allow for a more successful campaign or intervention, as a result of definite consumer opinions, thoughts, and behaviors.

Commonly there is an emphasis on the framing of social, environmental, and health changes as problems in need of solving. As Rundle-Thiele (2018) states, emphasis on explaining and predicting rather than changing behavior is the primary psychological lens used to tackle such "problems." Rather than focusing on current practices and behaviors, SMT aims to understand human behavior, as it applies to a specific social, environmental, or health care, and

thereby use that information to gauge how to transition behaviors from current to marketing intended (Rundle-Thiele, 2018).

Social Marketing Theory & Health

The social marketing approach has been taken with regard to many health-related topics. Rioncancio's (2019) study on HPV vaccine initiation among young Hispanic individuals utilized social marketing theory to gauge how to promote vaccination successfully. The research showed that the desire to prevent illness and protect children was the greatest motivation for participants to decide to vaccinate. It was found that most did not experience barriers; however, the ones who did, most commonly referenced, needed more information about the vaccination before deciding to vaccinate. Rioncancio found that interventions should target schools, clinics, and community centers in order to raise awareness about the vaccine. These results cover the various 4 P's (product, price, place, and promotion) in informing how the proposed behavior change would be attainable in the marketing mix.

Another study (Daniel, 2009) looked at the use of social marketing theory to help increase early identification and, thereby, treatment of developmental disorders in children. The initiative aimed to create a campaign targeting parents, healthcare professionals, and educators, to increase awareness of developmental disorders and precipitate action if such disorders are suspected. Daniel's looked at the barriers and motivators for such a change in behavior, finding a lack of knowledge and resources and a willingness to learn some key factors. Gathering information on all four P's thereby informed the study, finding that images visualizing the severity of such disorders was a helpful tool in increasing awareness, and participants want to take action.

The study found that understanding the wants and needs of the target audience, as well as informing healthcare professionals and early educators, aided in creating a successful campaign that resonated and prompted behavior change/action (Daniel, 2009). An awareness of individuals that could help precipitate the desired behavior change is crucial, creating another realm of the target audience for the current study, as audiences other than patients and care partners could be pivotal in propelling the target audience towards an acceptance of the campaign and thereby taking action and utilizing that resources that Me Over PD are creating for both patients and care partners.

Other research has sought to gauge whether participants' risk perceptions and efficacy beliefs could be used to divide audiences into segments to aid in interventions that aim to change behaviors relating to HIV (Rimal, 2009). Households in Malawi participated in a survey and used cluster analysis in order to categorize the participants' risk assessments and ran an analysis of covariance models to determine how people without certain risk perception attitude groups would affect knowledge about HIV. The study showed how audience segmentation could serve as a tool to determine whether HIV intervention messages should include perception of risks, self-efficacy beliefs, or both. Social marketing theory was the approach that guided the segmentation, aided in identifying what types of intervention messages would be most beneficial to the target audience.

An issue of health communication is the proper dissemination of information on research to audiences. Lock's (2000) research looked at how to facilitate brief alcohol intervention to general practitioners best. Principles of social marketing theory were applied in order to identify best how to manipulate audiences. The study found that personal marketing was the most effective strategy of dissemination; however, telemarketing was the most cost-effective. This

study shows how the use of social marketing theory aided in understanding how best to infiltrate and manipulate the market, being that of general practitioners, as a means for spreading valuable information.

Another issue concerning health disparities is that of ethnic minority women and white women, comparatively. Duerksen's (2005) study looked at the differences in exposure to health-related media messages, having to do with racial and ethnic imbalances as it relates to health outcomes, and whether there are variations in health advertisements among magazines aimed at African American, Hispanic and Caucasian women. Duerksen found that ethnic minority women were exposed to less health-related advertisements than Caucasian women and that they were exposed to more negative advertisements, featuring images of ethnic minority women, whereas positive advertisements predominantly featured Caucasian women.

This goes to show the lack of health education that certain ethnic groups are faced with. This study shows the importance of targeting the social marketing mix to all individuals who could benefit from such information. As it relates to the current study in that Me Over PD aims to aid both patients and care partners in gaining information about Parkinson's Disease, making sure that such information is private to those who may need it.

Social Marketing Theory & Neurodegenerative Diseases

Though several neurodegenerative diseases have been studied through the scope of social marketing theory, none have yet used it with Parkinson's disease. This gap in research allows the current study to fill a gap in terms of how social marketing is understood through the eyes of care partners and patients, tailoring the product to their needs.

Much of the previous research conducted by way of SMT has focused on campaigns worked to destigmatize, promote awareness, and raise money. For example, in a dementia

campaign with the key goals of raising awareness and reducing the stigma surrounding the disease, research was conducted on the general public, the care partners and the individuals with dementia, to gauge their beliefs and informational needs regarding the disease. Results showed that conveyed the importance of realistic portrayals of individuals with dementia, as well as avoiding the instilment of fear of the condition in public. By using a social marketing approach to understand what components would be integral to creating a campaign that successfully educates and brings awareness of the actuality of the disease and the disease itself (Devlin, 2006).

However, focusing on risk factors, preventative measures, and early intervention strategies for dementia is another realm wherein social marketing theory was used. Andrews' (2011) campaign targeted awareness of hypertension as a risk factor for dementia through the framework of SMT, specifically the four P's, to plan, implement, and evaluate the campaign. The aim of the campaign was to prevent, monitor, and manage hypertension and to prevent the onset of dementia by changing a population's behavior concerning the disease and lead to widespread adoption of the campaign that would result in better management of hypertension.

Multiple sclerosis is another neurodegenerative disease that has been used in the context of SMT. In a cycling fundraiser for the Multiple Sclerosis Society, SMT was employed to gauge participant experiences (Higgins, 2008). Data were collected on perceptions of benefits, costs, as well as efficacy ratings based on the event. Furthermore, interviews sought out reactions to marketing and communication, as it relates to improving the overall event, reducing costs, maintaining and gaining more participants. These essential factors were examined through the lens of SMT to understand what factors would allow the organization to attain its goals.

Chapter Three

Methodology (Study 1 & 2)

Prior to the commencement of the following interviews with Parkinson's disease patients and care partners, Institutional Review Board (IRB) approval was obtained.

The goal of Study 1 was to garner an understanding of the experiences of PD patients and care partners when they initially were diagnosed and following, through the use of a Grounded Theory approach.

The goal of Study 2 was to garner an understanding of what elements and information would be most beneficial in creating an educational website for newly diagnosed PD patients and care partners, through behavioral factors outlined by Social Marketing Theory's four P's (product, price, place, and promotion).

Participants

The same recruitment requirements were set for the purpose of Study 1 and Study 2. Parkinson's patients and care partners over the age of 18 were selected for participants in this study. Both male and female participants were recruited between the ages 50 and 81. Due to the purpose of the study being to extract information about patient and care partner experiences with PD, participants must have either been diagnosed with PD or have a spouse or partner who had.

For Study 1, the researcher's committee chair, Dr. Janelle Applequist, Associate Professor at the University of South Florida (USF), aided in the recruitment of participants. Dr. Applequist, through her position as Marketing Director of Me Over PD, reached out to the President of the organization to enlist potential participants. Upon receiving names and email

addresses from the organization's President, potential participants were emailed directly by the researcher. In order to recruit participants for Study 2, the researcher reached out to previous participants and points of contact through Me Over PD, and also sent emails each potential participant directly.

The emails sent out included details about the purpose of the study, the Informed Consent Form, research procedures, and participant confidentiality protection. Participants who signed the Informed Consent Form were again contacted to set up an interview time and date, and guidelines for the interview process and procedures. Interviews were scheduled through a doodle-poll which allowed the researcher to easily track sign-ups and allowed for no overlap in requested interview dates and times.

This process for Study 1 occurred between February and April of 2019 and the process for Study 2 occurred between September 2019 and March 2020. Recruitment and interviews concluded once data saturation had occurred (Tracy, 2019, p.261) meaning that little to no new information was surfacing. Saturation was achieved at a total of 10 participants (N=10) for each study (Study 1 & 2), equaling a total participant number of 20 (N=20). Each study (1 & 20 included 5 participants of which were patients and five of which were care partners, respectively. Due to this study being part of a larger project, listed participant numbers are higher than the total N=20.

Interviews

The same interview methods and process were used for both Study 1 and Study 2. Qualitative interviews were the primary method of data collection for Study 1. The reason for this is that this method is used in studying individuals' lived experiences (Merriam, 1998) which is particularly important when considering the individuality surrounding PD progression and

journey. Through qualitative interviewing, a participant is able to explicate in their responses allowing for thick description which aids the researcher in understanding the conditions and circumstances surrounding a participant's response, allowing the researcher to draw conclusions based on greatly detailed facts of that aid in contextual interpretations of participant experiences (Tracy, 2020, p. 24-25).

For this study, all interviews were conducted via Go To Meeting which is an online video conferencing service. Go To Meeting was a beneficial way of conducting interviews, as it allowed the researcher to connect with individuals who were not in the immediate vicinity and allowed for more flexibility for when both participants and the researcher were available to interview. In addition, the video conference service was beneficial in that it allowed for face-to-face interaction which aided in establishing personal connections and comfortability with participants.

At the beginning of the interview, the researcher identified herself as a master's student at the University of South Florida and research assistant for the study, informed of the purpose of the study and the procedure of the interview, and informed the participation of their right to withdraw from the interview at any time and the protection of their identity. Pending the approval of the interviewee, the interviews were recorded via video and audio recording, which were automatically transcribed as part of a service provided by GoToMeeting. Throughout the interview, the researcher wrote handwritten notes, allowing for tracking of important points of conversation to return to upon analyzing the data.

Semi-structured interviews were used for this study, as they permit natural conversation based on participant responses which elicit thick description and the emergence of topics that the researcher may not have considered prior. Using this approach lets the interviewer move around

the guide and generate questions organically based on participant responses. Semi-structured interviews were appropriate for this study due to the nature of the topic being researched. Every individual's experience with PD, both in terms of their journey and the progression of the disease is specific to that person, no two cases or journeys are identical and therefore allowing participants to respond to questions without confinement and exact protocol of questioning, a comfortable rapport was developed with participants.

The researcher used an interview guide (Appendix C) to direct the flow of conversation during the interview, beginning with, "Please take me back to the initial diagnosis, what was that like, how did that come about?" The question allowed participants the opportunity to express their experience leading up to, during and immediately after their initial diagnosis, to get an understanding of their mental state during that time period. All remaining interview questions were open-ended questions, encouraging participants to answer organically and allow for the natural flow of conversation between the participant and the researcher. When needed, follow-up questions aided in probing further into responses, points or experiences of participants (Fylan, 2005).

For the purpose of Study 1, questions were posed in order to gauge the experiences of PD patients and care partners at their diagnosis appointment and following. As the Grounded Theory approach was used to guide Study 1, questions were formed and posed that would allow themes to emerge naturally. A question such as 'Can you tell me about the doctor's visit when you (or your partner) were diagnosed? Was anyone there with you? How did you feel before and after?' was asked in order to guide the topic of conversation, while allowing participants to divulge and tell their story the way that they felt most comfortable with. Furthermore, a question such as 'Can you tell me about your life since your (or your partner's) diagnosis?' was asked, which

aimed to garner an understanding of how their lives have changed since the initial diagnosis. By creating a question such as this in the light of the Grounded Theory approach, the researcher is able to very broadly ask about an experience that, in turn, leads to the natural emergence of information about what aspects of their lives that have changed the most and been more significant. Additionally, a question such as 'Did you feel like you knew a lot about PD when you (or your partner) were diagnosed? How did this "knowing" versus "not knowing" feel for you?' was asked in order to understand the level of knowledge that participants had or did not have and what feelings it resulted in. Again, remaining aware of the purpose of the study and the topic, but allowing participants to explain in an open-ended, non-conforming way, what their knowledge was or was not and how it affected them. The questions developed for Study 1 were all founded in the Grounded Theory approach so that themes were able to naturally emerge via the participant responses. Though the questions were created in order to guide the topic and progression, they were created in a way that did not endorse a particular response and allowed the participants to guide the findings.

The results from Study 1 informed the use of SMT in Study 2, aiming to garner a better understanding of what elements and informational components would be most agreeable to participants. The researcher added two questions to the interview guide (Appendix C) from Roncancio, Muñoz, Carmack, and Ward's (2019), based on SMT, in order to best gauge and how to understand what preferred elements and information would be most useful for newly diagnosed PD patients and care partners in developing a educational website.

The questions aim to identify the four P's (product, price, place, and promotion) for the Me Over PD website. The researcher formulated two questions in order to gauge the necessary information:

1. If you need it, where did you look for information about Parkinson's Disease? (adapted from Roncancio, Muñoz, Carmack & Ward, 2019) -- *Place*

2. What would make you choose to use a specific organization as your primary source of information about PD (format, medium, accessibility, connectivity, etc.)? (adapted from Roncancio, Muñoz, Carmack & Ward, 2019) -- *Product*

2a. Price: what would be a barrier for you using a website? What would make it difficult/make you less likely to use it?

2b. Place: What would be your ideal place to look for information, if you had just been diagnosed? (website, doctor, library, etc.)

2c. Promotion: What would allow you to engage with a product/where would you want to hear about a product? (Local newspaper, from your doctor, pamphlet, etc.)

2d. Product: What would make you more like to use a website? (usability, easy to navigate, information and clinical trials, educational information, etc.)

The two questions that were added to the interview guide were developed through the guidance of SMT in order to clearly identify the most integral components of the theory. The first added question was created in order to firstly garner a clear understanding of the preferred source/medium of information for participants. Beyond this, the second question was aimed at gauging what aspects of a website would be viewed more positively by participants. Additionally, the four p's are defined in order to probe at what would make a participant not want to use a resource and where they would like to receive information about a resource and give context to product and place which questions 1 and 2 are geared towards. These questions and subparts were developed in order to best extract information pertaining to each of the four P's of SMT. By creating questions that cater to best understanding the four marketing pillars, the

researcher would be able to, through theory, have the best understanding of what elements and educational material would be most beneficial to participants.

To ensure the credibility of the research findings, participants' responses were explored thoroughly by way of interviews lasting between 60 to 130 minutes. The varying length of interviews depended on the information shared and the depth of conversation with the participant. The video and audio recordings were automatically recorded by Go To Meeting immediately following the interview. Thereafter the researcher proofread the transcription along with the audio recording to assure the accuracy of transcription, taking an average of 3 hours per interview.

Data Analysis & Intercoder Reliability

Interviews were conducted until saturation was reached, which means that little or no new information is emerging. When the criteria for participating is narrow, the optimal number of participants decreases (Tracy, 2020, p. 260-261). Saturation was reached at N=10 for each study (Study 1 & 2) respectively. Each study included five participants who is patients and five who is care partners, equally 20 participants total (N=20).

The data from both studies (Study 1 and Study 2) was analyzed through open, axial and selective coding. Open coding shows and explains what is happening, axial coding narrows down the categories from open coding, and selective coding gives meaning to the major categories found during axial coding (Walker, 2006). For the studies, a second coder was recruited, who is a graduate student at the University of South Florida, who is a research assistant on the Me Over PD research project and has familiarity with the organization and content. The second coder aided in creating a Grounded Theory approach codebook and reaching appropriate intercoder reliability, for the codebook. Intercoder reliability increases the trustworthiness of the

realist claims of frequency and existence of behavior in a study by quantifying researchers' level of agreement about such frequencies and behaviors (Tracy, 2020, p. 403-404).

For the first phase of coding (open coding) for each study (Study 1 & 2) respectively, the transcriptions of the interviews were analyzed for recurring words and ideas. The researcher and coder reviewed the transcripts manually, highlighting phrases and sentences that were considered significant to the research questions, respectively. Each analyzed the transcripts several times until consistent categories of phrases and sentences emerged from the data. Then, each coder added names to each of the categories, whereafter she coded each transcript and created a file documenting each of the codes and their respective definitions.

Thereafter the researcher and the coder conducting their first round of reliability testing. During this phase, the two coders used Miles and Huberman's reliability equation, where they found their number of agreements and divided them by the number of disagreements plus the overall number. Using this reliability test, the required agreement percentage is 90% or above, in order to be considered thoroughly valid. For Study 1, three rounds of reliability testing were conducted before reaching an agreement of 93%. The coders met in person to discuss the codes and their definitions and calculate reliability. Between each test, the coders revised their codebooks, rewording codes in order to create more clarity in code definitions, whereafter they analyzed all 10 transcripts again. The coders spent approximately 18 hours coding transcripts, working through codebooks, discussing, and calculating reliability. For Study 2, two rounds of reliability testing were conducted before reaching an agreement of 97%. The coders met in person to discuss codes and definitions and calculate reliability. Between each test, the researcher worked to reword codes in order to create more clarity in code definitions, whereafter

they analyzed all 10 transcripts again. The coders spent approximately 14 hours of coding transcripts, working through codebooks, discussing them, and calculating reliability.

Once appropriate intercoder reliability was achieved, the researcher continued onto axial coding, which entailed creating categories for the codes agreed upon previously. To do so, the researcher analyzed the transcripts for the frequency of codes, in order to quantify the frequency of them, thereby allowing for major categories to be derived from the codes. Thereafter, such categories were reinterpreted as major themes. The emerging themes present as the narratively described results of the study, giving meaning to the categories in terms of overarching behaviors and experiences, generalizable for the participants in the study. For Study 1, the researcher spent approximately 15 hours coding over all three phases. For Study 2, the researcher spent approximately 13 hours coding over all three phases.

Chapter Four

Results Study 1

The data collection of Study 1 and subsequent results served as a pilot for Study 2. Primary themes emerging from this pilot phase showed that SMT would be an appropriate framework to explore further because of the importance of informational and social resources and/or lack thereof as expressed by participants. Informational resources, as a category, addressed how participants required more information to be provided by their healthcare providers, in the sense of resources and educational material concerning PD, emphasizing how important their own information seeking quest became for them. Social support addressed participants' emphasis on the importance of social and familial support and how it was missing for many in the months following their diagnosis.

Diagnosis & informational resources: misdiagnosis

Patients expressed many obstacles in their quest for a diagnosis, however, prior to receiving their diagnosis of PD, many patients received misdiagnoses. In fact, 60% (⅗) of patient participants reported receiving a diagnosis other than Parkinson's for their symptoms. The misdiagnoses ranged from participant 6 being suspected of having a B12 deficiency to Participant 1 showing symptoms of a stroke. Participant 14 explained,

> "It began when I lost my sense of smell years before I was diagnosed, in 2014. I started having pains in my hip because I think my rigidity was working to skew my skeletal system. I started having problems with my pain in my neck...I went to a neurologist and he said that he had to operate in my cervicals. He said that my cervicals were misaligned

and were hurting the nerve, the spinal nerve. So I had spacers put in my neck. They

paralyzed my vocal cord in the process. Yeah, that was in 2013, I believe."

Thereafter, her right arm started becoming increasingly rigid and they experienced

shaking when in stressful situations. This was followed by a freezing episode where she could

not move her feet and another occasion where she almost fainted due to dizziness. The

participant eventually went to another neurologist who diagnosed her with a brain tumor,

however, this did not appear to be the cause of all of her symptoms. Participant 14 continued,

"You see how complex this is. So I had my head opened a tumor excised and my arm still

wasn't working. So I went to a third neurologist and he saw me walk and he said you

have Parkinson's. That was February 10th, 2014 at 1:15 in the afternoon."

This participant went through three years of misdiagnosis before reaching her PD

diagnosis, which left her with increased symptoms as a result of going untreated. This is,

presumably, largely due to the broad range of symptoms that patients exhibit that could indicate

other health conditions, and considering the individualistic nature of PD.

PD is so complex in nature that it is difficult to diagnose patients correctly in some cases,

which leads to increased uncertainty about a patient's condition and results in lost time during

the misdiagnosis period. One participant (1) expressed his frustration at this loss of time, stating,

"Well, I was basically pissed that it took a good six months from the time that I began

telling my internist about what was going on, to getting me to the neurologist. And again

this is an example, I think, of how frontline docs are not aware enough of the, you know,

just an infinite number of symptoms that Parkinson's can present."

This exhibits a lack of understanding or knowledge and the frustration that can

accompany a late diagnosis, and illustrates the importance of receiving a timely diagnosis.

Many care partners too, expressed their frustrations with their partners' misdiagnoses. A total of 60% (⅗) of care partner participants too reported their partners having experienced misdiagnoses prior to their PD diagnosis. When describing how PD was canceled out as a potential reason for her husband's tremor, Participant 7 stated that "I mean that hadn't, I mean it did come up when he first had a tremor that his internist had really thought was just a tremor a non-essential tremor." Furthermore, Participant 2 stated, "he had a false diagnosis. He probably told you and lost a year, which is you can imagine pretty significant as a loss, and during that time he had been in denial that something was seriously wrong." This exhibits additional cases of misdiagnoses which lead to significant loss of time wherein the care partner and patient could have been seeking out information and find other resources to treat PD.

In another instance, a care partner and their spouse had suspected Parkinson's, as they believed that the spouse's father had suffered from PD but had gone undiagnosed upon his death. Participant 13 stated that,

> "[her spouse] originally mentioned his tremor to his general practitioner who recommended that he see a neurologist which we did and she diagnosed him with essential tremor, which was a little bit of a surprise to me, but I was like, okay. Well, that's good, you know, so I just took that and went with that even though it wasn't what I thought I was going to hear and so we went on like that for about a year and a half and then we went to see the motion disorder specialist...and they diagnosed Parkinson's. That was in February of 2016."

This, again, shows the complexity surrounding PD that makes the diagnosis so troublesome, for example, in this case, the tremor was believed to be caused by something completely different from PD. However, this does not change the fact of a patient losing valuable

time going misdiagnosed that can result in the progression of the disease and greater uncertainty about how to proceed.

The high number of misdiagnoses surrounding PD points to the complexity of the disease and the individuality of the symptoms. With the ever-changing and personalized trajectory, progression, and symptoms for each PD patient, it is also evidently difficult to definitively diagnose an individual with the disease as some symptoms can point to many other health complications. However, with misdiagnoses, patients and their care partners lose valuable time that could have been spent learning about the disease and better their condition.

Diagnosis & informational resources: lack of information upon diagnosis

As a result of numerous misdiagnoses and uncured symptoms, many patients (60%) expressed a sense of relief upon receiving their diagnosis, Participant 14 stating,

> "So then I knew everything made sense and you could see that the puzzle finally came together to give you the accurate diagnosis before it's just like pieces all over the map. So then my loss smell makes sense, the loss of equilibrium, the freezing episode, the handshaking, the neck pain, the hip pain, everything made sense" and Participant 1 stating, "It was sort of a relief though, because some of the symptoms you would think I'd had a stroke."

However, this relief was short-lived when not much information was provided to patients upon receiving the news of their diagnosis, most participants (60%) reported receiving a prescription and a follow-up appointment a few months later. The majority of participants expressed feeling a lack of empathy surrounding their diagnosis. Participant 1 stating,

> "[it] made it feel like it was less significant than what was that and if it's more significant why didn't he spend more time, you know, this is a really threatening event. Why aren't I

getting more information?" and participant 6 stated that the nurse said, "I'm pretty sure you've got Parkinson's. And I said OK well tell me more. She said, well this is progressive and incurable, but treatable. That's all good as I said, OK where do we go from here. She said well I want to start you on Sinemet because this is the real test whether you have Parkinson's. And here's the prescription I want you to get filled and start the dosage and then come back in three months. I said OK what else and she said well that's it. And so there I am basically in the parking lot of a university medical center, which was supposed to be a center of excellence for Parkinson's care. I said Holy mackerel what's going on here. What do I tell my wife? What do I tell my family? Well, what's going to happen, all of those questions. And I was provided no information whatsoever at diagnosis or afterward being treated."

Many patients described accounts of receiving their diagnosis and feeling somewhat helpless as they were provided no information on how to proceed and where to find resources and information.

Another participant (5) described her distress of receiving no information and their spouse simply being put on a pill when he was diagnosed, stating,

"I think oh my God what kind of bedside manners is that you've just hit us with a diagnosis of a disease and not really giving us any explanation what we can expect or anything else. And right away he wanted to put this on this drug right away."

From the participants, it is clear that the complexity of the disease and the little knowledge of how individual cases can and will progress leads to physicians providing what many patients and their care partners describe as inadequate information and resources.

As a foundational and premiere feeling when diagnosed with an incurable disease, this sets up the patient and/or care partner with a feeling of not being important or acknowledged. Patients and care partners expressed feeling as though they were merely being processed through the healthcare system. Poor bedside-manner and lack of expressed knowledge about the disease itself seemed to correlate in most participant responses, participant 6 stating "You're on your own. You basically have to do it yourself in terms of the lack of any protocol for treatment and any system." The lack of basic information that could allow patients and care partners to understand what PD is and grant them further sources for diving deeper into the disease and how to treat it in ways that do not merely include a pill was largely unavailable to participants.

With many negative emotions associated with their initial diagnosis due to the lack of information and resources provided, the feeling described by participant 5 gives a clear indication of his experience stating,

> "They were not telling you what you needed to hear not handing you any literature or anything just more or less, here's a prescription get a pill, and I might come back in three months and I'm like really you know I felt like a guinea pig or a number and that was it."

This notion of feeling like a number was something that resonated across the board, leaving the majority of participants to their own devices in terms of finding information, and other resources, including new doctors or specialists.

Diagnosis & informational resources: information seeking & the internet

Though some participants felt as though they got a general sense of the disease, it was not nearly enough for them to move forward with direction and purpose, participant 3 stating,

> "I wasn't sure what we were getting into and I wasn't familiar with Parkinson's and didn't know anything about it right there in the very beginning, and I guess the first doctor I saw

he explained some stuff, I guess, but there was still a lot of stuff we didn't, you know,

understand and know about."

Participants, whether they received some information about the disease or not, expressed

a need for more. In fact, 90% of patients and care partners described seeking out information and

resources, regardless of prior knowledge or receiving guidance from their physician. This

exhibits a need for a greater explanation of what the disease is as well as what resources are

available to affected individuals.

From the initial diagnosis and getting what participants described as insufficient

information or none at all, most patients and care partners were left to their own devices. A total

of 30% of participants reported having some prior knowledge about the disease due to family

members being diagnosed or having a suspicion of their own or their partner's condition,

participant 18 stated

"It wasn't a surprise. It was a small confirmation of what I had suspected unconsciously

or subconsciously, but I had not done any research because I didn't want to find out that

that was really it. I was going to wait for the doctor to determine that so it was not a big

surprise."

Participant 8 continued this notion of self-diagnosis stating,

"Well in my case it was a lot of self-diagnosis with my wife, my care partner, which was

who was first sharp about you know basically doing the research to realize [my

symptoms were] indicative of Parkinson's or maybe some other things."

However, their suspicions and research had at that point not been enough to fully grasp

what Parkinson's is and how to treat it and find resources for it, the vast majority of participants

delved into their PD journey with a clean slate.

Participant 13 described her experience of her partner's diagnosis stating,

"Um the doctor's visit... where he got the diagnosis was, I would say that I was pretty much expecting to hear what we heard. I'm not sure if [he] was he he went through all the things that [the physician's assistant] did with him to you know, the all the little things that they do and I just watched all that and I knew enough about PD at that point that I was pretty sure that what she was seeing was PD and then she called in [the doctor] and he and she said, you know what she had done. She said we need to talk about diagnosis and then [the doctor] was the one who said yes, this is this is PD."

This participant went on to explain that she felt that the doctor's conveyance of the news showed poor bedside-manner and that they appreciated the good rapport they had built with the physician's assistant. She continued,

"So we had a couple other visits, you know, four months six months later with the [physician's assistant], but we never ever saw [the doctor] again because that's apparently just the way his up office operates. [My husband] is pretty, was kind of pretty overwhelmed here what it was because...he's strong he's always been athletic he um, for him the idea was I guess the the the idea was was a lot worse than what the reality has proven over the last couple of years, you know, but if you go online and look at you know, you watch YouTube videos or its it can be very scary and you need to get you need to get good information, not just whatever you can find."

This participant's retelling of her experience with her husband's diagnosis makes clear that she does not feel that they received proper, empathetic treatment from the doctor, but also that even though she had a suspicion of her husband's diagnosis, she did have sufficient

information. Furthermore, as she stated, if you merely start searching and looking at all available information regarding PD, you will not necessarily end up with good and useful information.

As a result of the lack of information provided by healthcare providers and the unfiltered and not curated information available, participants had to filter through materials in order to find useful and reputable resources on their own. The participants began their own journey of information seeking upon receiving their diagnosis. However, the time from the initial diagnosis to when they started seeking information varied from participant to participant based on when they accepted the diagnosis and what information, specifically, they were looking for. Participant 12 explained his process of acceptance and information-seeking, stating,

> "I'm the type of person that when something happens that's really really big. I kind of stopped. I don't have to react. I have to kind of sit back and sit down before I react to it. So I would have to say I really didn't think about it. I can't think of the word. I'm trying to say I really didn't accept the diagnosis probably till about maybe a year later a year and a half later."

With taking time to process, his wife then took over the information-seeking process in order to keep the ball rolling with regard to how they would proceed with their lives, explaining that

> "I'm fortunate because I have a, I have my wife who really delves more dives more into getting to the internet and finding that information and doing that when I was sitting back and trying to just get involved and thinking about this."

This participant was fortunate to rely on his spouse to commence with seeking out information which eventually led them to great and useful resources and aided the participant in accepting his diagnosis and moving forward.

Furthermore, throughout the entire information-seeking process 90% of patients and care partners reported using the internet as a source of information, with most participants claiming it as their main source of information in their information-seeking quest. It was expressed by participants to be the most easily accessible way to find information, participant 12 reporting, "[their care partner] started just doing research online, just by typing in PD and [they] went to different websites." Furthermore, participant 17 explained she and her spouse did not feel comfortable telling people about her spouse's diagnosis and the internet proved a great resource for keeping his diagnosis a secret until they were ready to share it. She stated "When we came home we started to go on our Websites, Googling things, finding books. And at that time, we hadn't told anybody, we would order books online, we wouldn't go to Barnes & Noble." Additionally, participant 8 stated

"I devoured a lot of literature I just spent hours and weeks and weeks and weeks time hours every day scouring the Internet and there's a lot of junk out there but you get into authoritative articles. I had a separate the weed from the chaff and what you're reviewing and adjusting."

Though this participant (8) used the internet a lot, there was a significant portion of time dedicated to finding reputable sources of information. This factor was mirrored by another participant (13), who described seeking out authoritative sources stating

"I spent a lot of the first year you know reading everything I could get my hands on. I read a number of books. I went to all the really authoritative websites. I went to the, you know, the foundation websites the ones where they were they have good information and I learned and I made this binder and I had this filing thing and you know, I'd print stuff."

For this participant, again, the internet proved an integral information-seeking tool, however, reiterating the importance of the information being authoritative in nature. Another participant (14) explained that upon her diagnosis the doctor sent her online stating,

"[my doctor] actually sent me to the internet to find out about the condition. He sent me to some WebMD medical thing so that I could read all about the symptoms. He never gave me a kind of like saying, you can prepare for this and that and so forth."

However, the participant did not bury their head, she decided to find out as much as she could about her disease, stating "I decided to arm myself with knowledge. I decided to take action." Participant 5 also used the internet as their main resource, stating,

"during those beginning years it just kind of blew me off like look, believe in me, but I did a lot of reading on the Internet on every piece of information I could find about Parkinson's because Parkinson's does not kill you but it seems like it's an autoimmune deficiency type of disease which causes other health issues to happen with that person in due time and that's what I experienced over his lifetime."

This participant used the internet to understand the complexity of how PD affects an individual, in that it does not kill a person but rather can lead to other health complications that can be fatal. The internet allowed her to understand this concept better in a way she did not feel that she and her spouse were told during the diagnosis appointment.

Another participant (1) expressed that when they did not receive much information at their initial diagnosis, he went online, stating,

"I did start following the online webinars put up like Michael J. Fox Foundation and the Parkinson's Foundation. They put together quite nice webinars and those sorts of

things and they're very educational and I found them, you know all of them, but most of

them are very applicable, that sort of thing."

Using webinars allowed this participant to receive information to move forward and

gather other resources, social systems, and contacts that could help him with PD. Many

participants (50%) reported eventually finding websites such as Michael J. Fox Foundation and

Parkinson's Foundation, however, getting to the point of finding good a resource and it being

compatible with what the patient or care partner needs is a case of trial and error. The majority of

participants expressed being in need of resources that would encompass all PD needs, ranging

broader than what is currently available, pertaining to educational information and coping

methods other than the prescription that most patients were given upon their diagnosis.

Social support: organized groups

Another major resource that participants overwhelmingly reported to have been missing

at their initial diagnosis and the months that followed (80%) was a social component; having

people to talk to about what they were experiencing, to relate to, and to aid them in garnering a

sense of hope and direction as they moved forward with their diagnosis. Many participants

expressed what great of a difference it made for them to find social resources. The support that

participants sought out and/or found differed depending on the individual needs of each

participant, as well as their status as either patient or care partner.

Participant 14 created her own social support, taking matters of socialization and support

into her own hands stating,

"So what I did was first I founded a support group in New Port Richey because I look for

support groups. I said, where are the other Parkies? I want to see them. I want to talk to

them. I want to see what they are going through and there when I had the opportunity I

met an instructor a, physical instructor...I said I have Parkinson's and he said well, I was I was thinking of starting a Parkinson's exercise group. So we started a hybrid meeting like he thought it would be just exercises to stretch our muscles. I was looking at it from the support group kind of kind of way. So what we did was we have built a support group that's been going on I think 2 years now...You meet twice a week. And we talk about are we, we always share."

By combining exercise with support group components, this participant was able to create a group that could cater to two very important aspects of PD treatment, which are exercise and social support. Another participant (6) expressed his feelings of uncertainty with PD, emphasizing that when you do not know what the next day brings, having a support system of people like you is integral to your wellbeing, stating,

"I mean the way it feels is you don't know what you've got each day when you wake up, what capacity you have, what control you have, what strength you have because it varies from day to day, but within the day you may be fine in the morning, but feel awful in the afternoon and the only thing you can do is take a nap. So basically where we Parkies are thrown on our own...and what we're finding there clearly is that we are stronger together. And when we basically form our tribe and figure out how we can lean on one another. I like that phrase 'lean on one another' support group right. We lean on one for assistance. So that's when my dedication, and it will be that until I can no longer function as a whole person."

This signifies the support that support groups can provide, which can and has made a real difference for individuals affected by PD.

Though there is no treatment to cure PD, there are many lifestyle choices that patients and care partners can and have made that have shown to make a visible physical and mental difference for people. Participant 13 stated,

"I just I see what Rocksteady boxing has done for so many people and when we went to Indianapolis to do the coaches training, which that was January of 2018 met people there who had seen such a reversal of their symptoms and nobody is claiming. This is a cure or this is everything nobody. Nobody believes that but I just saw so many people who did so well with it."

Her husband is very involved with boxing, as physical activity had always been something he was drawn to. Participating in such activity had halted the progression of his PD and had allowed him to stay in good physical shape. However, if he stopped going to the classes, both she and her husband saw his physical shape regress very quickly, as symptoms would reappear.

Social support is a crucial part of coping with a disease like PD according to many participants. One participant (1) explained a situation he had experienced while attending a support group meeting, stating,

"Everybody needs support systems when they've got something like this, you know, it's serious stuff. We're not, we're not talking about fun and games here. So it's just serious stuff and you need people need support. I've heard several these guys say, when we go around the room and talk sometimes in our sessions, this saved my life. I was sitting there waiting to die."

It is clear from participants that if individuals are not provided with such resources immediately after their diagnosis, there is a great sense of loneliness.

Participant 14 explained having gotten a phone call about a newly diagnosed patient who had no social network, stating,

> "We got word that a friend of ours said can you give a call to this woman, she's just been diagnosed with Parkinson's yesterday and she's freaking out. So we were like the Parkinson's Squad, as if we had put the siren on her car and went to the rescue of the newly diagnosed woman and she was truly freaked out. She thought, I mean she was panicking. She was alone. She didn't know what to do. So it was very reassuring when we arrived and we said well your life is not over, look at us. We're not dead."

Another participant (5) spoke of an experience she had at a PD conference with the Davis Phinney Foundation, stating,

> "That really gave you hope. A lot of hope and you got to see a lot of people that had Parkinson's that we're all in the same shoes and we were all fighting for a quality of life, and that was one of my better ones, but I've been to the ones that USF put on like I said, anybody that would have something that came into town...even now after my husband is dead because I am a support group leader and I want to keep informed of what's going on and I want to be able to help people so that they don't have to go around and try to figure out what they need to do. I want to be able to be a source for them."

Even after her husband passed, she is an active member of the PD community, working to inform people affected by the disease. Parkinson's is a very complex disease, there are a plethora of psychological and physical effects felt by both patients and their care partners. Working to create social networks of support in any way patients need, whether combined with physical education or to talk about experiences, social support in organized group settings has been something that the vast majority of participants expressed as core coping strategies.

Social support: family & friends

Support through family and friends was another key component that was expressed by participants. 70% of patients and care partners reported great appreciation for their family and friends upon being diagnosed with PD and expressed them being a great source of help and comfort.

Participant 13 expressed her concern for the individuals who do not have someone there to help them and motivate them, stating

"You know becoming discouraged and letting your mind venture a lot more into the what if and we don't know and all of the uncertainty one of my biggest concerns, when I think about the state of care for PD right now in the state of information, is like for those people who have you know, maybe they live alone and or they don't have a social network. They don't get connected to one. You're just it's just like one person said, I think it was [participant 6] that said, you know, they just sit home in their in their recliner and just get worse. Yeah, that's I worry about those people the people that don't have that and I also think I worry about the people that don't have the resources or the motivation to go, you know to go get it to go find it to go look for it as I have processed this whole thing. I have come to the conclusion that [my husband] and I are incredibly blessed with just everything that we need to be able to do this... we have a strong marriage, you know for people that don't have all those things, those are the ones I really worry about."

Through this experience, she has come to greatly appreciate the strong bond she and her husband have. Unfortunately, not everyone is fortunate to have a partner to battle PD with, which can lead to a lack of motivation and, essentially, giving in to the diagnosis, according to participant 13.

Furthermore, many participants expressed their gratitude for their partner and family, participant 12 stating

> "Well, I'm very lucky again a very blessed that I have a family that is supportive. And so when I gave them the news that you know, they were they were there to help they know they're like ready to do anything for me."

Participant 14 also felt gratitude in the situation she found herself in, support wise, upon being diagnosed, stating,

> "I have a husband who was willing and able to listen learn about the disease, accompany me to my meetings. I fell very soft. I had a soft landing, but now I know that not many people can do that."

Some participants also expressed how their relationship had changed upon them or their spouse receiving their diagnosis, participant 17 stating "I always say we've gotten closer for sure. And I will tell you, if there's something that bothers me or something about him that I want to tell him, I just tell him, we have open conversation."

> Spending time with loved ones was another key activity that many participants expressed the importance of, participant 2 stating,

> "so we do family dinners at least at least once a week. We get to see both the son and his two little boys and their daughter and son-in-law and we see them every day, the little boys, but the four boys so they can get together the cousins and so on and so it's all about family and they know it. So it's that's a part of it, a part of a network."

This participant reiterated the importance of family time and family bonding, making it a weekly tradition to spend time together, something that she expressed had a very positive effect

on both her and her spouse, emphasizing that family comes before all else. This point was again illustrated by participant 7 stating,

"I know at one point our youngest son had said well maybe I'll just take the year off from college and come live with you all to help Dad, which we certainly think will not at that point, but that was that showed me that he really was tuned in to what could happen and he wanted to be there for us which I thought was very sweet."

The point of their son wanting to stay home to help with his father showed how seriously he took his father's diagnosis and his dedication to taking care of him and helping any way he could.

Many participants reiterated the point that PD is a family disease, it is not something you can or should battle on your own. Social support systems have through the words of participants proven to be important in dealing with and living with their diagnoses. Having others to lean on while navigating through the complexities of PD, both through family and organized group settings, was categorically expressed as a key factor in determining participants' wellbeing.

These two major categories that emerged based on Study 1 give evidence of the need for a resource that can aid in providing information and social support for newly diagnosed patients and their care partners. The results from this study create the framework for understanding what resources are the most important to participants. The expressed use of the internet by all participants along with their needs, pave the way for Study 2

Chapter Five

Results Study 2

Based on Study 1, we found that informational and social support were two of the main factors that altered their experience with PD for the better. Lack of information left participants feeling lonely and without real direction or knowledge of what to expect with the diagnosis. Furthermore, social support was a major factor of importance to participants as it had allowed them to garner more information and allowed them to connect with other individuals going through similar things. In addition, the internet was reported the most used source for information seeking.

Informed by the findings of Study 1, the data collection of Study 2 allowed for the emergence of themes that highlighted the determining factors for participants in deciding to choose a website as a primary resource for their PD information. With the 4 P's providing the foundation for how to separate the emerging categories, subcategories of each of the P's worked to exhibit the evidence for how best to create a website tailored to help newly diagnosed patients and care partners. The following results show the emergence of key themes expressed by participants.

Product

In Study 2 various components were expressed as being key factors for participants to be more likely to use a resource for their PD needs, specifically a website. The majority of participants expressed the importance of new and authoritative information and articles on a website. They want to stay informed through reliable resources, participant 36 stating "I guess,

more current information, things that might be being researched or in trials, things that are being tried."

Participant 32 followed up that point stating,

"I think if it were as if it were...I want to say like backed by science or from an authority or you know, that kind of thing and not just a bunch of people throwing out anything. I mean, I can find that on Facebook. That's not what I want. But yeah, if there were so, maybe we wanted it to be curated, curated by authorities. Are experts in some sense. So, for example, when you were talking about that, one of the things I was thinking of that I haven't mentioned yet, is one of the challenges we went through, is looking for tools to help him with mobility for when he was facing. And we found doing, you know, we did research, we google stuff, and he's very good at googling stuff, and we found a walker, specially made for Parkinson's people...So, finding resources like that."

This emphasizes the importance of verified information, rather than websites such as Facebook where anyone can write what they wish. Furthermore, she added that including real-life accounts of patients and care partners would be beneficial to include on a potential website, stating "Yeah, so just, you know, resources like that, you know, maybe there should be some portion of the site where it's kind of like real stories from real patients." Including patient and care partner stories would be beneficial in adding authenticity and hopefulness to newly diagnosed individuals and their partners.

Additionally, several participants (40%) praised the Michael J. Fox Foundation website as it provides much updated, authoritative information and updates on new drugs and trials. Participant 23 stating,

"Well, I follow faithfully Michael J. Fox because he has the newest drugs that come out, and luckily my neurologist even though he is not a specialist in Parkinson's, I think he is very knowledgeable and he's up with the newest stuff."

Another participant (31) reiterated the importance of the Michael J. Fox Foundation website stating,

"Um, I think all along, we have always been interested in therapies that are under development. Um, once you get the initial information about Parkinson's, I don't think there's a lot more heavy reading. You need really need to do, I've never read the Michael J. Fox book, in part because I didn't really want to know...I'm mostly interested in I mean, the site that I usually use a lot is his site."

This participant added that he is impressed with much of what is included in that website and for him to be attracted to a website it must include "research, you know, advances being made, message boards in the community and that kind of stuff."

Many participants (50%) expressed a want for information that they can rely on so that they do not have to search other sources and websites to verify such information. Just as physician input is considered authoritative due to the nature of their occupation, participants stated wanting information coming from individuals or organizations with the same level of validity and reliability. In addition, they reported wanting current and up-to-date information, as well as drugs and trials underway, as this also illustrates the ongoing research being done to better understand and treat the disease. The importance of having current information available for visitors of the website is that such content would allow people to follow along with what is being done to combat PD, which could aid in providing hope to participants who struggle to feel

hopeful about their diagnosis, and would allow them to see what is being done to ameliorate their disease.

Another factor that was mentioned repeatedly by participants (70%) was the importance of usability. Participant 29 stating,

"Something that was really easy to navigate. If it had the information that was presented, that we could understand it fairly easy...But I would say, especially for somebody with Parkinson's, it needs to be really easy to access and getting around the website, it needs to be very easy, because I struggle with things I've noticed, my wife doesn't have that issue, but a lot of the others that come to the boxing, a lot of them can barely even write. Logging on to your computer, having them make a lot of clicks, or things like that might be difficult."

This participant emphasized the point that many PD patients may not be able to use a computer very well, much less navigate a difficult website, so the importance of a user-friendly browser is integral in order for more patients to be willing and able to use such a resource.

This was again reiterated by participant 33 who stating "Um, usability. Being able to navigate it, navigate around to find the information that we're particularly looking for. Um, the Michael J fox foundation, you know, the website is just it's amazing" and participant 36 stating "Yeah, as long as it's fairly easy to use, easy to move, move around, I can't think of anything that would, um, maybe not want to use it."

Another point that was brought up by participants was that of finding information about what things they should be considering and looking into certain things such as Medicaid, Medicare, and so forth. Participant 32 stating,

"You know, looking back, it would have been nice to have a, OK, so, so you have

Parkinson's is, this is what to expect....but also these are the things that you should

navigate, you should look into at some point. Applying for disability, looking for these

kinds of motor supports, or you know, I don't know that. You know, like, almost, like, a

stepwise thing."

This emphasizes the point of there not being a protocol for what to do upon receiving a PD

diagnosis. There must be more guidance on how individuals should proceed with their lives and

what steps they must take. This was reiterated by participant 22, stating that if something were to

make her want to use a website as a resource it would "Probably be the educational component

of the organization if I felt it was relevant. A lot of the educational stuff that comes out is not

relative relevant to me."

Price

The second pillar of SMT is the price, which presents as the barriers of usage for

participants when determining content and design for a website. Usability, which was

highlighted as a major factor for making participants want to use a website as a resource for PD,

was also mentioned as a reason for why participants would not want to use it. Participant 31

emphasized the importance of usability stating,

"I was an IT executive, a software developer. I run development groups. If it's a clunky

pain in the butt website, I'm not going to use it. If I look at it, and I say, you know what? I

could code this better than chances are, I'm not going to use"

and participant 34 stating that it would be a barrier "If it were overly complex and

difficult to navigate."

Furthermore, one participant (30) expressed the point of the advanced vocabulary of PD websites and how that could make someone less likely to use a resource, stating,

> "The website developers never have the same vocabulary, as the poor person going to look and you don't know what word or what thing is clickable. And you don't know which word or thing to click and so I advocate as few words as possible...Because if I went to a PD website, I wouldn't know where to go, I wouldn't know what I was looking for."

This emphasizes the importance of creating a website made to be read and understood by patients and care partners first and foremost. Such a resource should be tailored to the needs of the people who would use it the most, and that would include all aspects of what makes a website user-friendly.

However, several other categories emerged as barriers to usage for participants, specifically finding information catered to younger individuals who may have younger children, participant 22 stating,

> "the other thing that's that's really hard is talking to, there's not many resources out there about your children and I think we're finding out more and more that there is a genetic aspect to it. And how do you talk to your kids about that? I have, I've asked a million people. Well, that's what resources for your children about Parkinson's and there's stuff out there on how to tell them."

This participant emphasized the necessity for information that is tailored to the broader demographics of people, specifically individuals with younger children. This notion was repeated by another participant (33) stating,

"Um, just how hard it is to find information. Um, because there's so little information out there, you start typing it in. The really is nothing out, there's really not much out there. We got lucky, there's a book out there that you can actually print out, yourself, that we actually printed out for for our boys. It's called my mom has PD and it's OK."

Though he found a useful resource eventually, such an asset and more alike, should have been more readily and easily available. The importance of understanding the wide demographic of people affected by PD cannot be underestimated. Though PD predominantly affects older demographics, that cannot overshadow other demographics affected, as their needs must be catered too as well.

Another category that emerged was that of websites requiring or requesting various actions by participants, and this notion was expressed in several ways. One participant (29) who works as a Rock Steady Boxing instructor stating,

"Just, it was asking, I guess, too much personal information. Because I know, I know we're running into that issue now with our boxing class, where we have it. The Macon county recreation department, where we have it in the gym, they go through a website for us to log the boxers in and out when they come into the facility. A lot of them are concerned with putting information on there."

Though, as previously stated, PD affects a broad range of demographics, the older individuals affected, according to this participant, have hesitant tendencies when it comes to internet usage and divulging personal information.

Participant 27 also touched upon the topic of websites asking things of websites-visitors stating "No, maybe, well, I don't know. I would venture to thought, though, maybe, if they aren't trying to get your money know, in other words, looking for donations, making that come up all

the time." This illustrates the point of websites asking for donations as a negative aspect to be included on a website. This participant expressed that the request for money felt insincere and would not make her feel comfortable when first visiting a new website.

Another barrier was that of pop-up videos, which participant 32 explained stating "If when you bring it up, it has a ton of videos that just start playing...I hate that." From this participant's statement and the previous ones, it is clear that any forced task is not one that is welcomed by participants, as they want their choices of what to share and actions to take on a website to be solely their own. Influence to divulge or complete a certain task, whether it be watching an advertisement or supplying monetary donations, are not welcomed by participants, as they expressed the lack of choice and insincerity they would feel when forced in one direction or the other. Various components were expressed by participants as barriers to their usage of a website. Based on participant responses, creating a PD resource should cater to all parties affected by the disease, as well as not prompting site-users to take actions or share anything they do not wish to, would make for a more acceptable choice of a PD website.

Place

When gauging where participants would be most likely to seek information if they had just received their diagnosis, not having the knowledge, information, and resources that they have currently, 90% of participants reported that they would first seek out information and resources via the internet. Participant 32 stating, "Yeah, I'd definitely, definitely go to the internet. I'd start looking. I would probably start with Parkinson's resources in Florida." This participant expressed the internet as her first information-seeking destination, especially looking at geographically tailored information.

Another participant (29) mentioned going to some of the current major PD websites available, stating, "You know, like the Davis Phinney website or, you know, Parkinson's or the Michael J. Fox...we did, we just did a lot of Google searching." However, a simple google search as participant 29 also stated, seemed to be the most common starting point for people, participant 30 stating "You'd have to fall high on a Google search. I use Google a lot" and participant 34 stating "I start with Google."

Another participant (36) stating "I would go to the internet" if she was newly diagnosed but explained that now she has access to her neurologist via an online portal, stating "Now, I would go to my neurologist I have access to a patient portal. So, you know, if I have questions, or you know, if I see changes in my symptoms…" This is, of course, not an option for all patients and care partners, but bearing in mind that such interactions can also be translated to an online community, may be beneficial in giving individuals another avenue of information-seeking that is not solely text-based, as stated by participant 36.

Almost every participant had some variation of expressing their choice of the internet as one of their main tools, if not their only tool for seeking out information and other resources online. These findings are a great reflection of the day and age we are currently living in and the bountiful resource that is the internet. People have moved away from libraries and other sources of information that are not as easily accessible. The great access that most people have to the internet made it the main source for participants, as was also expressed in Study 1.

Promotion

The promotional component of SMT refers to how an individual would like to get information about a product or resource. For this category, there was one overwhelming theme in terms of where participants would like to be receiving information about the website. 90% of

participants reported wanting to receive information about a PD website resource from their physician. Participant 32 stating, "I would say definitely in a doctor's office, like somebody who is diagnosed with Parkinson's should be handed some information, some resources. Yeah. So, that would be number one." This emphasizes the importance of being given a resource immediately after receiving the diagnosis, thereby negating the time patients and their care partners would potentially spend searching for resources on their own. Another participant (33) explaining,

"The first, the first and foremost places to ask, you know, obviously as soon as you get diagnosed. The neurologist is there. She's diagnosed you, he's diagnosed you. That's going to be the first person that should be, you know, you know, you're probably flooded with a thousand questions in your mind right now. The Rolodex is spinning you know? That should be the person, or somebody in that office should be the person that says, OK, relax, take a breath. We're here to help. Let's get you situated. Here are the resources, you know, here is a resource packet here is, you know, go home, do they do the steps?"

This participant made clear the point and importance of being aware of the wide array of thoughts and feelings overwhelming a person upon diagnosis and how physicians should have resources readily available for patients and their care partners in order to aid them in answering some of those questions and understanding how to move forward. Participant 31 stating,

"I mean, I guess ideally it would be through my doctor because I don't know how else to. I don't know where else I'd be registered, for instance, for you to be able to figure out that this is something that it'd be of interest to me, you know"

and participant 34 stating, "I like the idea of hearing about it right from the doctor's office," reiterating the importance of being given resources immediately upon diagnosis and from a person of authority who has the credentials to make such recommendations.

As physicians are the ones giving patients their diagnosis, they are in positions of authority, and as such, patients and care partners rely on and trust the information that they are given by their doctors. There is great trust in doctors, therefore people would be more likely to use a resource because of a doctor's endorsement as carries a great deal of weight. This would make a doctor's office the ideal place to receive information about a website resource for patients and care partners.

Chapter Six

Discussion

The following chapter will describe the findings of the study as it relates to the research questions posed in the first chapter. Parkinson's disease is a neurodegenerative disease that affects thousands of individuals. The nature of the disease is superbly complex in that no two PD cases will ever present or progress the same, the trajectory of the disease is never the same. This fact alone makes the diagnosis of the disease and well as a treatment plan very difficult to prescribe. Due to the complexity and uncertainty surrounding PD, cases many times go misdiagnosed, and even upon diagnosis, a clear protocol for how to proceed is rarely received by patients and their care partners. The findings from Study 1 demonstrated various themes that emerged from the use of the Grounded Theory approach and interview guide created and used during interviews.

From Study 1, which acted as a pilot study informing Study 2, various themes emerged to shed light on the most prominent aspects of being a newly diagnosed patient or care partner. Informational and social resources emerged as the two major categories encapsulating the experiences of the participants. Many participants reported their frustration over being misdiagnosed (60%), some going months or years believing their symptoms were caused by things other than PD, ranging from being diagnosed with a B12 deficiency to showing signs of a stroke. Furthermore, upon finally receiving their PD diagnosis, many participants expressed further frustration and anger at having lost valuable time that they could have used to find treatment and educational resources.

In addition, upon receiving their diagnosis, the majority of participants reported merely receiving a pill prescription and a follow-up appointment a few months later. This brought about the recurring theme of lack of information. Many patients during their diagnosis appointment or immediately following, were left feeling lost. Being diagnosed with an incurable disease and essentially being left to their own devices as a result of there not being a set protocol of treatment or resources that patients and their care partners are provided with, participants were essentially left to find their own information and resources that they felt would help them with their PD.

All participants reported seeking out resources and information, depending on their individual needs as patients, care partners, or as a couple. The majority of individuals sought out exercise groups, Rock Steady Boxing was a particular organization that was repeatedly mentioned. The participants expressed the importance of staying active and engaged with activities and other people. Participant 13 stating that the individuals who do not have the social network or motivation to stay active "they just sit home in their recliner and just get worse." That statement is exemplary in illustrating how a lack of motivation can quickly overtake a person's will to fight. Many participants (80%) expressed the extremely positive impact support groups had had for both patients and care partners. They found what participant 6 described as their "tribe" which is essentially a group of people who are going through the same things as themselves that they each can lean on. The majority of participants stated how great of a difference it made for them to have others who are going through the same things as themselves to talk to. Finding the resources that allowed participants to interact and participate in organized group settings is, according to them, a vital part of their continuous well-being with PD.

In addition, finding resources for exercise, diet, and medical specialists, among other things are additional integral components expressed by participants. However, as some

participants stated, finding authoritative information is a difficult task and many spent months and years searching for as much information as possible.

Specifically, what medium patients and care partners predominantly used in their information and resource seeking quest was that laid the foundation for the premise of Study 2. In Study 1, 90% of participants reported using the internet as their main source for PD information. That statistic, along with the general lack of information and resources, pertaining to educational and social components/resources, and the gratitude felt upon receiving them, was what prompted the need for understanding what elements and information to include in a PD website for newly-diagnosed patients and care partners.

The Grounded Theory approach was vital to Study 1 in that it allowed for the natural generation of major categories that had had a great impact on participants' experiences with PD. This study may not have generated such findings had the participants been limited in their responses based on the guiding principles of another theory. Moreover, this study has informed theory as it has added to the body of literature that offers evidence of studies that provide substantial results, that are guided by data, rather than a rigid theoretical framework. It works to inform and add quality to studies based in the Grounded Theory approach, by illustrating substantive findings that can be used to better the circumstances of PD patients and care partners both through the Me Over PD initiative, but also through the health communication and healthcare communities garnering a better understanding of such a sensitive demographic.

As mentioned above, this study adds to a body of literature. As Roger's (2010) examination of patients and their close family's managing of their identity together, brought about themes of lacking independence and self-sufficiency. Through the Grounded Theory approach, it illuminated their feelings and experiences, and the current study adds another layer

of understanding to this. By understanding the experiences of PD patients and care partners, a gap is filled in terms of how we understand the trajectory of physical and emotional progressions, which could potentially hinder such lack of independence in the future.

In addition, Abendroth (2012) examined the healthcare decision making of care partners and the lack of communication between healthcare physicians and care partners. This was even further illuminated during the current study, as the specific conditions that caused the lack of communication, such as receiving a pill prescription and a follow-up appointment several months later, not receiving adequate information and resources, and poor bedside manner were brought to light. This adds to previous generalizations made with the use of the Grounded Theory approach. Through the current study, previous studies such as Abendroth's are backed up further and added to, which informs the use of the theory in that patterns of findings concerning a topic and/or specific group of individuals become consistent.

The findings of Study 1 informed the use of Social Marketing Theory in Study 2 and the research questions that were created to guide the study. SMT has previously been used in the context of other neurodegenerative diseases, but never PD. This study filled a gap in understanding how to best cater to the PD affected population and best create a resource that understands and meets the needs of those people. In researching such a specific and sensitive demographic such as PD patients and care partners, researchers and others can aim to better understand what many of these people have experienced and how to aid future affected individuals.

Through the use of SMT, various themes emerged from Study 2 that could greatly aid in understanding how to determine the content and design of a PD informative website. Theory can help inform the design of an educational website for newly-diagnosed PD patients and care

partners in that it shed light on the aspects of the product that would make participants more likely to use a product, what would make participants less likely to use a product, where the product would be and how it would be promoted, outlined in the major themes of Product, Price, Place, and Promotion.

However, this study also informs theory, in that is it uses the premises of SMT in a way much different to research previously conducted in the context of other neurodegenerative diseases. SMT has most commonly been used for intervention and campaign research, such as Devlin (2006) examination of a dementia campaign that aimed to promote awareness for the disease, raise money and destigmatize. The study narrowed in on the importance of realistic portrayals of persons affected by dementia and reversing the fear that many people associate with being around affected persons. Through SMT the study aimed to understand perceptions of people in order implement or change behavior. Similarly, the currently study aimed to understand what factors would encourage or discourage the use of a certain resource, thereby also implementing or changing a behavior. However, this study differs in that it aims to encourage behavior concerning use of a website, rather than changing perceptions and behaviors. This study informs theory in that it broadens the scope of SMT. Through this study, different notions of how to view and use the four P's are enacted.

Furthermore, Higgins' (2008) study examined the participant experiences of individuals involved with a cycling fundraiser held by the Multiple Sclerosis Society. The study aimed to determine experiences through SMT relating to benefits, cost, and reaction to marketing and communication. This study used SMT in order to best understand how to improve the event, reduce the costs, and increase participants. Through the use of theory, the study was able to narrow in on the four P's of SMT. The current study used the theory in a similar way as it aimed

to understand how to best market to a certain demographic of people. However, the current study, differs and informs theory in that it aimed to gauge perceptions of something that had not yet been implemented. Higgins' study used SMT to gauge how best to improve the event, whereas the current study used the findings from Study 1 to inform the use of SMT to create a website in Study 2. The current study informs SMT by using the theory for the purpose of creating an educational resource in the context of PD, which is novel to both the theory's use and the study of PD as a whole.

The following research questions were developed by the researcher as guiding principles for best understanding what elements and information would be most beneficial in creating an educational website for newly diagnosed PD patients and care partners by using theory.

RQ1: How can theory help to inform the design of an educational website for newly-diagnosed PD patients and care partners?

Study 1 was based on a Grounded Theory approach wherein the researcher had identified the topic and select participant group, from which they developed the interview guide. A Grounded Theory approach informed the study in that it allowed for themes to emerge naturally based on the experiences of the participants. By using the Grounded Theory approach, the researcher was able to gather great insight into the experiences of PD patients and care partners through their diagnosis, how they coped and what they felt was missing. The Grounded Theory approach was vital as it allowed the data to be guided by the participants. The study was informed by this theory, in that it allowed for a sensitive demographic to shed light on their individual experiences in a way that had not been possible is the study had been guided by a rigid theoretical framework, rather than the concepts generated through the experiences reported by the participants.

The Grounded Theory approach aided in informing the design of an educational website for newly diagnosed PD patients and care partners in that is shed light on what aspects of participants' experiences with PD had been most noteworthy. Through the results found in Study 1, the researcher saw evidence for the need to use SMT in Study 2, in order to delve into one of the major categories that emerged, which was the internet as a resource for information seeking. Furthermore, in Study 2, the researcher aimed to understand, based on the findings of Study 1, which highlighted the importance of information and social resources, what would be most beneficial to include in such a website, bearing those two major categories in mind.

SMT aims to gauge what factors or elements when marketed will result in behavior change by a target group of individuals. The principles of SMT were the guiding pillars of the study and how interview questions were formulated. The four P's of the theory outline the major areas to consider when marketing to large populations of people, and thereby understanding what elements and content would be preferable for a given population. Through Product, the researcher gauged to understand what would make a website more attractive to the participants, through Price, the researcher gauged what would make participants less likely to use a website, through Place, the researcher gauged what medium participants would prefer seeking out information and resources and through Promotion, the researcher gauged where participants would prefer to hear about the website. By allowing these four categories to guide the questions being posed to participants, SMT aided in informing how best to design an educational PD website for newly diagnosed patients and care partners.

RQ2: What elements should be considered in the creation of an educational website for newly-diagnosed PD patients and care partners?

In Study 1, 90% of participants reported using the internet as a source of information seeking, following 60% reported that they did not receive adequate information at their initial diagnosis appointment. PD is a very complex disease that can be hard to diagnose, 60% of participants reporting having been misdiagnosed prior to their PD diagnosis, which leads to a lot of frustration that is then amplified when individuals do not receive apt information and resources on how to proceed once they have been diagnosed.

From the categories that emerged from Study 1, it was clear that participants did not feel as though they received enough information upon their diagnosis. Participants sought out their own information and resources via the internet to help ameliorate the uncertainties surrounding their diagnosis and aid themselves in living a more informed life with PD. The Me Over PD initiative was created in order to help newly diagnosed PD patients and care partners navigate the complexities surrounding PD. From the results from Study 1, wherein the internet was the most reported resource for information seeking, the researcher, in Study 2, aimed to determine what elements and information would then be most beneficial for PD patients and care partners.

Within each of the major categories, themes emerged illustrating the specific elements that were most prominent to participants in Study 2. Firstly, the internet was reported to be the preferred source for information-seeking by 90% of participants. Patients and care partners both expressed the internet as being their first choice for seeking out information, were they to imagine themselves at their initial diagnosis in need of resources. Many participants reported using Google as their initial search tool, from which they would search for localized or national resources, such as The Davis Phinney Foundation and The Michael J. Fox Foundation websites. As the results show the internet as the dominant search resource for participants, the premise for Study 2 is reassured as the appropriate resource to be researching.

Furthermore, what emerged as both a positive attribute for a website to have, conversely was also considered a barrier if not successful. Usability was a recurring topic that the majority (70%) of participants expressed to be vital in order for them to use it. Furthermore, this was also reported to be a great barrier to usage if a website was not user-friendly. Many participants attributed the need for a user-friendly browser to the generally older demographic. This point was emphasized by participant 29 who stated, Participant 29 stated "Something that was really easy to navigate. If it had the information that was presented, that we could understand it fairly easy...But I would say, especially for somebody with Parkinson's, it needs to be really easy to access and getting around the website, it needs to be very easy, because I struggle with things I've noticed, my wife doesn't have that issue, but a lot of the others that come to the boxing, a lot of them can barely even write. Logging on to your computer, having them make a lot of clicks, or things like that might be difficult." Creating an interface that is founded in simplicity and that caters to the specific demographic to which it was created would be very important for participants to use and continue to use the resource.

In addition, participants also reported the need for information catered to a broader demographic of people. Though PD predominantly affects older individuals, it also affects younger individuals. Participant 22 and 33 expressed the need for information useful for people who have younger children, participant 22 stating "the other thing that's really hard is talking to, there's not many resources out there about your children and I think we're finding out more and more that there is a genetic aspect to it. And how do you talk to your kids about that? I have, I've asked a million people. Well, that's what resources for your children about Parkinson's and there's stuff out there on how to tell them." The statement emphasizes the necessity for a

generally broader scope in terms of who the website would be designed for and that includes the content as well.

Other topics that were brought up were the dislike of being forced to watch pop-up ads, being asked to donate money, and being asked to give great personal information. These three factors were expressed as less desirable aspects to a website and should be considered when creating a website. Participants were not very accepting with regard to websites requesting or requiring them to complete tasks or take action in order to access website resources. In the creation of a PD website for newly diagnosed patients and care partners, making sure that the website is solely created to provide the individuals with the necessary information is crucial.

RQ3: What types of information is most important to include in an educational website for newly-diagnosed PD patients and care partners?

In Study 1, various categories emerged of what participants felt had been missing at the time of their initial diagnosis. It was reported by 80% of participants in Study 1, that they did not feel as though they had ample social support in the months following their diagnosis. This is a crucial element that participants expressed had made a great difference for them, some outlining the importance of social support groups and work out groups specifically. Furthermore, lack of information upon diagnosis was reported by 60% of participants in Study 1. Receiving educational material and being guided to resources that can aid PD patients and care partners in what the next steps are once having been diagnosed, was something many participants reported as missing. The lacking social and informational components of Study 1 guided in garnering a better understanding of what resources are integral to newly diagnosed PD patients and care partners in Study 2.

Various types of information were reported by participants to be the most important in order for them to use a website as a resource for PD information in Study 2. Here, 50% of participants expressed the want for current and up-to-date PD information from authoritative sources. Participant 32 stated, "I think if it were as if it were...I want to say like backed by science or from an authority or you know, that kind of thing and not just a bunch of people throwing out anything. I mean, I can find that on Facebook. That's not what I want. But yeah, if there were so, maybe we wanted it to be curated, curated by authorities." Participant 32 made the comparison to Facebook which allows anyone to post anything they want. Rather, they expressed the want for information that has factual and scientific backing, instead of merely opinions. This point is very noteworthy too in that by providing a resource that contains high caliber information, the patients and care partners do not have to engage with as much content and use as much time filtering out the bad content.

Additionally, several participants reported wanting information including new drugs and drug trials, participant 36 stating "I guess, more current information, things that might be being researched or in trials, things that are being tried." The importance of new drugs and trials underway allows for patients and care partners to stay up-to-date with what is being done in the medical and scientific community to treat PD. By including such content, it gives participants something to look forward to and get a sense of the progress being made.

Lastly, another important factor mentioned was the need for a step-by-step of what things patients and care partners should consider upon diagnosis. Participant 32 explained that there were many things she did not think about when her husband was first diagnosed because she did not know it. She stated, "You know, looking back, it would have been nice to have a, OK, so, so you have Parkinson's is, this is what to expect....but also these are the things that you should

navigate, you should look into at some point. Applying for disability, looking for these kinds of motor supports, or you know, I don't know that. You know, like, almost, like, a stepwise thing."

Many participants expressed feeling overwhelmed upon receiving their diagnosis, participant 33 stated "being flooded with a thousand questions." By providing people with a place to go to receive this information and a step-by-step of how to proceed with their lives would be a great resource as the vast majority of participants expressed helplessness upon diagnosis, not knowing what to do or where to go. Having a website that could aid in ameliorating something of the uncertainty and lack of direction would, according to participants, be very beneficial.

The results found in this study are significant in illustrating what components PD patients and care partners value in using a website as a resource. By creating a website catering to the specific needs of people affected by the disease solely, the website would be more user-friendly to patients and could hopefully provide individuals with the resources needed to aid them in living a more informed life with PD.

Me Over PD, as previously mentioned, is an initiative created to aid patients and care partners in navigating the complexities that surround living with PD. The findings of this can be used to inform the creation of a website for the Me Over PD initiative (Please see Appendix D). By understanding what elements are significant, Me Over PD can carefully curate a website tailored to those needs. These results of SMT give clear understandings of how best to market a website to the specific demographic. This theory would also be useful in garnering an understanding of how other elements of the initiative should be designed and what would be favored by the people who would use them.

Based on the high statistic from both Study 1 and 2 which showed that 90% of participants from both studies, respectively, reported the internet as a main resource for information seeking. The Me Over PD organization would benefit from hiring a website developer/designer in order to create website mock-ups. These mock-ups should be tested on additional PD patients and care partners in order to narrow in on what design would be considered most usable and agreeable for the individuals who will be using it.

Furthermore, it would be beneficial for the organization to hire individuals who would have access to or would be able to gain access to sources that could provide the information that participants reported as most important to them, such as clinical trials, new drugs to treat PD and authoritative information. Hiring individuals with ties to healthcare facilities or clinics may be beneficial in attaining such information.

When considering the perceived barriers of usage (SMT's price pillar) or elements that would individuals more or less likely to use the website, it is also important for the organization to consider the price of creating and maintaining such a resource. The organization will want to consider the potential cost of developing and designing a website, specifically hiring website developers to bring the Me Over PD vision into fruition. Additionally, another price of such a website would be the cost of maintaining the website, which would include updating information such as new information about PD drugs and clinical trials which several participants reported as important, as well as, updating information about local support systems, exercise groups, physicians specialized in PD and more.

In addition, other maintenance elements would include potentially answering user questions and making sure that the website as a whole is running smoothly in terms of links working, graphics being updated and so forth. Hiring an individual or individuals in order to

maintain a website would be an important component for the organization to consider as they proceed with the development of the website based on the findings from this study. Furthermore, another element of price to consider would be the cost of accessing the information mentioned above. Creating partnerships with local healthcare systems, gyms, and support groups may be beneficial in creating access to such resources.

Another major theme that was reported excessively by participants (90%) was their want to receive information about a PD website as a resource at their doctor's office. Participants see their physician as a figure of authority and would trust their recommendation with regard to where they should be seeking out information. Additionally, having just received the initial diagnosis, patients and care partners should be provided with information and resources immediately thereafter. Leaving the doctor's office with a plan for where to go for information could help ameliorate some of the uncertainty that patients and care partners feel immediately following the diagnosis.

As a result of the dominant report by participants of wanting to receive information about the website from a doctor's office, the organization would benefit greatly from forming partnerships with local healthcare providers in order to more easily access the target demographic, PD patients and care partners, through their preferred source. Individuals involved with Me Over PD reach across several states, therefore appointing members in various areas to contact healthcare providers about partnerships would be a useful way of reaching more individuals across a larger area. However, keeping in mind that a trial area may be useful to see how well the website does in terms of traffic from doctor referrals and whether any adjustments to the way by which the information about the website is promoted should be made before increasing partnerships.

This study has also provided a clearer image of what is truly lacking in terms of how PD patients and care partners are treated and what they are provided with. There is a great disconnect between what resources PD affected individuals are receiving and what they need. This study will hopefully illuminate some of the areas where the most improvement of care is needed. Also, the health communication community can use the study's findings as a foundation for better communicating with PD patients and care partners, getting a deeper understanding of their experiences and values in terms of how they are communicated with. By garnering a greater understanding of the experiences of patients and care partners, the health communication community can work to better the circumstances of such individuals and improve the availability of resources.

Limitations

A limitation for the current study was the narrow age range of the participants. The age range of participants was not fully and evenly indicative of all persons affected by PD. Having interviewed a broader range of individuals affected by PD may have allowed for new themes to have emerged. It may have brought forth different experiences and opinions of what should be included in the design of a new educational PD website that were not evident with the current study's sample.

Future Research

In conducting future research, it would be interesting to create mock-up websites to show participants to get a more definitive understanding of whether they like or dislike a design and the information on it. Doing message testing would be a great way to test whether the elements identified by the sample in the current study is indicative of the greater population's opinion. In addition, by creating mock-ups, researchers would get a better understanding of design

components relating to the font, font-size, colors, and other more visual components, not easily explained.

Conclusion

This study expressed some components to consider when determining the content and design of a website for newly-diagnosed PD patients and care partners. The researcher made recommendations, based on the findings the Grounded Theory approach of Study 1 and the 4 P's of SMT (product, place, price, and promotion) of Study 2, that according to participants would make them more likely to use such a resource.

Study 1 highlighted the importance of authoritative informational and social resources for PD patients and care partners upon diagnosis and following. It shed light on many of the hurdles that participants faced with regard to misdiagnoses, poor bedside manner, lack of information and resources upon diagnosis, and lack of social support. From these findings and participants repeatedly reporting having used the internet to find information, Study 2 aimed to determine what elements and information would be most beneficial to include in creating an education website for PD.

The findings from Study 2 illuminated the importance of authoritative content, social components, and new medications and trials, as they emerged as attractive components of a PD website to patients and care partners. It showed the importance that usability and easy navigation have to participants, especially considering the generally older demographic of people affected by PD. The study showed that the internet is the core source that people seek out when searching for PD information, which reiterated the results in Study 1. It expressed the want for doctors to be the liaison between the patient and the care partner and the website. Overall, expressing the

need for authority, trustworthiness, and socialization as major indicators of a website that participants would want to use.

This study fills a void in that Grounded Theory approach was used to understand the experiences of PD patients and care partners upon diagnosis and following which has not been done before. The themes that emerged naturally from using that approach illustrated the individual experiences of the participants and allowed for greater understanding of the individualistic nature and trajectory of the disease. The findings shed light on aspects of participants' experiences with PD that had not before been studied and allowed for greater understanding of how to cater to these individuals. In addition, SMT had never before been used in the context of PD and highlighted what major factors should be considered for a PD website. Using SMT filled a gap in understanding how to cater and market to this sensitive demographic, whereas previous literature has been focused on intervention and campaign testing. Many more steps including testing website design and content must be conducted in order to definitively say that a website will be successful and designed based wholly on the opinions of PD patients and care partners. However, garnering a better understanding of the experiences and needs of these individuals is a great step in hopefully aiding PD patients and care partners in living a more informed life with PD.

References

Abendroth, M., Lutz, B. J., & Young, M. E. (2012). Family caregivers' decision process to

    institutionalize persons with Parkinson's disease: A grounded theory study. *International*

    Journal of Nursing Studies, *49*(4), 445–454.

Ahn, S., Lee, J., Chu, S. H., & Sohn, Y. H. (2017). Uncertainty and depression in people with

    Parkinson's disease: A cross-sectional study. *Nursing & health sciences*, 19(2), 220-227.

Andrews, K., Phillipson, L., Jones, S. C., Hall, D., Potter, J., & Sykes, G. (2011).

    Implementation and

    evaluation of a community-based social marketing campaign to create

    awareness of hypertension as a risk factor for dementia.

Charmaz, K., & Belgrave, L. L. (2007). Grounded theory. *The Blackwell encyclopedia of*

    sociology.

Clark-Hitt, Rose; Dean, Marleah; Smith, Sandi W.; Nazione, Samantha; Atkin, Charles K.; and

    Whitten, Pamela, "Relative Frequency of Breast Cancer Website Information Topics:

    Environmental Risk, Prevention, Detection, Treatment, Awareness, Social Support, and

    Survivorship" (2010). *Communication Faculty Publications*. 694.

Cutrona, C. E., & Suhr, J. A. (1992). Controllability of stressful events and satisfaction with

    spouse support behaviors. *Communication Research,* 19(2), 154-174.

Daniel, K. L., Prue, C., Taylor, M. K., Thomas, J., & Scales, M. (2009). 'Learn the signs. Act

    early': A campaign to help every child reach his or her full potential. *Public Health*, 123

    (Supplement 1), e11–e16. https://doi-org.ezproxy.lib.usf.edu/10.1016/j.puhe

DeMaagd, G., & Philip, A. (2015). Parkinson's Disease and Its Management: Part 1: Disease

    Entity, Risk Factors, Pathophysiology, Clinical Presentation, and Diagnosis. P & T: *a*

    peer-reviewed journal for formulary management, 40(8), 504–532.

Devlin, E., MacAskill, S., & Stead, M. (2007). 'We're still the same people': developing a mass

    media campaign to raise awareness and challenge the stigma of dementia. *International*

    Journal of nonprofit and voluntary sector marketing, 12(1), 47-58.

Duerksen, S. C., Mikail, A., Tom, L., Patton, A., Lopez, J., Amador, X., ... & Sadler, G. R.

    (2005). Health disparities and advertising content of women's magazines: a cross-

    sectional study. *BMC Public Health*, *5*(1), 85.

Entman, R. M. (1993). Framing: Toward clarification of a fractured paradigm. *Journal of*

    communication, 43(4), 51-58.

Eriksson, B. M., Arne, M., & Ahlgren, C. (2013). Keep moving to retain the healthy self: the

    meaning of physical exercise in individuals with Parkinson's disease. *Disability and*

    rehabilitation, *35*(26), 2237-2244.

Fylan, F. (2005). Semi-structured interviewing. A handbook of research methods for clinical and

    health psychology, 5(2), 65-78.

Glaser, B. G. (2002). Conceptualization: On Theory and Theorizing Using Grounded Theory.

    International Journal of Qualitative Methods, 23–38.

Glaser, B. G., Strauss, A. L. (2009). The Discovery of Grounded Theory: Strategies for

    Qualitative Research. *United States: Aldine Transaction.*

Grier, S., & Bryant, C. A. (2005). Social marketing in public health. *Annu. Rev. Public Health*,

    26, 319-339.

Heath, H., & Cowley, S. (2004). Developing a grounded theory approach: a comparison of

    Glaser and Strauss. *International journal of nursing studies*, *41*(2), 141-150.

Hastings, G., & Saren, M. (2003). The Critical Contribution of Social Marketing: Theory and

    Application. *Marketing Theory*, 3(3), 305–322.

    https://doi.org/10.1177/147059310333005

Higgins, J. W., & Hodgins, A. (2008). The grape escape–a FUNdraising bike tour for the

    Multiple Sclerosis Society. *Journal of Nonprofit & Public Sector Marketing*, 19(2), 49-

    67.

Holton, A., Lee, N., & Coleman, R. (2014). Commenting on health: A framing analysis of user

    comments in response to health articles online. *Journal of Health Communication*, 19(7).

    825-837.

Keim-Malpass, J., Mitchell, E. M., Sun, E., & Kennedy, C. (2017). Using Twitter to Understand

    Public Perceptions Regarding the #HPV Vaccine: Opportunities for Public Health Nurses

    to Engage in Social Marketing. *Public Health Nursing – Cambridge*, (4), 316.

Kotler, P., & Zaltman, G. (1971). Social Marketing: An Approach to Planned Social Change.

    Journal of Marketing, 35(3), 3-12. doi:10.2307/1249783\

Lee, K. S., Merriman, A., Owen, A., Chew, B., & Tan, T. C. (1994). The medical, social, and

    functional profile of Parkinson's disease patients. *Singapore medical journal*, 35(3), 265-

    268.

Lock, C. A., & Kaner, E. F. (2000). Use of marketing to disseminate brief alcohol intervention to

    general practitioners: promoting health care interventions to health promoters. *Journal of*

    evaluation in clinical practice, *6*(4), 345-357.

Lubi, K., Vihalemm, T., & Taba, P. (2014). Illness-related information-seeking: the case of Parkinson's Disease patients. In 2nd International Conference on Social Science and Health (ICSSH 2014), PT (Vol. 5, pp. 98-111).

McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2011). Living and coping with Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*, 25(2), 177–182.

Manikam, S. and Russell-Bennett, R. (2016), "The social marketing theory-based (SMT) approach for designing interventions", *Journal of Social Marketing*, Vol. 6 No. 1, pp18-40. https://doi.org/10.1108/JSOCM-10-2014-0078

O'Brien, M., Dodd, K. J., & Bilney, B. (2008). A qualitative analysis of a progressive resistance exercise programme for people with Parkinson's disease. *Disability and Rehabilitation – London and Washington – Taylor and Francis*, 18, 1350-1357.

Orona, C. J. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science & Medicine*, (11), 1247.

Orizio, G., Rubinelli, S., Nava, E., Domenighini, S., Caimi, L., & Gelatti, U. (2010). The Internet and health promotion: a content analysis of the official websites of Italian Public Health Authorities. *Journal of Medicine and the person*, (3), 121.

Pinder, R. (1990). What to Expect: information and the management of uncertainty in Parkinson's Disease. *Disability, Handicap & Society*, 5(1), 77–92.

Poteat, T., German, D., & Kerrigan, D. (2013). Managing uncertainty: a grounded theory of stigma in transgender health care encounters. *Social science & medicine*, *84*, 22-29.

Rimal, R. N., Brown, J., Mkandawire, G., Folda, L., Böse, K., & Creel, A. H. (2009). Audience segmentation as a social-marketing tool in health promotion: use of the risk perception

attitude framework in HIV prevention in Malawi. *American Journal of Public Health*, *99*(12), 2224-2229.

Roger, K. S., & Medved, M. (2010). Living with Parkinson's disease—managing identity together. *International Journal of Qualitative Studies on Health and Well-being*, 5(2), 5129.

Roncancio, A. M., Muñoz, B. T., Carmack, C. C., Ward, K. K., Cano, M. A., Cribbs, F. L., & Fernandez-Espada, N. (2019). Understanding HPV vaccine initiation in Hispanic adolescents using social marketing theory. *Health Education Journal*, 78(7), 743–755.

Rundle-Thiele, S., David, P., Willmott, T., Pang, B., Eagle, L., & Hay, R. (2019). Social marketing theory development goals: an agenda to drive change. *Journal of Marketing Management*, 35(1/2), 160–181. https://doi.org/10.1080/0267257X.2018.1559871

Sanders-Dewey, N. E. J., Mullins, L. L., & Chaney, J. M. (2001). Coping style, perceived uncertainty in illness, and distress in individuals with Parkinson's disease and their caregivers. *Rehabilitation Psychology*, 46(4), 363–381.

Scheufele, Bertram. "Framing-effects approach: A theoretical and methodological critique." *Communications* 29, no. 4 (2004): 401-428.

Shoup, J. A., Narwaney, K. J., Wagner, N. M., Kraus, C. R., Gleason, K. S., Albright, K., & Glanz, J. M. (2019). Social Media Vaccine Websites: A Comparative Analysis of Public and Moderated Websites. *Health Education & Behavior*, 46(3), 454.

Smith, A. (2017, August 8). Parkinson's: Not Your Grandfather's Disease.

Soleimani, M. A., Negarandeh, R., & Bastani, F. (2015). Exploring for self-care process in patients with parkinson's disease: a grounded theory study. *Journal of hayat*, *21*(1), 6-22.

Sullivan, H. W., Aikin, K. J., & Squiers, L. B. (2018). Quantitative information on oncology

      prescription drug websites. *Journal of Cancer Education*, 33(2), 371-374.

Sundstrom, B. (2014). Breaking Women's Health Taboos: Integrating Diffusion of Innovations

      Theory With Social Marketing. *Social Marketing Quarterly*, 20(2), 87–102.

Williams, S., & Keady, J. (2008). 'A stony road… a 19 year journey':'Bridging' through late-

      stage Parkinson's disease. *Journal of Research in Nursing*, 13(5), 373-388.

Wilson, H. S. (1989). Family caregiving for a relative with Alzheimer's dementia: coping with

      negative choices. *Nursing research*.

Wuest, J., Ericson, P. K., & Stern, P. N. (1994). Becoming strangers: the changing family

      caregiving relationship in Alzheimer's disease. *Journal of Advanced Nursing*, 20(3), 437-

      443.

Wymer, W. W. (2015). Innovations in social marketing and public health communication:

      improving the quality of life for individuals and communities. *Springer*.

van der Eijk, M., Faber, M. J., Al Shamma, S., Munneke, M., & Bloem, B. R. (2011). Moving

      towards patient-centered healthcare for patients with Parkinson's disease. *Parkinsonism*

      & related disorders, 17(5), 360-364.

Appendix A

Codebook for Grounded Theory approach

Negative medical communication/ bedside manner	Medical professionals speaking with PWPs or care partners in a manner that may be confusing, most likely using medical jargon as opposed to a language that is universally understandable.	This may be cold, unfriendly, uncaring. "PWP feeling like they are just another number in the system."	Include criteria about care partners and PWPs feeling angry, upset, about the interactions they've had with their doctors.

Self-diagnosis	When a PWP or care partner has a symptom, such as stiffness, etc. and starts to research on the Internet or through other sources, such as social support in order to form a diagnosis of PD before getting confirmation of disease from a doctor or medical professional, resulting in lack of surprise when the diagnosis is made.	This may look like a PWP feeling a confirmation at diagnosis because they have already done their research.	Include content about information seeking before an official diagnosis from a doctor. Exclude criteria about post-diagnosis info-seeking.

Emotional Response	Participants expressing hope, embarrassment, relief, anger, concern, etc. at diagnosis or throughout the experience with PD	"She didn't sign up for this." This may look like a PWP or care partner feeling optimistic or having faith in their current situation in terms of their ability to live a "normal" life or hope for a cure. Ex: "Not a nail in the coffin."	Include PWP describing their reactions or emotions as a result of diagnosis or PD related instance Exclude any emotions felt as a result of anything not PD related.

Uncertainty about pre-PD symptoms	When PWP seeks medical attention to decrease confusion about symptoms they are currently experiencing without knowing it is PD.	For example, PWP having leathery hands, flip flop falling off of foot while walking, becoming antisocial, not being able to walk as he/she normally has."	Exclusion: Do not include symptoms associated with PD post-official diagnosis. Inclusion: Include phrases and content that mentions unnatural symptoms, such as stiffness without PWP knowing it is PD along with denying these symptoms meaning anything.

Alternative Treatment/Coping Strategies	Support groups: Ex. A PWP feeling understood or like "himself" or "herself" through shared experiences with a fellow PWP/support group/community. PWP or care partner passively gathering information from others. When a PWP or care partner seeks out other forms of treatment besides medicine, such as lifestyle, which may include exercise or diet changes to seek beneficial results or slow symptoms or progression.	For example, "It's so much easier to talk to a person with Parkinson's. You're talking to him and you'll say yeah I almost peed on my shoes yesterday. I say Oh yeah I got it." Participant 6. Page 4. Example, rock steady boxing, dancing, diet, etc.	Include criteria specifically addressing a PWP feeling supported by a fellow PWP or a care partner feels supported by another PD care partner. Exclude content that addresses support from those who do not share the same experience. Include criteria about rock steady boxing, socialization, diet, mental health, emotional health. Exclude criteria such as prescription drugs.
Familial and spousal social support	A PWP's network of peers, family members, and friends who can provide support and positivity throughout their life.	This may look like a PWP's family and spouse supporting their decisions and independence.	Include criteria that acknowledge family and spouses being supportive in all aspects of life. Exclude criteria about support from support groups.

Active Information seeking	Trying to find information about PD outside of what was provided by the doctor.	Example, seeking support groups, researching on the Internet, calling sources, or peers to hear about their experiences, researching other medical professionals. For example, "You're on your own. You basically have to do it yourself in terms of the lack of any protocol for treatment and any system." Participant 6. Page 3.	Include criteria about PWPs or care partners going out of their way to find out more information associated with PD. Exclude criteria of a PWP or care partner hearing about information in passing, such as in the doctor's waiting room, in a group setting, etc.

Appendix B

Codebook for Social Marketing Theory

Identifying the four P's associated with Social Marketing theory (product, price, place & promotion).

Product - desired behavior targeted by social marketing (Wilson et al., 2013). This refers to the product, the behavior, or benefit that researchers aim to steer individuals toward (Zaltman & Kotler, 1971). What participants stated made/would make them decide to use a website; What participants stated are the positive effects of having a PD website. Example: the product has educational information; the product has interactive features (Roncancio et al., 2019).

Price - the social, economic, and psychological and physical costs involved in achieving the product (Wilson et al., 2013), the price is potential barriers to behavior change, such as price, transportation cost, or general resentment of the proposed or potential behavior change/benefit (Zaltman & Kotler, 1971). What participants stated would/did make it difficult/less likely for them to use a website (barriers, as mentioned above). Example: the participant is not psychologically ready to seek information; the participant does not feel that the product targets their specific age/PD progression needs (Roncancio et al., 2019).

Place - the setting, community context, or distribution channels for the product (Wilson et al., 2013). It refers to where and when people will go to perform/use the product (Zaltman & Kotler, 1971). Where participants would first decide to seek information, their preferred medium. Example: participant uses the internet as their main source for information; the participant would be most likely to use the internet as an information-seeking resource (Roncancio et al., 2019).

Promotion - all actions designed to make the audience aware of the product and its benefits (Wilson et al., 2013), the promotional aspect, how do they engage, meaning, how is it presented in a way that encourages interest (Zaltman & Kotler, 1971). What marketing features would most likely engage with and research the target audience. Example: participants would like to be informed of the product via their doctor; the participant would like a pamphlet that would guide them to the resource.

Appendix C

Interview Guide

The following questions are designed to be semi-structured in nature, meaning that the moderator will be able to engage in a conversation with the participants. Follow-up questions related to the above goals will be asked when appropriate.

1. When were you (or your partner) first diagnosed with PD?
2. Do you remember your first thoughts after you heard your (or your partner's) diagnosis? What were they?
3. Can you tell me about the doctor's visit when you (or your partner) were diagnosed? Was anyone there with you? How did you feel before and after?
4. Can you tell me about your life since your (or your partner's) diagnosis?
5. Did you feel like you knew a lot about PD when you (or your partner) were diagnosed? How did this "knowing" versus "not knowing" feel for you?
   - If you needed it, where did you look for information about Parkinson's Disease? (*adapted from Roncancio, Muñoz, Carmack & Ward, 2019*)
6. Can you tell me about anything in your life that makes you feel unsure or has caused you to have more questions about PD?
7. How has not knowing or uncertainty affected your life? The life of your family (if applicable)?
8. How do you manage not knowing about how your symptoms will progress?
9. If your partner is feeling uncertain about something, what do you do to help manage this stress?
10. What are some of the coping strategies you used when you first discovered you (or your partner) was diagnosed with Parkinson's disease? In what ways were those strategies helpful or not helpful? (each of these three adapted from Williamson, Simpson, & Murray, 2008)
11. What information was missing from your initial Parkinson's diagnosis healthcare experience that would have helped you 'live well' with PD? *(adapted from Kleiner-Fishman, Gryfe, & Naglie, 2013) – Place*
12. What would make you choose to use a specific website as your main source of information about PD (format, medium, accessibility, connectivity, etc.)? (*adapted from Roncancio, Muñoz, Carmack & Ward, 2019) – Product*
    2a. Price: what would be a barrier for you using a website? What would make it difficult/make you less likely to use it?
    2b. Place: What would be your ideal place to look for information, if you had just been diagnosed? (website, doctor, library, etc.)
    2c. Promotion: What would allow you to engage with a product/where would you want to hear about a product? (Local newspaper, from your doctor, pamphlet, etc.)
    2d. Product: What would make you more like to use a website? (usability, easy to navigate, information and clinical trials, educational information, etc.)

13. In your own words, I would like you to tell me about your experience of living with Parkinson's disease, and the problems it has caused for you. *(adapted from Gibson, 2016)*

Appendix D

Punch list for Me Over PD website development

Study 1:
     The first study aimed to gather an understanding of the experiences of PD patients and care partners. We asked questions regarding their initial diagnosis and how the experience had been, what information was provided, how their lives had been after their diagnosis, how they have coped with their diagnosis, and what information they would have liked to receive when they were initially diagnosed. These various types of questions were created and asked in order to gather a wholesome understanding of PD patient and care partners' experiences to have insight into what resources and information was missing. Having this information will aid the Me Over PD initiative in creating a website geared to helping newly diagnosed PD patients and care partners in a way that has not previously been done.

Findings from Study 1:
     For Study 1, 10 people were interviewed. Various themes emerged from the interviews that shed light on much of what PD patients and care partners had experienced.

- Misdiagnosis: 60% of people who were interviewed expressed that they or their partner had been misdiagnosed prior to receiving their PD diagnosis.
  - Creating more awareness in healthcare clinics could increase the likelihood of earlier diagnoses.
- Lack of information at diagnosis: 60% of people who were interviewed expressed that they did not receive enough information about PD or resources upon their diagnosis.
  - Though some said they received little information, they still did not feel like it was enough to move forward well informed and with a clear idea of what steps to take moving forward.
  - By Me Over PD providing healthcare clinics with information about the organization, they can help guide both healthcare providers, patients, and their care partners to the resources and information they need.
- Receiving a pill and a follow-up appointment: 60% of people who were interviewed expressed that they received a prescription for a medication and a follow-up appointment 3-6 months after having their initial diagnosis appointment.
  - Many of the people who were interviewed felt like they were just another number and by not receiving information or any more medical attention after receiving their diagnosis, it added to the uncertainty they were already feeling about what PD is and how to proceed.
- Internet usage: 90% of people who were interviewed expressed using the internet as one of, if not their most preferred resource for finding information and other resources to help with their PD.

- From this very high percentage, it became very clear that the internet was a valuable resource that the Me Over PD initiative should tap in to by creating and developing a website in order to help newly diagnosed patients and care partners.
- The Michael J. Fox Foundation website: 50% of the people who were interviewed expressed the MJF Foundation website as a very good and useful resource.
- It may be beneficial to mirror some of the foundational elements from that website and use it as a template for the Me Over PD initiative.
- Missing social support: 80% of the people who were interviewed expressed not having apt social support and interaction in the months that followed their diagnosis. As this was something that the vast majority of people said they were missing, it is very clear that not receiving information and resources upon diagnosis can lead to significant loneliness in PD patients and care partners.
- Friends and family: 70% of the people who were interviewed expressed their gratitude for their partners or other friends/family after their diagnosis. This emphasizes the importance of PD as a family disease and something that individuals should not be tackling on their own.

What results mean:
- These results show the significant themes that were expressed by the individuals who were interviewed.
  Misdiagnosis:
  - It is necessary to provide healthcare providers with information, through the organization, aimed at better informing physicians of the many ways that PD can present itself.
- Lack of information upon diagnosis:
  - It is clear that healthcare providers do not have a clear guide for how newly diagnosed patients and care partners should proceed once diagnosed.
  - Creating partnerships with healthcare facilities and clinics would be beneficial in making Me Over PD educational materials and resources available. It would aid physicians in directing patients and care partners to a resource immediately upon being diagnosed.
- Receiving a pill and a follow-up appointment:
  - Again, partnering with healthcare facilities and discussing different treatments and creating a better system of communication is vital in creating a better bedside-manner for patients and care partners in the future.
- Internet usage:
  - The vast majority of individuals said they used the internet as a resource for finding out more about PD and gathering resources. Creating a website for Me Over PD would be very beneficial as it could attract new individuals to the organization through the preferred information seeking resource.
- The Michael J. Fox Foundation website:
  - This website was described as being very useful for patients and care partners. It may be beneficial for Me Over PD to look more closely at the website to see what is included in the site and how it is set up design-wise.
- Missing social support:
  - This ties back to the lack of information upon diagnosis and receiving a pill and a follow-up appointment, in that if people are not given resources then they are

essentially left to their own devices. Me Over PD would be vital for many individuals who face the disease on their own as it could provide information concerning support groups and exercise groups, among other things.

- Friends and family:
  - This reiterates the importance of not facing the disease on your own. Many of the individuals who were interviewed were expressively thankful for their friends and family, which reemphasizes the point above. Individuals who do not have the support and are not given resources to find it are put at a disadvantage. By partnering with healthcare organizations, Me Over PD would play an integral part in providing newly diagnosed patients and care partners with the resources to find the social support they need via a website.

Study 2:

The second study, Study 2, was based on the findings from Study 1. In the first study, we found that there was a general lack of information when patients and care partners were initially diagnosed. This was caused by misdiagnoses, not receiving apt information about PD, receiving a pill and a follow-up appointment, which combined, led to a lot of frustration in the individuals who were interviewed. In addition, many of the people interviewed emphasized the importance of social components to their well-being, many not having received any following their diagnoses. This lack of informational and social resources were two major areas that people felt that they did not receive adequately when they were initially diagnosed. Furthermore, the vast majority of individuals said that the internet as their main source of information and resource seeking. Due to the lack of informational and social resources, as well as the high usage of the internet, Study 2 aimed to find out what elements and information would be most beneficial and useful for newly diagnosed patients and care partners.

Findings from Study 2:

For Study 2, 10 individuals were interviewed. Various categories emerged as being of great importance to patients and care partners in terms of what elements and information would make a website for newly diagnosed patients and care partners.

- Website: 90% of the people interviewed reported wanting to get information about PD from the internet.
  -Reiterating the findings from Study 1, Study 2 also found that the internet was the most sought-after resource. Creating a website for newly diagnosed PD patients and care partners would, therefore, be very beneficial for the Me Over PD initiative.
- New and authoritative/reliable information: 50% of people who were interviewed expressed wanting new and authoritative information on a website.
  - Me Over PD would benefit from creating contacts and partnerships with authoritative sources such as physicians who specialize in PD.
  - The organization would benefit from hiring an individual or individuals who were in charge of curating authoritative information and maintaining partnerships with sources to provide current and constant new information
- Michael J. Fox Foundation website: 40% of the people interviewed said that the MJF Foundation website provided up-to-date, authoritative information, and information about clinical trials and PD drugs.
  - Me Over PD may benefit from viewing the MJF website to gather an understanding of how it set up the various categories mentioned above.

- Usability: 70% of people interviewed emphasized the importance of usability.
  - People want a website that is easy to navigate, that has clear instructions on where to go for various things, such as for example, medications, clinical trials, and support groups. It is important to create something that caters to the people who will be using it.
  - Me Over PD would benefit from hiring a web designer who can create an easily navigable website, with tabs that can easily navigate users to the most pertinent information.
- Trials and drugs: 30% of the people interviewed wanted information pertaining to new clinical trials and drugs to treat PD.
  - Including information about trials and drugs would be a good way too, to show users that things in the medical community are being done to treat PD.
  - Creating partnerships with pharmaceutical companies or healthcare facilities may be a good way for Me Over PD to gain access to such information.
- Educational material: 20% of the people interviewed reported wanting educational material about PD.
  - Creating partnerships with authoritative sources, such as PD specialists, would be beneficial in curating information to help educate newly diagnosed PD patients and care partners.
- Broader age groups: 20% of people interviewed emphasized the importance of catering to a broader age range.
  - PD predominantly affects older age groups of people, however, the disease also affects younger individuals. Me Over PD would benefit from including information catered to younger demographics as well as older ones.
  - Two of the individuals interviewed in particular expressed wanting resources that would aid in telling young children that a parent was diagnosed with PD.
- Non-medical jargon: 10% of people interviewed expressed wanting vocabulary that is easy to understand.
  - This reiterates the importance of creating a resource catered to the people who will be using it. The organization may benefit from hiring an individual or consulting with an individual that can aid in translating some of the medical language that surrounds PD into language that the average person would more likely understand.
- Pop-up ads: 10% of the people interviewed reported not wanting pop-up ads on the website.
  - Pop-up ads are a source of income for websites as they allow advertisements to play on the website when visitors enter the site, however, people would most likely not want to stay on a website such pop-up ads appear. The organization may benefit from creating income in a way that does not include such ads.
- Personal information: 10% of participants reported not wanting to give personal information.
  - When creating accounts for users of the Me Over PD website, it may be beneficial for the organization to lower the required information that a user would have to provide. This means not asking for information that is not vital or, instead, giving the user the option of whether or not they wish to provide certain information, such as address, age, etc.

- Doctor's office: 90% of the people interviewed reported wanting to hear about a website from their doctor's office.
  - Doctors are trusted by patients as authoritative sources, therefore receiving information about a PD resource from a doctor would be make individuals more likely to take the advice and recommendation.
  - Me Over PD would benefit from creating partnerships with healthcare facilities and clinics in order for newly diagnosed PD patients and care partners to hear about the website from their preferred source.

Future elements to consider:

- Me Over PD would benefit from hiring a website developer to create mockups for how a potential website would look, such mock-ups should then be shown to PD patients and care partners for feedback to narrow in what would be most easily usable for PD patients and care partners.

- The organization would benefit from compiling information in the categories listed above and lay out the information for PD patients and care partners to give feedback on.