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### A novel approach to tailored communication

*Optimizing online health information for older patients*

Nguyen, M.H.

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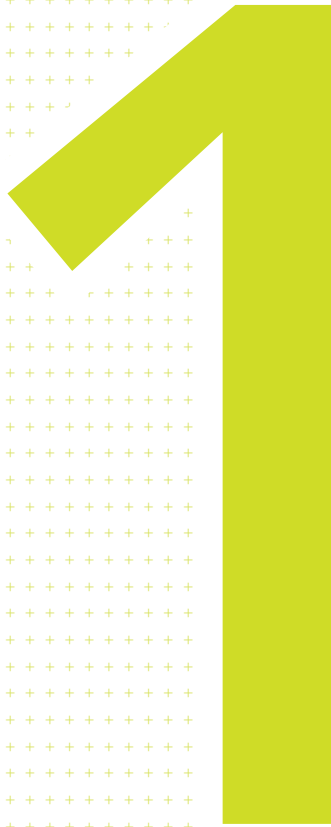
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# **Chapter 1**

## **Introduction and dissertation outline**

## INTRODUCTION

Today's information society is characterized by the availability of and relatively easy access to cancer information on the Internet. In Western countries, many patients, including those of 65 years and older, turn to the Internet for information to prepare for consultations with their health care provider (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; Flynn, Smith, & Freese, 2006; Medlock et al., 2015). Older patients ( $\geq 65$  years) make up the majority of the cancer patient population (Pilleron et al., 2018). Age-related declines (e.g., hearing loss, visual impairment, reduced processing speed and working memory) may pose barriers for communication with healthcare providers and thereby processing of medical information (Brown & Park, 2003; Cohen et al., 2017; Noordman et al., 2017; Sparks & Turner, 2008; Williams, Haskard, & DiMatteo, 2007). For instance, compared to younger patients, older patients ask fewer questions during consultations (Goss et al., 2015), feel less confident in communicating with their provider (Maliski et al., 2004), have many unfulfilled information needs (van Weert, Bolle, van Dulmen, & Jansen, 2013), and recall less information from consultations (Jansen et al., 2008a). It is thus not surprising that older cancer patients have indicated a need for supportive interventions to overcome these communication barriers (Noordman et al., 2017). Online health information (e.g., online patient education) in addition to patient-provider communication can support patients in achieving their information goals (Friedman, Cosby, Boyko, Hatton-Bauer, & Turnbull, 2011; Ryhänen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010), and has shown to be effective at increasing older patients' health-related outcomes (Bolle et al., 2015).

Online health information is considered to be even more effective when *tailored* to individual needs and preferences. Tailored online health information provides recipients with *content* adapted to their individual characteristics, needs and/or preferences (Rimer & Kreuter, 2006). While tailored information has been proven to be more effective than non-tailored information, the effect sizes are typically small (Krebs, Prochaska, & Rossi, 2010; Lustria et al., 2013; Noar, Benac, & Harris, 2007; Portnoy, Scott-Sheldon, Johnson, & Carey, 2008; Sohl & Moyer, 2007). Such tailored communication interventions provide personally relevant content, but have overlooked individual preferences for *how* this information should be presented, and thereby possibly limiting their effect sizes. While general differences in learning styles exist (e.g., verbal vs. visual learning; Mayer & Massa, 2003), especially older patients may have varying needs regarding the *mode* in which information is presented on health websites (e.g., via textual, visual or audiovisual information) due to age-related sensory (e.g., impaired vision and/or hearing; Ogozalek, 1994; Soroka et al., 2006) and/or cognitive

decline (e.g., reduced processing speed; Wright et al., 2008). Moreover, the way in which *content* is processed highly depends on *how* this information is delivered (Ritterband, Thorndike, Cox, Kovatchev, & Gonder-Frederick, 2009), which might be especially true for older patients (Lang, 2006). To ensure that older cancer patients can adequately process online health information, websites targeted at this population should consider tailoring information to individual visual, auditory, and/or cognitive capabilities that may determine their mode preferences as well.

This dissertation investigates ‘mode tailoring’ as a novel tailoring strategy, with the aim to optimize online health information for older patients with cancer. In this dissertation, mode tailoring refers to the possibility for individuals to adapt the modality of online information presentation to their preferences, using textual, visual, and/or audiovisual elements. **The central question in this dissertation is whether *mode tailoring* online health information is of added value for older patients’ (≥65 years), and whether effects of mode tailoring are different from younger patients’ (<65 years).** An age cut-off of 65 years is employed, since cancer most frequently occurs in individuals above this age (Pilleron et al., 2018). Moreover, clinical cancer-related trials often use this age as cut-off for inclusion (Hutchins, Unger, Crowley, Coltman Jr, & Albain, 1999), and studies focusing on older cancer patients and the Internet have used this age cut-off as well (Bol et al., 2018; Bolle et al., 2015; Noordman, Driesenaar, van Bruinessen, & van Dulmen, 2017; Smith et al., 2003). The primary outcome of interest in this dissertation is patients’ information processing, and in particular knowledge acquisition and recall of information from online information and medical consultations. Secondary outcomes include both short-term (i.e., after viewing the website) and longer-term (i.e., during and after consultations) outcomes, including evaluative (e.g., website satisfaction), psychological (e.g., anxiety), and communication (e.g., question-asking during consultation) outcomes. Thus, this dissertation offers a unique insight into how patients’ use of online health information may influence health-related outcomes before, during, and beyond the medical consultation.

## **OPTIMIZING ONLINE HEALTH INFORMATION FOR OLDER PATIENTS**

### **Cancer and the aging population**

Cancer is mainly a disease of the elderly (Yancik, 2005). Currently, the majority of newly diagnosed patients with cancer is 65 years and older, and the number of patients of this age is expected to grow globally (Pilleron et al., 2018; Yancik, 2005), including the Netherlands (Dutch Cancer Society, 2011). The increase in number of newly diagnosed cancer patients can be attributed to the ageing population: the elderly population has risen fast due to the aging of the ‘babyboom’ generation,

plus, people now tend to live longer (Dutch Cancer Society, 2011; Yancik, 2005). As a result, in the Netherlands alone, the prevalence of cancer is expected to increase from 118.000 patients in 2007 to 210.000 in 2020 (Dutch Cancer Society, 2011). Globally, the number of new cancer cases is expected to nearly double between 2012 and 2030 (Bray, Jemal, Grey, Ferlay, & Forman, 2012). This increase in cancer incidence goes hand in hand with a higher need to support elderly patients in terms of effective patient education and communication with health care providers.

Older patients are also the most at-risk population for poor communication with health care providers. For example, hearing is essential for good oral communication, but many older adults suffer from age-related hearing loss (Kiessling et al., 2003; Lin, Niparko, & Ferrucci, 2011). Other age-related declines in physical (e.g., visual impairment, co-morbidity) and cognitive (e.g., working memory) functioning also make it difficult for older patients to communicate effectively with providers (Brown & Park, 2003; Cohen et al., 2017; Sparks & Turner, 2008; Williams et al., 2007). Research in the cancer context has shown that older patients participate less actively during consultations and are less likely to express their information preferences and needs (Butow, Dunn, Tattersall, & Jones, 1994; Eggle et al., 2006; Goss et al., 2015; Siminoff, Graham, & Gordon, 2006). Furthermore, older patients often feel less confident in their ability to communicate with health care providers to gain knowledge, and understand treatment options and potential complications (Maliski et al., 2004). Consequently, older patients have more difficulty remembering information from consultations as compared to younger patients (Jansen et al., 2008a). This is unfortunate, because older patients do report that they would like to be well-informed (Jenkins, Fallowfield, & Saul, 2001). Moreover, there may be negative consequences on the long run as well, as patients who are less satisfied with information provision are left with unmet information needs, and are more likely to suffer from anxiety, depression, and lower quality of life (Faller et al., 2016; Husson, Mols, & Van de Poll-Franse, 2010). Adequate information provision for older cancer patients, with the aim to improve knowledge acquisition and recall of medical information, is in view of the aforementioned reasons a more timely topic than ever.

### **Online health information: The Internet as a patient education tool**

In Western societies such as the United States and the Netherlands, older adults are increasingly using the Internet to obtain health information (Pew Research Center, 2014; Statistics Netherlands, 2018), which makes the Internet a suitable tool for patient education. In the Netherlands, more than two-thirds of older adults ( $\geq 65$  years) uses the Internet to look up health information and this number is increasing yearly (Statistics Netherlands, 2018). For many people, including older adults,

the Internet is one of the first preferred health information sources next to their health care provider (Hall, Bernhardt, & Dodd, 2015; Medlock et al., 2015; Tustin, 2010). Patients often use online health information to prepare for their consultation with the health care provider (Caiata-Zufferey et al., 2010; Flynn et al., 2006; Medlock et al., 2015). Hospital websites can thus be used as a preparatory information provision tool to inform patients and support them in communicating with their providers (Albada, van Dulmen, Lindhout, Bensing, & Ausems, 2012; Bass et al., 2006; Bol, Scholz et al., 2013). For instance, when patients are well-prepared and informed, they might be more able to participate actively in consultations (e.g., in the form of question-asking). Furthermore, since older cancer patients have more difficulty processing medical information, the use of online health information in addition to patient-provider communication can be highly relevant for this group. Namely, when information is conveyed via different ways (i.e., spread over or repeated by multiple sources), medical information is anticipated to be better understood, processed and remembered by older patients (Sparks & Turner, 2008; Posma, van Weert, Jansen, & Bensing, 2009). A recent review showed that online health information tools have added value for older patients, as they can be effective at improving health-related (clinical) outcomes in older patients (Bolle et al., 2015).

Unfortunately, many older adults experience difficulties when using online health information and are not satisfied with the information they find online (Bolle et al., 2016; Rideout, Neuman, Kitchman, & Brodie, 2005). Particularly for older patients, age-related factors might negatively influence experiences with and use of (health) websites (Czaja et al., 2006). Despite the increasing amount of health information offered online, health websites – including credible sources such as hospital websites and patient portals – rarely consider the preferences and abilities of older patients (Becker, 2004; Bolle et al., 2016). This is a missed opportunity, because computer-based media such as websites (unlike traditional media like print, radio, television) offer the technical possibilities to *tailor* information (i.e., navigation, content, modality) to individual preferences, needs, and abilities of the older patient. For online health information to be effective for older cancer patients, websites should be developed in co-design with patients and consider their age-related abilities. Tailoring the *mode of information presentation* could be a promising strategy to optimize online health information for older patients.

## A NOVEL APPROACH TO TAILORED COMMUNICATION FOR OLDER PATIENTS

### What does tailoring entail?

The rise of computer technology has made *tailoring* an attractive strategy to optimize online health communication interventions (Lustria et al., 2013), including online patient education materials (Albada et al., 2012; Desteghe et al., 2018). Tailored health information refers to communication intended to reach one specific person, and thus involves adjusting information in such a way to match unique individual characteristics and preferences related to an outcome of interest (Kreuter, Oswald, Bull, & Clark, 2000; Rimer & Kreuter, 2006). The goal of tailored health information is to increase the perceived personal relevance of this information, and by doing so, to motivate and enable people to process information better. As information is processed deeper, this is in turn expected to elicit the desired changes in the outcome of interest in response to the information (e.g., information recall; Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008; Kreuter & Wray, 2003). Because tailored information materials facilitate deeper processing of information, tailoring is considered an effective strategy to optimize online information provision to older patients.

Tailoring has been applied as a communication strategy to address a wide range of health topics, ranging from health promotion and disease prevention behaviors (e.g., smoking, diet, physical activity), to screening and detection behaviors (e.g., cancer, STDs), and patient education materials in various disease contexts (Albada et al., 2012; Lustria et al., 2016; Oenema, Brug, Dijkstra, de Weerd, & de Vries, 2008; Te Poel, Bolman, Reubsat, & de Vries, 2009; Vernon et al., 2011). Different tailoring strategies can be employed, such as adapting the *content* to individual information needs and preferences, framing information in a *context* that is meaningful for the targeted person, or providing information in a *format* or *delivery mode* that fits with individual preferences and processing abilities (Rimer & Kreuter, 2006; Smit, Linn, & van Weert, 2015). The large body of research devoted to tailoring has, however, mainly focused on adapting the *content* of health information. Overall, systematic and meta-analytical reviews have reported superior effects of tailored health information over non-tailored information, but the effect sizes of content tailoring are typically small (Krebs et al., 2010; Lustria et al., 2013; Noar et al., 2007; Portnoy et al., 2008; Sohl & Moyer, 2007). These small effect sizes suggests room for improvement, and indicate a need to investigate novel tailoring strategies beyond content tailoring, to maximize the effectiveness of online health communication interventions.



## Tailoring the mode of information presentation

Health communication interventions that have adapted the content may provide information that is deemed personally relevant, but overlook individual preferences for how this information should be presented as well as cognitive abilities to process different formats of information. Individuals, for example, differ in their modality preferences (e.g., textual vs. audiovisual online information; Heo & Cho, 2009), processing styles (e.g., verbal vs. visual learners; Truluck & Courtenay, 1999; Wehrwein, Lujan, & DiCarlo, 2007), and cognitive motivations (e.g., low vs. high need for cognition; Bakker, 1999). Especially older adults may vary in these areas, since their preferences for formats of information presentation can highly depend on age-related abilities such as vision, hearing and cognition (Loos & Romano Bergstrom, 2014). For instance, studies have shown a large variance in preferences for textual, visual, and audiovisual computer-based information among older adults with sensory (e.g., declines in vision and hearing) and cognitive (e.g., working memory) impairments in different contexts (i.e., prescription drugs, information brochures, route maps; Ogozalek, 1994; Soroka et al., 2006; Wright et al., 2008). Tailoring the *mode of information presentation* can have added value, as the way in which content is processed highly depends on how this information is delivered (Lang, 2006; Ritterband et al., 2009). This is even more true for individuals who have difficulty with processing information, such as older adults (Lang, 2006). Since age-related declines, and the variability in these domains, influence which information modes work most effectively in transferring information, this calls for a mode-tailored approach when designing online health information for older patients.

## A user-initiated perspective on mode tailoring

Traditionally, tailoring starts with an assessment of individual characteristics and preferences (e.g., demographics, behavioral constructs, relevant topics of information). This individual data is then used as input for a computer algorithm to tailor and deliver information to the individual, and can therefore be considered as 'system-initiated tailoring' (Rimer & Kreuter, 2006; Sundar & Marathe, 2010). Alternatively, a more 'user-initiated' approach to tailoring information can be applied. Technological possibilities, allow individuals for example to select personally relevant content (e.g., health information topics) and modalities (e.g., text, images, video) that fit their preferences and needs while using websites. Such technological advancements induce a shift from a more traditional system-initiated approach to a more user-initiated perspective, which imposes a new conceptualization of tailored health communication and warrants more in-depth investigation. Outside of the health domain, for example in news media and e-commerce, the user-initiated approach to tailoring (also referred to as customization) has led to positive evaluative, cognitive and behav-

ioral outcomes (Arora et al., 2008; Kalyanaraman & Sundar, 2006; Kang & Sundar, 2016; Sundar & Marathe, 2010). Although user-initiated tailoring has hardly been explored in the health domain, it could be a promising approach to maximize the effectiveness of online tailored health information. Moreover, traditional system-initiated tailored interventions can be quite costly in their development (Lairson, Newmark, Rakowski, Tiro, & Vernon, 2004), especially when tailoring algorithms and intervention materials become more sophisticated. Engaging individuals in the tailoring process can relieve some of these costs as part of these system-driven algorithms are replaced, while still providing respondents with health information that is adapted to their individual situation. This dissertation applies a user-initiated approach to mode tailoring of online health information. From now on when mentioning ‘mode tailoring’, we refer to a *user-initiated* approach, where individuals can *self-tailor* the *mode of information presentation* by selecting any combination of textual, visual, and/or audiovisual information.

## **HOW DOES MODE TAILORING WORK? ENHANCING OLDER PATIENTS’ MOTIVATION AND ABILITY TO PROCESS INFORMATION**

The elaboration likelihood model (ELM, Petty & Cacioppo, 1986) and limited capacity model of motivated mediated message processing (LC4MP, Lang, 2006) offer a theoretical framework to understand how tailored health information is being evaluated, processed, and recalled from memory. The basic assumption of the LC4MP is that individuals have limited cognitive resources to process information (Lang, 2006), which resonates with the idea of ‘cognitive aging’, explaining why information processing may be more challenging for older patients (Brown & Park, 2003). Both theories posit that under conditions of high *motivation* and *ability*, people are more likely to actively process information, resulting in more positive outcomes. First, individuals may lack the *motivation* to process information, and may choose to allocate fewer resources to a task than it requires. Mode tailoring can increase the *motivation* to process online health information in several ways. For instance, providing people with *active control* over the pace, order, and content of online information increases the motivation to process information (Dillon & Jobst, 2005; Eveland & Dunwoody, 2001). Furthermore, the *perceived personal relevance* of information motivates people to process information deeper (Lang, 2006; Petty & Cacioppo, 1986), which explains why people are more likely to *engage* with tailored health information as compared to non-tailored information (Ruiter, Kessels, Jansma, & Brug, 2006; Lustria et al., 2016). Besides lack of *motivation*, a processing task might exceed the message recipients’ *ability* to process the information, as it may require more cognitive resources than the individual has available to allocate to the task. This

is particularly true for older patients, because of their increasingly limited cognitive resources to process information (Brown & Park, 2003). Mode tailoring can play an important role in facilitating the *ability* to process information, for example by leaving out irrelevant information, thus limiting the amount of information and, thereby, relieving the cognitive resources needed to process the information (Jensen et al., 2014b). More importantly, as information presentation modes on websites (e.g., textual, visual, audiovisual information modes) are adapted to individual processing styles and abilities, it is anticipated that mode tailoring decreases *cognitive load* and enables optimal information processing (Lang, 2006). Together, the ELM and LC4MP suggest that for information to be evaluated more positively and processed adequately, designers should develop messages that increase individuals' *motivation* and *ability* to process information. To gain a better understanding of *why* mode tailoring is an effective strategy to optimize online health information for older patients, the current dissertation will examine which mechanisms of *motivation* (i.e., perceived active control, perceived personal relevance, website engagement) and *ability* (i.e., perceived cognitive load) explain the effects of mode tailoring on health-related outcomes.

## DISSERTATION AIMS AND OUTLINE

This dissertation aims to gain insight into how online health information can be optimized by tailoring the mode of information presentation. **The central question in this dissertation is whether *mode tailoring* online health information is of added value for older patients' ( $\geq 65$  years), and whether effects of mode tailoring are different from younger patients ( $< 65$  years).** To this end, a tailored online information tool as preparation for a medical consultation will be developed, with the goal to support patients' processing of medical information. Therefore, the primary outcome of interest in this dissertation is patients' knowledge acquisition and information recall from online information and medical consultations. This dissertation consists of six chapters in total, of which five empirical chapters that are based on four data sets, and one chapter which describes a website development study. The studies conducted in this dissertation include both samples of older and younger adults from the general population as well as cancer patients. As Figure 1.1 visualizes, this dissertation starts with examining the theoretical mechanisms and effects of mode tailoring in an experimental setting among the general population, with the ultimate goal to investigate the value of a mode-tailored preparatory website for cancer patients visiting the hospital. The following two research questions will be answered:

1. What are the theoretical mechanisms and effects of tailoring the mode of presentation (vs. no tailoring) on older ( $\geq 65$  years) and younger adults' ( $< 65$  years) website satisfaction and recall of online cancer-related information?

2. What are the effects of a mode-tailored preparatory website (vs. non-tailored websites) on older ( $\geq 65$  years) and younger ( $< 65$  years) cancer patients' evaluative (e.g., website satisfaction), cognitive (e.g., information recall), psychological (e.g., anxiety), and behavioral (e.g., question-asking during consultation) health-related outcomes?

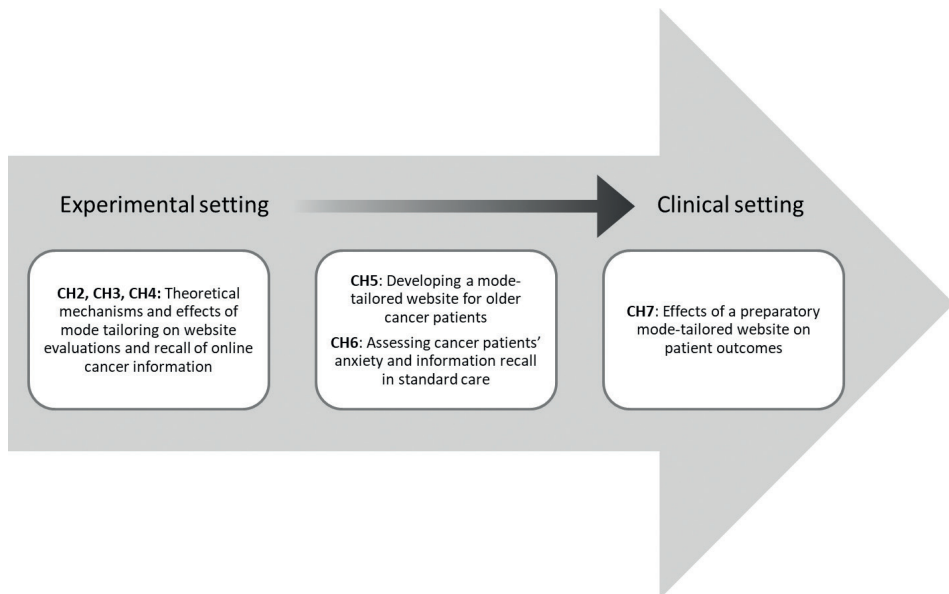


Figure 1.1. Dissertation outline

This dissertation starts with two experimental studies ( $N = 559$ ;  $N = 392$ ) that explore the mechanisms and effects of tailoring the mode of information presentation on older ( $\geq 65$  years) and younger ( $< 65$  years) adults' website satisfaction and information recall (**Chapter 2, 3, and 4**). Specifically, in **Chapter 2 and 3**, the effects of exposure to a mode-tailored website compared to four non-tailored websites (text-only, text with visuals, text with video, and a combination of all modes) are examined, as well as age differences (25–45 years vs.  $\geq 65$  years) in website use and effects. **Chapter 4** complements these studies by focusing on unravelling the underlying mechanisms explaining these effects. In this chapter, a theoretical model of mode tailoring effects is proposed, in which existing mechanisms that have been identified in the tailoring literature (e.g., perceived relevance, website engagement) are tested and additional mechanisms (e.g., perceived cognitive

load, perceived active control) that may explain mode tailoring effects are included as well. This study included a representative sample of the Dutch population with participants ranging from 25 to 83 years. The results from **Chapter 2, 3 and 4** shed light on the effectiveness and explanatory processes of mode-tailored online information (vs. non-tailored versions) on website satisfaction and information recall, and conclude with a theoretical model of mode tailoring effects.

Moving from the experimental context to a clinical setting, **Chapter 5** describes the development of the preparatory mode-tailored website (with text, visuals, and patient videos) containing information for patients to prepare for their first visit to a multidisciplinary fast-track clinic in the Netherlands that is specialized in one-day diagnostics and treatment planning. In this chapter, an existing hospital website is systematically redesigned in a co-design process with patients and professionals (i.e., researchers, clinicians, policymakers, website designers), with the aim to make the website more user-friendly for older cancer patients. The chapter concludes with guidelines for redesigning online health information tools. **Chapter 6** describes an observational field study conducted at the fast-track clinic, with the aim to assess the level of and relation between anxiety and information recall from consultations in 'standard care' (i.e., without a website intervention), and whether age moderates this relationship. This study functions as a no-information comparison group for patients who will receive a website intervention in the next chapter.

All preceding chapters ultimately lead to **Chapter 7**, which describes a randomized controlled trial in newly diagnosed cancer patients ( $N = 232$ ), testing the effectiveness of the preparatory mode-tailored website (vs. three non-tailored website versions) on older and younger cancer patients' evaluative (i.e., website satisfaction), psychological (i.e., anxiety), cognitive (i.e., information recall), and behavioral (i.e., patient participation) health-related outcomes. Moreover, the interplay between online and offline communication channels is examined. Specifically, it will be investigated whether different website experience outcomes (e.g., website use, website evaluation, knowledge before the consultation) and consultation experience outcomes (e.g., question-asking and anxiety during consultation), explain patients' information recall from the website and from consultations. The dissertation is completed with **Chapter 8**, which presents the key findings and implications of the studies that make up this dissertation (**Chapter 2 through 7**). In this final chapter, the general findings will be related to the current literature and future directions for both research and practice will be proposed.