

COMMUNICATION BEYOND THE CLINICAL INTERACTION: DELIVERING
COMPREHENSIVE HEALTHCARE TO PATIENTS WITH INTELLECTUAL
DISABILITIES

by

Brenda L. MacArthur
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to Patients with Intellectual Disabilities

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LIST OF ABBREVIATIONS

Patients with Intellectual Disabilities	PWID
Healthcare Provider	HCP
Theory of Planned Behavior	TPB
Perceived Behavioral Control.....	PBC
Anxiety/Uncertainty Management Theory	AUM
Communication Accommodation Theory	CAT
Respect Accommodation Follow-Up Time	RAFT

ABSTRACT

COMMUNICATION BEYOND THE CLINICAL INTERACTION: DELIVERING COMPREHENSIVE HEALTHCARE TO PATIENTS WITH INTELLECTUAL DISABILITIES

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This dissertation develops, delivers, and evaluates an evidence-based communication skills training curriculum for healthcare providers (HCPs) servicing patients with intellectual disabilities (PWID). This dissertation also tests a theoretical model combining elements of interpersonal communication (Anxiety/Uncertainty Management Theory; Communication Accommodation Theory) and behavior change (Theory of Planned Behavior) theories to examine predictors of HCPs' patient-centered communication with PWID. Specifically, this dissertation examines HCPs' attitudes, perceived behavioral control, uncertainty, and anxiety in predicting intention to engage in patient-centered communication. HCPs representing a variety of subspecialties participated in a two-hour face-to-face training intervention that included lecture, discussion, role-play, and case study analysis. Participants completed pre- and post-test questionnaires prior to and immediately following the completion of the training intervention, which contained items

that represented each variable in the study. Paired-samples t-tests indicate that after exposure to the training intervention, HCPs reported increased intentions to engage in patient-centered communication, improved attitudes toward doing so, and decreased uncertainty about such interactions. HCPs reported no significant change in perceived behavioral control or anxiety levels following exposure to the intervention. With regard to the predictive power of variables in the theoretical model, multiple regressions determined perceived behavioral control to be the strongest predictor of intention. Uncertainty and anxiety were not significant predictors of intention when perceived behavioral control was included in the model. HCPs' attitudes were significantly associated with uncertainty and anxiety, but did not predict intention. This dissertation provides support for the integration of interpersonal and behavior change theories when developing health communication interventions, to directly target factors that are likely to influence a particular communication interaction. This dissertation also holds implications for the Theory of Planned Behavior and highlights the unique role that perceived behavioral control plays in predicting HCPs' intentions for patient-centered communication with PWID.

CHAPTER ONE: INTRODUCTION

Healthcare Reform in the United States

The 2016 presidential race will be hard to forget. One issue that the candidates, as well as the American public heavily debated was healthcare reform. Issues related to healthcare ranked in the top five most important topics for debate in this election, along with the economy, foreign policy, the federal deficit, and financial equality (Caldwell, 2015). In general, concerns over healthcare reform typically focus on how health messages shape the debate over what is desirable and possible within the U.S. healthcare system (Wright, Sparks, & O'Hair, 2013). Access to healthcare, the costs and expenditures associated with care, and the quality of healthcare are notably the most debated issues within the healthcare system, yet they are not treated equally – action on the part of one dimension is followed by reaction from the other two (Barton, 2010). For example, in the 1960s an attempt to increase access to healthcare through programs like Medicare and Medicaid caused a spike in costs. This spike was so high that in the 1970s, efforts to reduce those costs raised concerns about quality of care issues (Barton, 2010). This domino effect is important to recognize in debates about healthcare costs and expenditures. The continued push toward decreasing healthcare costs and increasing access has again put strain on the quality of care that patients receive (McClellan & Rivlin, 2014).

The 2016 presidential candidates were not the only ones focused on issues related to healthcare costs and expenditures. Activist groups also stepped forward to raise concerns about quality of care issues. RespectAbility is a nonprofit organization that supports healthcare equality for individuals with disabilities. Developed in 2013, RespectAbility's primary goal is to, "Get all the candidates thinking about these issues, talking about these issues, and coming up with plans" (Samuels, 2016). In January 2016, the organization asked the presidential candidates to complete a questionnaire about their stance on a range of disability issues, one of which included barriers to quality healthcare (Samuels, 2016). The World Health Organization explains that quality of care issues for individuals with disabilities can be attributed to their physical health condition (e.g., Down syndrome or Autism), as well as a variety of personal and environmental factors such as negative attitudes that impact the care they receive (WHO, 2015). Stigmas about health conditions are directly linked to the quality of care that individuals receive (McCarthy, Koval, & MacDonald, 1999), and thus should be considered in debates over healthcare reform.

Although discussions related to healthcare inequality and health disparities for minority groups were prevalent among the 2016 presidential candidates, discussions related to similar quality of care issues for individuals with disabilities were scarce. This disproportionate focus on issues such as economic status and race in healthcare over disability is disconcerting given that disability transgresses age, race, class, and political boundaries (WHO, 2015). Regardless of the type or degree of the disability, all individuals with disabilities have the same general healthcare needs as those without

disabilities, and according to Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD), all individuals with disabilities have the right to attain the highest standard of healthcare (WHO, 2015). Unfortunately, individuals with disabilities are particularly vulnerable to deficiencies in healthcare services. They report seeking more healthcare, having a greater amount of unmet needs, engaging in higher rates of risky health behaviors, and are four times more likely to describe their health as poor or fair compared to those without disabilities (Altman & Bernstein, 2008; WHO, 2015).

It is clear that individuals with disabilities are increasingly at risk for poorer health outcomes due to inequalities related to the quality of healthcare they receive. Without immediate attention to this issue and the implementation of active measures to improve quality healthcare for those with disabilities, they will continue to carry unnecessary burdens in poor health and increased healthcare costs (Krahn, Walker, & Correa-De-Araujo, 2015). These issues may have been at the forefront of the 2016 presidential election, but they will remain a prominent issue in the healthcare system until they are properly addressed. Efforts to improve the quality of healthcare for individuals with disabilities nationwide should focus on *quality assessment* – to measure essential elements and outcomes of healthcare, *quality improvement* – to compile a set of techniques to meet the needs and expectations of patients, and *quality assurance* – to assess the full cycle of interventions to maintain quality of care over time (Barton, 2010). The Healthy People Initiative is designed to do just that.

Healthy People 2020

The Healthy People Initiative led by the U.S. Department of Health and Human Services, is a collaborative health promotion and disease prevention effort that promotes improved health outcomes and a reduction of health disparities for a healthier nation (ODPHP, 2016a). It provides science-based, 10-year objectives for improving the health of Americans nationwide. Healthy People 2020 launched on December 2, 2010, and represents the fourth generation of the Healthy People Initiative. The program contains four overarching goals to (1) attain high quality, longer lives free of preventable disease, disability, injury, and premature death, (2) achieve health equity, eliminate disparities, and improve the health of all groups, (3) create social and physical environments that promote good health for all, and (4) promote quality of life, healthy development, and healthy behaviors across all life stages (CDC, 2015). To achieve these goals, the initiative sets forth over 1,200 objectives across 42 topic areas. Of particular interest considering the current issues surrounding healthcare inequality for individuals with disabilities, is the topic area titled *Disability and Health*, which directly relates to the second goal set forth in the current initiative – to eliminate disparities and improve health for all groups.

The *Disability and Health* area aims to “Maximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages” (ODPHP, 2016b). Healthy People 2020 acknowledges that individuals with disabilities, their cognitive and physical abilities, and their health outcomes are often defined by their social and environmental circumstances. To be healthy, individuals with

disabilities need equal opportunities to take part in meaningful daily activities that add to their growth, development, fulfillment, and community contribution, which includes their health and healthcare (ODPHP, 2016b). Health People 2020's efforts to promote individuals with disabilities to become more actively involved in their own healthcare mirrors the general shift in the healthcare system to more patient-centered models that is currently underway in the United States (Rickert, 2012). To further support these efforts, evidence-based and theoretically-grounded interventions are needed to reinforce these ideas not only among patients with disabilities, but also the healthcare providers (HCPs) treating them.

Opportunities for Research

For more than a decade, researchers have cited the importance of increasing the quality of healthcare for patients with intellectual disabilities (PWID) through the development of evidence-based interventions aimed at HCPs (Snell et al., 2010; Ryan & Scoir, 2014; Tuffrey-Wijne, Hollins, & Curfs, 2005; Wilkinson, Dreyfus, Bowen, & Bokhour, 2013). This issue has come to the forefront of U.S healthcare equality discussions in recent years, now that Healthy People 2020 has identified a need to increase the implementation of evidence-based health and wellness programs for individuals with disabilities (ODPHO, 2016b). Suggested topics for these interventions include: implementing training on the important relationship between disabilities and effective communication, improving staff and HCP attitudes toward PWID, increasing awareness about patients' needs, and documenting those needs at admission and intake (see Hemsley & Balandin, 2014). Although these suggestions call attention to important

issues in providing quality care to PWID, few are accompanied by concrete ways to address these issues (Hemsley & Balandin, 2014).

Similarly, many of the communication skills training interventions that are becoming increasingly popular are not well informed about the influences on the audiences they are designed to help, and are often backed by limited data to guide their development and implementation (Kreps, 2014). Poorly conducted interventions lead to inaccurate conclusions that mislead researchers and practitioners about the needs for and directions of future interventions (Kreps, 2014). This is a growing issue that has emerged in response to intervention research in recent years – evaluation needs to be considered early, often, and before the implementation of any intervention (Kreps, 2014). Due to the complexity of health communication interventions (Faes, Reelick, Esselink, & Olde Rikkert, 2010), researchers agree that more attention needs to be paid to evaluating the effectiveness of these interventions to grow the evidence-base for their continued use (Craig et al., 2008; Kreps, 2014). To avoid misleading results, Brown and Bylund (2008) suggest that health communication training interventions should be developed with evidence-based curriculums that are closely aligned with the program's assessment methods.

Evaluation research is the backbone of health communication interventions. Good evaluation procedures help researchers clarify the audiences they should target, define measurable goals and outcomes, guide the adoption of relevant theories and intervention strategies, and ensure sensitivity to audiences' unique needs and cultural orientations (Kreps, 2014; Neuhauser & Paul, 2011). However, too often evaluation is not considered

until the conclusion of the program, when it is too late to modify the curriculum and opportunities to collect valuable assessment information may have already passed (Kreps, 2014). One way to address these concerns early is through formative research, which identifies a need for interventions based on the target audience's needs, as well as the social context and environments in which these needs occur (Kreps, 2002, 2014). Related to the current study, Vrijmoeth et al. (2016) suggests that PWID, their caregivers, and HCPs' perspectives be considered in the development of tools and interventions for HCPs. In this way well-rounded interventions can be developed to address the complexity of these interactions. By understanding the important insights formative research provides, researchers are better prepared to develop effective interventions (Kreps, 2014). This process is essential to reveal potential facilitators or barriers to the intervention, or identify potential confounders before the intervention is launched (Campbell, Fitzpatrick, & Haines, 2000).

In addition to formative research, the development of theoretical models based on existing theory and evidence should be used to guide interventions and identify relationships between key variables (Faes et al., 2010; Lipsey, 1997; McGilton, Fox, & Sidani, 2005). The theoretical modeling process strengthens researchers' confidence in the potential success of the intervention, as it provides evidence for exactly which features of the intervention should be linked to specific outcomes (Lipsey, 1997). This theory-driven approach is particularly important in designing interventions that acknowledge the complexity of the real world situations wherein these behaviors actually take place (Lipsey, 1993; Sidani & Sechrest, 1999). Rather than controlling for factors

related to the audience and context, theoretical models allow for them to be integrated into the design of the intervention (Sidani & Braden, 1998).

Purpose of Study

This dissertation seeks to answer researchers' calls for: (1) theory-driven interventions to train HCPs how to effectively communicate with PWID, and (2) accumulation of evidence on the effectiveness of these interventions. Specifically, the purpose of this study is to implement and evaluate an evidence-based, and theoretically-grounded communication skills training curriculum for HCPs on providing comprehensive patient-centered healthcare to PWID. This study adopts a systematic approach to achieve these goals by building on accumulated knowledge of best practices in health communication interventions as well as drawing on formative research conducted in conjunction with this study. The formative research used to inform the development of the intervention in this study is described next. For the remainder of this dissertation, this unpublished formative research will be referred to as: (Keeley, Burns, Cafferty, MacArthur, & Villagran, 2015).

Through a partnership between health communication researchers and Special Olympics Texas, experienced qualitative researchers conducted interviews with PWID (n = 5), their caregivers (n = 12), and HCPs (n = 8) to inform the development of the communication skills training curriculum. All caregivers were caring for an immediate family member with intellectual disabilities at the time of the interview. HCPs represented a variety of specialties including Pediatrics, Audiology, and Occupational Therapy, and all were actively involved in providing care to PWID. Participants were

recruited using network and snowball sampling techniques at public meetings and forums sponsored by Special Olympics Texas. Potential participants received an overview of the study and the nature of the questions. Interested participants scheduled appointments by email or phone to meet with the researchers in person. Researchers conducted semi-structured interviews with those who consented to participate, and audio recording devices documented the interviews. All interviews were transcribed and coded for themes. The four core modules in the training intervention represent the main themes identified in the formative research. The resulting acronym RAFT represents each theme, which stands for Respect, Accommodation, Follow-Up, and Time. These themes are briefly summarized next.

Respect brings to light the fact that all patients, regardless of their physical or cognitive ability, should be acknowledged and actively involved in all communication about their health and healthcare (Chew, Iacono, & Tracy, 2009). PWID and their caregivers interviewed noted that too often HCPs do not treat PWID “like people” because they “appear different.” But these patients tend to have strong receptive skills and typically understand more than would seem apparent from their expressive ability (Olney, 2001). One patient explained, “I could tell the way he was acting, I guess, the reactions.” Therefore, HCPs should show respect for PWID by acknowledging their presence and allowing them to play a role in their own care.

Accommodation acknowledges that PWID possess varying communication abilities and may utilize a number of different verbal and nonverbal strategies when interacting with HCPs (Chew et al., 2009). Often, their disabilities and limited

communication abilities are viewed as challenging and off-putting, rather than an expression of a need that should be met (Northway, 2014). One HCP explained, “Even though I’m trying to speak as simple as I can, they still may not understand what I am saying. And so that’s definitely challenging.” Therefore, to maximize effective communication, HCPs need to be audience-centered and make accommodations to meet these patients where they are and on a level that they can understand.

Follow-Up suggests that establishing sustained relationships with patients is fundamental in providing high quality healthcare and achieving long-term continuity of care, especially for those with disabilities (Hemm, Dagnan, & Meyer, 2015). Caregivers reported retaining the same HCP for extended periods due to the amount of effort required to find the right one. One parent discussed her experience of finding a new HCP after moving saying, “We can’t do this again. The switching of doctors on any family is hard. To go through the history, have to explain everything. It’s the hardest thing.” A HCP also alluded to concerns over not knowing the patient, “A lot of time it’s communicating with the actual individual [that is most difficult], especially when we don’t know them.” Selecting a HCP in the right location, with the right specialty, and who has a good reputation with patients is not an easy process (Sparks & Villagran, 2010). Therefore, HCPs who are able to show a genuine interest in patients’ experiences and concerns can help build rapport, which can eventually lead to the development of a trusting relationship (Sparks & Villagran, 2010). As HCPs and PWID become more familiar with one another, the clinical experience should be more beneficial for both parties.

Finally, caregivers and HCPs noted a lack of *time* as a major challenge in providing quality care to PWID. One caregiver mentioned, “Just slow down, we know you are busy, we know you’ve got tons of patients to look at, we’ve waited in the waiting room for that hour, hour and a half, so we want more than just 10 minutes to get a proper diagnosis...” Time is a limited resource and this challenge puts strain on appointments that require increased involvement (Wilkinson et al., 2013). HCPs’ ability to maximize the amount of time they do spend with PWID is an extremely beneficial skill.

These four themes that emerged from formative research are also conceptually tied to variables that comprise the theoretical framework proposed in this study. The Theory of Planned Behavior (Ajzen, 1985), Anxiety/Uncertainty Management Theory (Gudykunst, 1985), and Communication Accommodation Theory (Giles & Ogay, 2007) are combined to provide a lens through which these highly specialized provider-patient interactions can be examined. By integrating insights from interpersonal and behavior change theories, the proposed framework hopes to further interventionists’ ability to understand, explain, and predict HCPs’ interactions with PWID.

This chapter introduces key terminology and presents the basic principles of the theoretical framework adopted in this dissertation. Specifically, the following sections define healthcare provider, intellectual disability, and patient-centered healthcare, as well as introduce The Theory of Planned Behavior, Anxiety/Uncertainty Management Theory, and Communication Accommodation Theory. Variables extracted from each theory that comprise the theoretical framework guiding this dissertation are also conceptualized and their interrelationships explained.

Definitions

This section will identify and define the terminology used in the study. Specifically, this section will define healthcare provider, intellectual disability, and patient-centered healthcare. A comprehensive review of literature surrounding these variables will be presented in chapter two.

Healthcare Provider. HCP is an umbrella term used to categorize any and all medical professionals who contribute to patient care (Hartzband & Groopman, 2011). Although physicians may be the most recognized of all HCPs, they only comprise a small proportion of the HCP segment of the healthcare system (Wright et al., 2013). HCPs include physicians, nurses, nurse practitioners, physician assistants, lab technicians, social workers, physical therapists, and office/reception staff, among others (Hartzband & Groopman, 2011; Ofri, 2011; Villagran & Weathers, 2014).

Although the term HCP was originally designed to represent those who provided independent care to patients (Ofri, 2011), its meaning has expanded over time because many other HCPs interact with patients as much, if not more than physicians (Wright et al., 2013). Regardless of varying levels of education, training, and experience, all HCPs who interact with patients share a responsibility to provide quality care leading to optimal health outcomes (Villagran & Weathers, 2014). Because this dissertation focuses on the continuum of the patient experience, the inclusion of office/reception staff under the umbrella of HCPs is essential, as these individuals are often patients' first point of contact when scheduling appointments and arriving at the office, and are important contributors to successful patient outcomes (Wright et al., 2013)

Intellectual Disability. Over 6.5 million individuals in the United States and approximately 200 million worldwide are currently diagnosed with an intellectual disability, the most common form of developmental disability (Special Olympics, 2016). Individuals with intellectual disabilities possess IQs below 75, and experience limitations in cognitive and adaptive functioning, communication, and occasionally self-care (NIH, 2015; Special Olympics, 2016). Symptoms of these disabilities include but are not limited to slow motor skills development, failure to grow or infant-like behavior, lack of curiosity, failure to adapt to new situations, and difficulty understanding or following social cues (NIH, 2015). Intellectual disabilities can include Down syndrome, Autism Spectrum Disorders, and Fragile X Syndrome (Special Olympics, 2016). Significant limitations in *cognitive functioning* distinguish intellectual disabilities from other developmental disabilities that cause physical limitations. However, they often co-occur with other disabilities so it is not uncommon for individuals to experience both cognitive and physical disabilities (AAIDD, 2016).

Intellectual disabilities can be caused by injury, disease, or a brain abnormality. The most common causes are genetic conditions, complications during pregnancy or birth, and disease or toxic exposure (Special Olympics, 2016). However, for 25% of individuals living with these disabilities, the cause is unknown (NIH, 2015). While there is no cure for intellectual disabilities, these individuals can still learn to do many things, but may take more time or require different approaches to learning than others (Special Olympics, 2016). This dissertation focuses on individuals with intellectual disabilities as

a specific population of patients within the healthcare system. In this dissertation, patients with intellectual disabilities are referred to as PWID.

Patient-Centered Healthcare. Patient-centered care represents a shift away from traditional care models where HCPs utilized their skills and expertise to determine the best course(s) of action for patients, who were expected to comply (Emanuel & Emanuel, 1992). Patient-centered care involves communication that revolves around the patient (Rickert, 2012). It requires HCPs to consider their patients' perspectives and use this information to respond directly to their needs and desires (Epstein & Street, 2007; Villagran & Weathers, 2014). Patient-centered care is rooted in the idea that by personalizing treatment recommendations, using language that the patient understands, providing clear explanations, and validating the patient's emotional state, HCPs should be able to increase the quality of care while decreasing use of diagnostic testing, prescriptions, hospitalizations, and referrals (Marvel, Epstein, Flowers, & Beckman, 1999; Rickert, 2012). Patient-centered care is particularly important for PWID whose limited cognitive and communicative abilities restrict their independence and limit their ability to communicate medical needs and understand health information (Blackstone, Beukelman, & Yorkston, 2015; Ogletree, Bruce, Finch, Fahey, & McLean, 2011).

This dissertation focuses on four patient-centered communication competencies for HCPs servicing PWID (Keeley et al., 2015). These are, (1) demonstrating *respect* for PWID by addressing them directly, (2) *accommodating* verbal and nonverbal behaviors to meet the needs of PWID by listening to and asking questions to understand their needs, (3) *following-up* with PWID by checking for understanding to build lasting relationships,

and (4) maximizing *time* spent with PWID by explaining health information completely and using simple terms.

Theoretical Framework

The theoretical framework proposed in this dissertation combines elements of interpersonal and behavior change theories to understand, explain, and predict HCPs' interactions with PWID. This approach to theory was selected for two reasons. First, the provider-patient relationship is an interpersonal relationship. However, in existing interventions aimed at promoting behavior change within the provider-patient relationship, interpersonal theories often remain overlooked (Bylund, Peterson, & Cameron, 2011). Therefore, this study attempts to combine elements of these theories to improve the predictive power of the proposed model.

Second, previous literature and the results of the formative research conducted in this study help us to understand HCPs' behaviors in interactions with PWID. Together, they inform the inclusion of the variables in the model and the theoretical connections among them. For example, HCPs' concerns related to expectations about PWID such as, potentially aggressive behaviors, unfamiliarity with them, communication barriers, limited time, and a lack of training and preparation were carefully woven into the conceptualization of each variable proposed in the theoretical framework. This process strengthens the validity of the proposed model by acknowledging the complexity of the real world wherein these specialized provider-patient interactions take place (Lipsey, 1993; Sidani & Sechrest, 1999). This process also provides important theoretical

implications by demonstrating the power of including components of interpersonal theories to expand the scope of the Theory of Planned Behavior.

The following sections present the tenets of each theory utilized in this study, followed by the theoretical model proposed. The Theory of Planned Behavior, Anxiety/Uncertainty Management Theory, and Communication Accommodation Theory are described next.

The Theory of Planned Behavior (TPB)

TPB is based on the assumption that humans typically behave in a sensible manner, in that they account for available information and consider possible implications of their actions (Ajzen, 2005). TPB postulates that human behavior is guided by beliefs about the behavior in question, normative beliefs about the expectations of others, and control beliefs about the presence of factors that may help or hinder the performance of the behavior (Ajzen, 1988). Beliefs about the behavior cause favorable or unfavorable *attitudes* toward the behavior, normative beliefs lead to perceived social pressure or *subjective norms*, and control beliefs result in perceptions about the ease or difficulty of enacting a behavior, or *perceived behavioral control* (Ajzen, 1985).

Taken together, these three factors predict behavioral intention, or an individual's intention to perform a behavior, although the relative contribution of each depends on the behavior being examined and varies by individual and context (Ajzen, 2005). TPB argues that intention is a direct antecedent to behavior, and thus is the best predictor of actual behavior (Ajzen, 1985). Theoretically, the intention to perform a given behavior should increase when attitudes toward the behavior are favorable, others are perceived to be

supportive, and perceived control is high. Taken another way, individuals intend to perform a behavior when they evaluate it positively, when they experience social pressure to perform it, and when they believe they have the resources and opportunity to do so (Ajzen, 2005).

TPB emerged from the Theory of Reasoned Action, which assumes that behavior is deliberate and can be planned and enacted if individuals are inclined to do so. Otherwise identical, TPB expands on the Theory of Reasoned Action to include the perceived behavioral control (PBC) variable to account for behaviors that may be out of our control, or *perceived* to be out of our control (Ajzen, 1985). With regard to PBC, there are two key features within TPB that must be noted. First, PBC holds motivational implications for intention, meaning that when individuals perceive a lack of resources or opportunity to perform a behavior, they are unlikely to form behavioral intentions. In this way, PBC can influence individuals' motivations behind forming behavioral intentions, and thus is linked directly to intention. Second, PBC can also be directly linked to behavior. If individuals substitute a *perceived* lack of resources or opportunity to perform a behavior for *actual* control, they are not likely to perform the behavior, even if they have intentions to do so. In other words, individuals may have the necessary resources and abilities to perform a behavior, but their belief that they do not will prevent them from performing the behavior.

For the purposes of this dissertation, TPB provides an avenue to increase HCPs' intentions to perform patient-centered behaviors by targeting their attitudes and perceived ability to do so. The subjective norms variable is not included in the theoretical

framework proposed in this study because it was not identified in the formative research as playing a major role in provider-PWID interactions, nor was it prominent in the literature as a significant barrier or facilitator to providing care to PWID. Instead, the behavioral intention, attitude, and PBC variables are borrowed from TPB. The conceptualization of each variable as it relates to this study is described next.

Behavioral Intention. Intention represents the idea that individuals can easily perform behaviors if they are inclined to do so, or refrain from engaging in behaviors if they decide against them (Ajzen, 2005). When individuals enact these behaviors, the occurrence is a direct result of deliberate attempts made by the individual. Taken another way, individuals must develop an intention to enact a behavior, which remains in a disposition until that individual takes the next step and makes an attempt to enact the behavior (Ajzen, 2005). Given that the behavior is within the individual's control, the intention may then translate into the behavior that the individual intends (Fishbein & Ajzen, 1975). In this way, behavioral intention is considered the most proximal predictor of actual behavior. For the purposes of this dissertation, behavioral intention refers to HCPs' intentions to engage in patient-centered communication with PWID. Based on the earlier conceptualization of patient-centered care, behavioral intention in this study refers to those four patient-centered competencies for HCPs – Respect, Accommodation, Follow-Up, and Time.

Attitudes. Human behavior is guided by beliefs about performing those behaviors (Ajzen, 1985). When an individual evaluates a behavior either favorably or unfavorably based on those beliefs, an attitude is formed (Ajzen, 1985; Eagly & Chaiken, 2007). This

conceptualization of attitude focuses on individuals' evaluations of specific behaviors, versus other conceptualizations of attitude as individuals' evaluations of a specific person or group of people (Fishbein & Ajzen, 1975). This dissertation focuses on the former – HCPs' attitudes toward engaging in patient-centered communication with PWID.

HCPs' attitudes are based on the valence of their beliefs about caring for this population of patients (Ajzen, 1985). It is not uncommon, especially in initial interactions, for individuals to hold inaccurate beliefs about the consequences of interacting with different groups of people based on their personal characteristics (such as race or age), as well as a host of different social classifications and stereotypes (Berger & Calabrese, 1975). Research suggests that attitudes toward interacting with PWID based on prejudice toward and/or misconceptions about disabled people are often embedded within the dominant culture (Shakespeare, 1994). In this way, HCPs' beliefs about the potential consequences of interacting with PWID impact their attitudes towards providing patient-centered care to that population of patients. In Keeley et al.'s (2015) study, one caregiver described her interpretation of HCPs' biased attitudes in caring for PWID stating, "They don't know how to treat, like, when it's a special... I mean, you can tell when they are used to treating a special patient and when they're not... They don't treat them like people. I don't want to say, they feel pity for them, or like you can feel it, you can see it." A patient explains, "It was just the doctor's attitude, like they don't even look at you, like you are not there."

Perceived Behavioral Control. An individual's perception about the ease or difficulty of performing a behavior is referred to as his/her PBC (Ajzen, 1985). It is

assumed that these perceptions reflect past experience as well as anticipated barriers to performing a behavior (Ajzen, 1988). This concept is similar to self-efficacy, which can be defined as an individual's beliefs about their capability to exert control over their own functioning and over events that affect their lives (Bandura, 1991). The key distinction between PBC and self-efficacy is that the former is focused on the ability to perform a particular behavior, versus control over the consequences or outcomes of performing a behavior (Ajzen, 2002). For the purposes of this dissertation, PBC refers to HCPs' perceptions about the ease or difficulty of engaging in patient-centered communication with PWID, based on available resources and opportunities. Research suggests that HCPs cite inexperience, poor communication, burden on resources, and lack of time as barriers to providing patient-centered care to PWID (Wilkinson et al., 2013). The interviews with HCPs echoed these issues. One HCP expressed a lack of training, "I wished I would have received more hands on training because in our class we learned the best ways to communicate with people, and the first time – there was a communication barrier." Another discussed poor communication, "When [PWID] leave, there's always that worry about what got through and what didn't get through...just that biggest concern – was the message received" (Keeley et al., 2015)?

Although TPB is one of the most influential frameworks for understanding human behavior (Ajzen, 2001), researchers continually cite affect and emotions as influential factors that are left out of the model (Conner & Armitage, 1998; Rapaport & Orbell, 2000; Wolff, Nordin, Brun, Berglund, & Kvale, 2011). While Ajzen (2011) argues that these variables are taken into consideration as background variables that influence

beliefs, other researchers suggest a more direct influence on behavior. For the purposes of this dissertation, these variables contribute important knowledge about the provider-patient relationship and thus are accounted for by incorporating features of Anxiety/Uncertainty Management Theory into the proposed theoretical model. This theory is described next.

Anxiety/Uncertainty Management Theory (AUM)

Uncertainty Reduction Theory is used to explain and predict initial interactions between two individuals who are assumed to be from the same culture (Berger & Calabrese, 1975; Gudykunst, 1985). However, given that this dissertation focuses on the interactions between HCPs and PWID, it seems appropriate to view these two parties as culturally distinct. There are several reasons to make this distinction. First, PWID experience limitations in cognitive and adaptive functioning including communication and self-care, and possess an IQ below 75 (Special Olympics, 2016). Because of these limitations they have trouble adapting to new situations and understanding or following social rules (NIH, 2015). This often puts them at the margins, if not entirely outside, of the mainstream culture. Second, HCPs' highly specialized training socializes them in ways that can lead to a much different perspective of health and healthcare than the average patient (Wright et al., 2013). HCPs, especially physicians are professionally trained much like soldiers in that they are able to set their emotions aside and perform highly skilled tasks quickly in a high stress environment (Korsch & Harding, 1997). Their training provides them with technical skills and a new language that enables them

to care for patients, yet at the same time distinguishes them from others without the same training (Hartzband & Groopman, 2011).

Finally, we know that communication is considered intercultural when the differences between individuals are so substantial that they can create different interpretations and expectations of the same message (Lustig & Koester, 1993). The American Association on Intellectual and Developmental Disabilities adds that cultural differences can be categorized based on the way individuals communicate and behave (AAIDD, 2016). In caring for PWID, HCPs often cite a lack of personal confidence and awareness, barriers to communication, and difficulty in obtaining the patient's perspective due to these cultural differences (Dunkley & Sales, 2014). Overall, researchers generally support the idea that HCPs and patients can be viewed as members of two cultural groups due to their differences in language and perceptions of health and healthcare (Wright et al., 2013). This cultural difference is likely to be particularly pronounced between HCPs and PWID.

AUM expands Uncertainty Reduction Theory to explain initial interactions between individuals from different cultures. It suggests that while a certain level of uncertainty and anxiety are experienced when meeting another individual for the first time, these feelings are heightened during intercultural encounters (Gudykunst, 1985). The larger the gap or difference that individuals perceive between their culture and a stranger's culture, the higher levels of uncertainty and anxiety the individual will experience. Although a minimal level of uncertainty and anxiety are necessary to motivate us to be aware of our communication and to avoid carelessness in what we say,

too much of either can influence our ability to focus on a message and cause us to fall back on negative stereotypes or withdraw from an interaction altogether (Gudykunst, 1985).

AUM postulates that mindfulness or a willingness to accommodate behaviors should help individuals tailor their uncertainty and anxiety to the appropriate levels leading to effective communication (Gudykunst, 1985). In other words, to be mindful, HCPs must deviate from traditional scripts of how typical provider-patient interactions should evolve and pay closer attention to their patients' individual needs, which is also a key feature of patient-centered care. Because of this overlap, mindfulness is conceptualized as patient-centered communication in this study. This process is especially important for HCPs who are often trained how to communicate with patients using standardized patients and predetermined scripts, which outline the trajectory of a provider-patient interaction. In deviating from these scripts, HCPs open themselves to new information that can help them more clearly relate to PWID. In this way, mindfulness moderates the relationship between uncertainty, anxiety, and effective communication, which is considered the goal of all interactions. From AUM's point of view, communication is considered effective to the extent that individuals can accurately predict and explain a stranger's behavior (Gudykunst, 1985). However, uncertainty and anxiety are two main barriers to achieving this goal. For the purposes of this dissertation, the uncertainty and anxiety variables are borrowed from AUM for inclusion in the proposed model. The conceptualization of each variable as it relates to this study is described next.

Uncertainty. Uncertainty refers to an individual's cognitive perception of doubt in terms of his/her ability to predict the outcomes of interactions with strangers (Berger & Calabrese, 1975). A stranger is someone who is physically near yet conceptually distant at the same time (Gudykunst, 1985). This dissertation focuses on HCPs' uncertainty regarding their ability to predict the outcomes of interactions with PWID. Because many HCPs lack sufficient knowledge and experience in caring for PWID (Jain, 2006; Martin, Roswell, Reid, Marks, & Reddihough, 2005; Saketkoo, Anderson, Rice, Rogan, & Lazrus, 2004), it is fair to view PWID as "strangers" as the term is defined here.

Individuals have maximum and minimum thresholds for uncertainty (Gudykunst, 1985). The maximum threshold is the highest amount of uncertainty HCPs can experience and still believe they can predict patients' behaviors. When HCPs feel as though they do not have enough information to predict patients' behaviors, they pass the maximum threshold and experience an uncomfortable provider-PWID interaction. The minimum threshold is the lowest amount of uncertainty a HCP can experience before becoming unmotivated or overconfident in predicting patients' behaviors. When uncertainty is below the minimum threshold, information that HCPs do have can cause overconfidence leading to a misinterpretation of PWID and their behavior. HCPs' assessments of their uncertainty thresholds are based on how they organize their thoughts about PWID and their own similarity or dissimilarity to them (Gudykunst, 1985).

According to AUM, HCPs will attempt to reduce uncertainty about PWID by evaluating and assessing them on a variety of factors and making cultural distinctions between different groups. In doing so, these patients are categorized as either a member

of an in-group (group with whom the HCP identifies) or an out-group (group with whom the HCP disidentifies) (Giles, Willemyns, Gallois, & Anderson, 2007). In-groups share a cultural identity, communicated through language and speech styles, nonverbal behaviors, dress codes, and shared beliefs. Members of out-groups are categorized as “different,” or not “one of them,” and these classifications are based on prior experiences with members of that group or social stereotypes about them (Giles et al., 2007). HCPs in Wilkinson et al.’s (2013) study revealed that they often categorize PWID as “simple, pleasant, and child like.” This finding is supported by Keeley et al.’s (2015) interviews with HCPs who admitted to “lumping” PWID together when it comes to identifying their levels of understanding in the provider-patient interaction. When HCPs categorize PWID as an out-group by making blanket statements to describe them, this dis-identification with those patients and unconscious biases and assumptions about them, could lead to feelings of discomfort and anxiety caused by uncertainty.

Anxiety. Anxiety is the feeling of being uneasy, tense, worried, or apprehensive about what might happen (Gudykunst, 1985). Individuals are most likely to experience anxiety when mutual satisfaction with strangers seems unlikely (Griffin, 2006). This dissertation focuses on HCPs’ anxiety about interacting with PWID. Similar to how individuals have minimum and maximum thresholds for uncertainty, they also have thresholds for anxiety. When HCPs’ anxiety reaches the maximum threshold, they are likely to feel uneasy and tend to process information exchanged in the provider-patient interaction in a simplistic manner. When HCPs’ anxiety is below the minimum threshold, they will not be motivated to communicate with PWID at all (Gudykunst, 1985). One

HCP explained how his anxiety about interactions with PWID was related to uncertainty about how the interaction would evolve (Keeley et al., 2015):

“There is a lot of anxiety because there’s so much diversity with disability, from Down syndrome and Cerebral Palsy, brain injury, Fetal Alcohol Syndrome, Autism. You’re going to see just a lot of stuff, and everybody is a bit different. So, just [the] anxiety of not knowing what’s going to happen hour to hour, 30 minute to 30 minute, That can be anxious.”

Based on the tenets of AUM, to manage uncertainty and anxiety levels, humans should accommodate their behaviors when interacting with individuals from different social groups or cultures (Giles, Coupland & Coupland, 1991; Giles, Mulac, Bradac, & Johnson, 1987; Gudykunst, 1985). In providing communication training for HCPs on how to navigate interactions with PWID, it is important to not only understand, explain, and predict how they might feel and behave, but it is also important to focus on specific strategies for helping them to change their behavior in ways that will enhance communication with PWID. However, few studies that focus on communication training provide a framework for organizing these skills (Cegala & Broz, 2002). This dissertation uses Communication Accommodation Theory to explain a specific strategy for HCPs to manage uncertainty and anxiety about interactions with PWID to reduce the social and cultural distance between them.

Communication Accommodation Theory (CAT)

CAT has been cited as “one of the best theories relating to interpersonal adjustment” (Littlejohn, 1999, p. 107), perhaps because of its heuristic value and the number of different contexts to which it has been applied. Moreover, the intercultural context has been noted as the most natural context for researchers to apply CAT (Giles &

Ogay, 2007). Based on these assessments about the value of CAT and the given context in the present study, this theory is used to explain how HCPs can reduce perceived social and cultural differences with PWID.

CAT explains the ways in which individuals can vary their verbal and nonverbal behaviors to accommodate where they believe others to be, their motivations for doing so, and the social consequences associated with them (Giles & Ogay, 2007). CAT is built upon four key assumptions (Giles & Ogay, 2007). They are: (1) communication within a given interaction is influenced by the historical context wherein it is embedded, (2) communication is not just a means for exchanging information about facts, ideas, and emotions, but it also negotiates social categories, (3) individuals have expectations for optimal levels of accommodation based on both stereotypes and norms, and (4) individuals use specific communication strategies – convergence and divergence – to signal attitudes towards others and social groups.

CAT postulates that individuals can engage in *convergence*, which involves adapting communication behaviors to reduce social and cultural differences, or *divergence*, which works to emphasize differences between these groups (Giles & Ogay, 2007). More specifically, convergence is a strategy where individuals adapt to others' communicative behaviors through verbal and nonverbal behaviors such as self-disclosure, jokes, adjusting speech rate, inserting strategic pauses, vocal inflections, smiling, and nodding (Giles, et al., 1991). Given this information, it makes sense that HCPs can use patient-centered communication to converge their behaviors to meet the needs of PWID. Specifically, researchers suggest that HCPs avoid interrupting patients, solicit patients'

beliefs, values, and preferences, validate patients' emotions, ask about family and social context, provide sufficient information using jargon-free explanations, check for understanding, maintain eye contact, and minimize distracting movements such as fidgeting (Epstein & Street, 2007; Wright et al., 2013). Given how these behaviors align with the four themes identified in the formative research, it is of utmost importance that HCPs ensure patient-centeredness when interacting with PWID. In doing so, HCPs can minimize the social and/or cultural differences between them and PWID (Giles, et al., 1991; Giles & Ogay, 2007). Individuals who attempt to converge their behaviors should be careful not to over-accommodate as this occurrence can be viewed similarly to non-accommodation (Coupland, Coupland, Giles, & Henwood, 1988).

Individuals who diverge their behaviors accentuate verbal and nonverbal differences between themselves and others (Giles & Ogay, 2007). Specifically, divergent behaviors can manifest directly, as muttered or whispered disapproval, or indirectly, as a simple lack of accommodation. When individuals refuse to accommodate, they keep their speech style and nonverbal behaviors congruent across situations so as to maintain integrity, distance, or identity (Giles, et al., 1991). HCPs can do this by emphasizing their medical expertise or social status (Wright et al., 2013). In the present study, HCPs are urged to avoid divergent behaviors such as using medical terminology and jargon, checking their watch to rush the patient, and communicating with caregivers while ignoring PWID.

CAT explains that individuals' motivations to converge or diverge are related to the desire to gain approval and liking by others (Giles & Ogay, 2007). This dissertation

proposes that by converging behaviors and asserting similarity to PWID through patient-centered communication, HCPs can improve communication effectiveness in provider-patient interactions. One PWID explained how he preferred a HCP who engaged in convergence saying, “He explained to me better. I understood him” (Keeley et al., 2015). Conversely, when discussing another HCP who engaged in divergence by phrasing all questions toward the caregiver, the PWID explained, “This is a fishy doctor.” How PWID evaluate HCPs’ motives for convergence/divergence are crucial in determining their responses to those behaviors. Generally, patients’ evaluations of their HCPs are based on the HCP’s competence, the amount of effort expended, and the external pressures compelling the HCP to enact such behaviors (Giles & Ogay, 2007). However, PWID may not be able to adequately evaluate their HCPs or may do so differently, which adds to the complexity of appropriate accommodation.

Theoretical Model

This dissertation proposes a theoretical model (see Figure 1) that contains elements of TPB, AUM, and CAT to: (1) understand HCPs’ cognitive, behavioral, and affective motivations for engaging or not engaging in patient-centered communication with PWID, (2) explain strategies that HCPs can employ to provide patient-centered care to PWID, and (3) predict HCPs’ intentions to provide patient-centered care to PWID. The theoretical linkages between variables are described next.

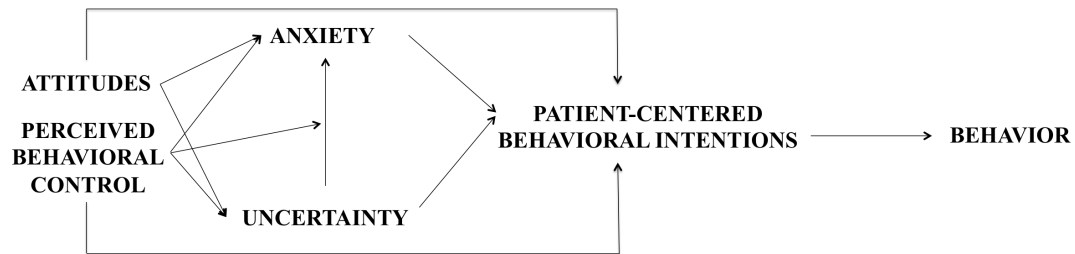


Figure 1. Theoretical Model

According to AUM, HCPs' attitudes toward providing patient-centered care to PWID function as background variables that shape their perceptions about uncertainty and anxiety. Therefore, more favorable attitudes should negatively predict uncertainty and anxiety. Additionally, AUM explains that the more uncertainty HCPs perceive about caring for PWID, the higher anxiety levels they will experience. Next, the relationship between uncertainty and anxiety is moderated by HCPs' PBC in providing patient-centered care to PWID. This moderation is predicted to account for contexts where HCPs may experience uncertainty about PWID, but their perceived ability to perform the behaviors helps them decrease their anxiety rather than allowing those uncertain thoughts to impact their anxiety – as AUM suggests. In this way, TPB offers a way to explain how HCPs can manage their anxiety even when they possess uncertain thoughts about PWID.

Next, AUM links uncertainty and anxiety to mindfulness, or for the purposes of this study, patient-centered communication. Similarly, CAT explains how individuals can enact patient-centered practices to converge their behaviors to accommodate the needs of their audience. Next, TPB explains the link from attitudes and PBC to intention. A combination of more favorable attitudes and increased PBC should predict increased intentions to enact patient-centered practices with PWID. According to TPB, behavioral

intention is the most proximal predictor of actual behavior. Finally, because individuals are most persuaded to change their attitudes based on direct behavioral experience, HCPs' experiences with providing patient-centered care to PWID are another important source of influence on their attitudes.

CHAPTER TWO: REVIEW OF LITERATURE

The previous chapter provided an overview of the rationale for the current study. This chapter reviews relevant literature related to provider-patient relationships, patient-centered communication, communication with PWID, patient-centered care for PWID, and communication training interventions. Following the review of literature, a rationale will propose the hypotheses and research question to be examined in this study.

Provider-Patient Relationships

Competent communication between HCPs and patients is a central aspect of quality healthcare across the continuum of care (Sparks & Villagran, 2010). Effective communication between HCPs and patients is correlated with less psychological distress, increased adherence to treatment plans, greater understanding of health information, higher quality of life, and overall satisfaction among patients (Dimatteo, Giordani, Lepper, & Croghan, 2002; Lazure, St-Germain, Gryfe, Trudeau, & Hayes, 2014). Relationship development is essential to achieving effective communication between HCPs and patients (Smith, Polis, & Hadac, 1981; Sparks & Villagran, 2010). Patients cite their relationships with both pediatric and adult HCPs as key to their healthcare (Kilroy, Egan, Walsh, McManus, & Sarma, 2015; McConkey & Collins, 2010).

Provider-patient relationships can be enhanced through communication behaviors that convey a sense of interpersonal closeness such as moving closer to one another,

direct eye contact, open body posture, gesturing, and using language that others will understand (Dimatteo et. al., 2002). These relationships also rely on trust (Brown et al., 2016; Pearson & Raeke 2000), which is developed through patient-centered care practices such as getting to know the patient as a person rather than just a case, understanding the patient's experience, and listening to the patient's concerns (Carr, 2001; Sheppard, Zambrana, & O'Malley, 2004; Thom & Campbell, 1997). A strong provider-patient relationship not only leads to better health outcomes for patients in the short and long terms, but it also underpins patient safety across patient populations (World Alliance on Patient Safety Drafting Group, 2009). Modern approaches to healthcare encourage patient-centered care through the development of these interpersonal relationships between HCPs and patients. However, traditional models of healthcare did not consider the patient as playing an equal role in these relationships. Before discussing the role of the provider-patient relationship in facilitating patient-centered healthcare, it is important to understand how the U.S healthcare system has evolved into the current system. The paternalistic, biomedical, and biopsychosocial models of healthcare are described next.

Paternalistic Model. Under the paternalistic model of care, HCPs were recognized as the sole providers of healthcare, who used their specialized skills and expertise to determine the best course(s) of action for the patient (Emanuel & Emanuel, 1992). This process ensured that patients received the interventions that best promoted their health and well-being, and assumed that patients would be thankful for HCPs' decisions, even if they did not initially agree with them (Emanuel & Emanuel, 1992). This provider-directed, hierarchical model of care promotes traditional HCP roles that

were heavily task-oriented. However, quality patient care requires a more dynamic and deliberative dialogue between HCPs and their patients (Jones & Stubbe, 2004).

Biomedical Model. The biomedical model approaches healthcare from a strictly biological perspective. It takes into account principles of the hard sciences such as physiology, biochemistry, and genetics as they relate to human functioning (Geist-Martin, Sharf, & Jeha, 2008). Under this model, it is assumed that disease is the mere product of a biological defect and thus discounts symptoms that cannot be explained using biologic terms (Johnson, 2012). Biomedical provider-patient interactions consist of closed-ended interviewing procedures to uncover these defects (Geist-Martin et al., 2008). When a growing body of literature demonstrated how patients' experiences of disease and illness were linked to psychological, social, and relational experiences in conjunction with biological issues, the biopsychosocial model was formed (Engel, 1980).

Biopsychosocial Model. Under the biopsychosocial model of healthcare promoted by government initiatives like Healthy People 2020, HCPs engage in dialogue with patients to identify psychosocial evidence of health issues (Engel, 1980). This approach fosters more open-ended questions not only focused on patients' experiences of physical health, but also on their emotional and mental health, as well as how their lifestyle decisions play a role in these issues. This interactive dialogue targets patients' attitudes, beliefs, emotions, and behaviors and thus requires the development of a closer relationship between HCPs and patients, where patients feel comfortable disclosing such information to their HCPs (Jain, 2006; McWhinney, 1989).

Patient-Centered Communication

As the foundation for the biopsychosocial model of care, patient-centered communication recognizes patients' expressions of symptoms as well as their emotions, concerns, and feelings. In this way, it is not enough for HCPs to simply treat patients' physical conditions, but they must also take into consideration the person experiencing the condition (Dean & Street, 2016). Taken another way, patient-centered communication explores patients' experiences of health to find common ground in terms of prevention and treatment, enhancing the provider-patient relationship, and being realistic about patients' personal limitations and potential barriers to improving health outcomes (Stewart et al., 1995). When this common ground is visible, patients are able to see similarities between themselves and their HCPs, which fosters a more open and thus enhanced provider-patient relationship (Villagran & Sparks, 2010). Patient-centered communication is a core component of quality healthcare, as it fosters patients' active participation in decisions regarding their health and healthcare through partnerships with their HCPs (Boykins, 2014).

Effective patient-centered healthcare is achieved through the interactive relationships between HCPs, patients, and families/caregivers. Together, these individuals are encouraged to focus on enhancing the provider-patient relationship, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling the patient to manage his/her own condition (Epstein & Street, 2007). Because of traditional approaches to healthcare that may be more familiar to patients, it is not uncommon for patients (especially older ones) to look to HCPs to lead

the provider-patient interaction (Eldh, Ekman, & Ehnfors, 2006). In this way, HCPs play a key role in fostering a patient-centered environment with their patients. HCPs can communicate patient-centeredness verbally through establishing the purpose of the visit, providing sufficient information, avoiding interruptions or distractions, soliciting patients' beliefs, values, preferences, and emotions, discussing expectations and options, asking about family and context, providing jargon-free explanations, checking for understanding, and offering reassurance and support (Epstein & Street, 2007). Patient-centeredness can also be communicated nonverbally through an open body posture, forward leans, maintaining eye contact, nodding to indicate understanding, and appearing physically relaxed (Epstein & Street, 2007). In fact, how the HCP communicates with the patient can be just as important as the content itself, as effective nonverbal communication between HCPs and patients predicts patient satisfaction, helps patients understand and recall health information, and increases patient adherence to prevention and treatment recommendations (Hall, Roter, & Katz, 1988; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Street & Weimann, 1987). Overall, when HCPs demonstrate empathy and are perceived as being warm and friendly, patients tend to experience a decrease in pain and a faster recovery (DiBlasi, Harkness, Ernst, Georgiou, & Kleijnen, 2001). Despite the improved health outcomes that patients experience as a result of patient-centered communication, HCPs do not engage in these techniques consistently with all patients (Zaleta & Carpenter, 2010).

HCPs and patients are likely to experience barriers to achieving effective patient-centered communication in the provider-patient interaction. Barriers to patient-centered

communication may be related to differences in language, developmental level, medical condition, disability, learning style, psychosocial, literacy, financial, and cultural factors (ANA, 2010). Barriers can also exist if HCPs are not willing to openly communicate with their patients, take the time to educate them about patient-centered practices, or involve them in decision-making (ANA, 2010). Unfortunately, research suggests that HCPs engage in patient-centered communication differently with different types of patients. For example, HCPs tend to be more patient-centered with patients whom they perceive to be better communicators, more satisfied, and more compliant (Street, Gordon, & Haidet, 2007). HCPs use more closed-ended questioning techniques in interactions with older and sicker patients (Roter et al., 1997). HCPs use less supportive talk with non-Caucasian patients (Street Gordon, Ward, Krupat, & Kravitz, 2005). Male patients are less likely to experience patient-centered communication from their HCPs than women patients (Bertakis, Franks, & Epstein, 2009). Such findings highlight the challenges that HCPs experience in maintaining the balance between the need to treat the patient and quality of care (Lezure et al., 2014). Street et al. (2007) explain that inequalities in the degree of patient-centered care that patients receive may be a function of limited time and personnel constraints (Holtrop & Jordan, 2010) that simply do not allow HCPs to spend extra time with patients who have comprehension issues.

Patients' perceptions about the degree of patient-centered communication in their provider-patient interactions are extremely important, as patients are more likely to avoid necessary healthcare if they perceive low levels of patient-centered communication from their HCPs (Faith, Thorburn, & Tippins, 2015). More specifically, when patients feel as

though their HCPs do not spend adequate time to get to know them on a deeper level, they perceive the quality of the relationship with that HCP more negatively (Faith et al., 2015). Based on this information, it is important for HCPs to incorporate patient-centered communication into interactions with all patients, regardless of the “type” of patient they may be categorized as. Although HCPs may be receptive of this information, it is common for them to experience difficulties engaging in patient-centeredness when the topic of discussion is considered sensitive (Sparks & Villagran, 2010).

Research suggests that by understanding each patient as a whole person, HCPs are better positioned to personalize treatment recommendations, use language that the patient understands, provide clear explanations, and validate the patient’s emotional state (Marvel et al., 1999). However, when it comes to providing healthcare to patients who experience limitations in their cognitive and communicative abilities, HCPs are likely to experience greater challenges in enacting these patient-centered processes, especially if they consider the patient’s intellectual disability to be a sensitive topic (Bertakis et al., 1998; Cooper-Patrick et al., 1999). HCPs’ interactions with PWID are explored next.

Provider-PWID Communication

People with intellectual disabilities are living longer and moving toward greater social inclusion in all aspects of their lives, including healthcare (McConkey & Collins, 2010; Wilkinson et al., 2013). However, their limited cognitive and communicative abilities restrict their independence and pose challenges when it comes to participating in decisions regarding their health (Ogletree et al., 2011). Unfortunately, the majority of PWID struggle to communicate medical needs or medical information to their HCPs

(Blackstone et al., 2015). Many PWID experience difficulties in accurately conveying their symptoms to HCPs or they do so differently than patients without intellectual disabilities, which makes it more challenging for HCPs to understand (Van Schrojenstein Lantman-De Valk & Walsh, 2008; DeKnegt et al., 2013). Because of these limitations HCPs may miss or misinterpret important signals that indicate a potential health issue (Vrijmoeth et al., 2016).

Miscommunication between patients and HCPs is the leading cause of medical errors, such as misdiagnoses and medication dosage errors, and can result in a host of adverse health effects (Starmer et al., 2014). PWID have a greater need for patient-centered care than patients without disabilities, but HCPs often jump to inaccurate assumptions about their goals, aspirations, and abilities, which has lasting effects on their relationships with these HCPs (Iezzoni, 2006). While HCPs are typically receptive of the importance of patient-centered communication in the provider-patient interaction, the unique interaction that takes place with PWID poses challenges to achieving effective patient-centered communication among those involved.

HCPs' encounters with PWID are inherently different from traditional provider-patient interactions. It is common for PWID to be accompanied by a family member or professional caregiver in these interactions. Caregivers are valuable resources because they are often the first to notice changes in patients' mood or behaviors that may go otherwise unnoticed by the HCP (Vrijmoeth et al., 2016). Caregivers also assist in translating important health information between the patient and HCP (Wilkinson et al., 2013). Patient-centered healthcare accounts for family/caregivers' presence in a patient's

health experience, and suggests that HCPs, patients, and family/caregivers work together to mutually understand one another's perspectives (Epstein & Street, 2007). However, HCPs and PWID often view caregivers' roles differently. HCPs indicate that they tend to rely almost entirely on caregivers for gaining a medical history, giving instructions, and to save time (Flynn, Hulbert-Williams, Bramwell, Stevens-Gill, & Hulbert-Williams, 2015; Wilkinson et al., 2013). This communication pattern is troubling and distressing for PWID, who prefer that HCPs speak directly to them rather than using their caregiver as a substitute for communicating with the patient directly (Keeley et al., 2015; Wilkinson et al., 2013). Many HCPs are not well trained to care for PWID (Peter, Forke, Ginsburg, & Schwarz, 2009), which may explain their preference for communication with caregivers over PWID directly.

Patient-centered healthcare defines effective communication not just by what an individual does, but what interactants can achieve together (Street, 2003). HCPs, PWID, and caregivers must be able to elicit and understand one another's perspective, reconcile differences, and achieve some degree of agreement on the status of the patient's health, along with the best course(s) of action (Street & DeHaes, 2013). Unfortunately, because of the uniqueness of these interactions, HCPs often cite a lack of confidence and awareness in caring for PWID, barriers to communication, and difficulty in obtaining the patient's perspective (Dunkley & Sales, 2014). These challenges can impact HCPs' perceived ability, or PBC in enacting patient-centered practices with PWID.

Perceived Behavioral Control. HCPs are often reluctant to treat PWID (Jain, 2006; Verger et al., 2005), and cite feelings of inadequacy in doing so (Emold, Schneider,

Meller, & Yagil, 2011; Thomas, Palmer, Coker-Juneau, & Williams, 2003; Wilkinson et al., 2013). An overwhelming 80% of HCPs agree that it is harder to provide quality healthcare to PWID versus patients without disabilities (Lennox, Diggins, & Ugoni, 1997). Providing care to PWID is both emotionally and physically demanding, and thus can result in a shortage of emotional availability to lend to patient-centered practices, such as getting to know the patient and empathizing with his/her health experience (Flynn et al., 2015). Many HCPs perceive that PWID require more time and assistance, and feel a logistic burden on their office's already limited resources when caring for these patients (Stein, 2000; Wilkinson et al., 2013). HCPs explain time as a "luxury" that they do not have, and link their frustrations to regret and guilt about an inability to spend extra time with PWID (Wilkinson et al., 2013). Because of barriers related to limited time, HCPs are often forced to address the physical problems that PWID present with first, causing inadequate coverage of preventative, non-urgent health issues (Lennox, Diggins, & Ugoni, 2000).

To add to the limitations in providing patient-centered care to PWID, because many PWID lack the ability to accurately communicate health information verbally, HCPs tend to experience difficulties in involving the patient in decisions regarding their care (Vrijmoeth et al., 2016). As a result, they tend to heavily rely on caregivers to make those important decisions (Vrijmoeth et al., 2016). Upon admission to hospitals, when HCPs lack access to information about patients' specific communication and care needs, caregivers must often repeat this information to new HCPs at each shift rotation (Hemsley & Balandin, 2014). HCPs' direct experiences with these limitations or

expectations about their potential impact influences their PBC. Such perceptions will likely also surface in their attitudes toward providing patient-centered care to PWID.

Attitudes. Although HCPs express concerns related to a lack of resources as a major obstacle to providing patient-centered care to PWID, they generally understand the importance of and hold favorable attitudes toward doing so. Even if communication seems difficult, HCPs report generally being willing to attempt it, even if that means communicating with the assistance of caregivers, or using strategies beyond speech to access PWID (Hemsley & Balandin, 2014). Some HCPs even allude to seeking advice from another HCP to supplement their own knowledge in communicating with PWID (Flynn et al., 2015). While some HCPs generally believe that they play a substantial role in caring for PWID and view their own roles and responsibilities related to that process favorably (Lennox et al., 2000), research suggests that there are still a significant minority that possess more negative attitudes toward providing care to PWID.

HCPs in oncology settings overall felt less positive about caring for PWID (Flynn et al., 2015). Lewis and Stenfert-Kroese (2010) found that HCPs in their study held significantly less positive attitudes toward PWID compared to patients without disabilities. These HCPs were more likely to segregate PWID in a side room, avoid invasive procedures, and spend less time explaining health information. Similarly, in their metasynthesis of provider-patient interaction literature, Hemsley and Balandin (2014) found that HCPs generally held negative attitudes toward PWID starting from the admission process, because they expected them to have more “support needs” to accomplish everyday tasks related to eating and drinking, mobility, and communication.

These types of negative attitudes can most likely be attributed to prior negative experiences or an altogether lack of experience with PWID. HCPs report experiences with PWID where the patient “lashed out” causing physical harm or damage to the surrounding environment (Wilkinson, Dreyfus, Cerreto, & Bokhour, 2012), where their patients could not understand what they were saying (Gibbs, Brown, & Muir, 2008; Wilkinson et al., 2012), where caregivers assumed control of the interaction (Tuffrey-Wijne et al., 2016), and where they had to spend upwards of 19.5 minutes with PWID causing a strain on already limited resources (Chew, Iacono, & Tracy, 2009). McManus et al. (2010) found that HCPs who were less experienced with PWID possessed more negative attitudes, and explained that both quantity and quality of contact with PWID predicts HCPs’ attitudes toward caring for and communicating with them. They found that increased exposure to interactions with PWID significantly improved HCPs’ previously negative attitudes.

Although many HCPs recognize their role in providing quality healthcare to PWID, there is a significant minority that does not feel as though their involvement is appropriate, or that added compensation is warranted to provide care to PWID (Stein, 2000). Researchers blame a lack of sufficient training and experience in caring for this population of patients, as well as an overall lack of knowledge, for HCPs’ negative attitudes toward caring for PWID (Jain, 2006; Martin et al., 2005; Saketkoo et al., 2004).

Uncertainty. There are a variety of explanations for why many HCPs experience a lack of confidence and awareness in caring for PWID. Perhaps the simplest explanation is “fear of the unknown.” HCPs see patients day in and day out, and form expectations

about how their appointments will evolve based on their training and experience (Wright et al., 2013). However, when it comes to appointments with PWID the trajectory of the provider-patient interaction is likely to vary based on the patient's communicative abilities, level of understanding, and the presence or absence of a caregiver. Chew et al. (2009) explain that augmentative and alternative communication strategies are widely used among patients with all levels of intellectual disabilities. These can include spelling and picture boards, key word signs, sign language, and electronic devices, which allow PWID to communicate with recorded speech. The introduction of such uncommon communicative devices as well as the third party caregiver into the provider-patient interaction may cause uncertainty among HCPs who are not used to working with these resources regularly (Chew et al., 2009). HCPs even report feeling as though they are “operating without a map” in interactions with PWID (Wilkinson et al., 2012).

Because HCPs have limited training and experience with PWID, they tend to hold cultural views that distinguish PWID as different from themselves and others based on their varied, sometimes uncommon needs (Iezzoni, 2006; Siasoco, 2014). Although as a society we have come leaps and bounds from traditional stereotypical views about PWID that concluded, “The mentally retarded present the physician with a maze of problems...” (Zarfas, 1970, p. 733), modern categorizations of PWID at times still faintly resemble these biased views. While HCPs typically discuss PWID in a favorable manner, they tend to hold unconscious biases toward them which surface in their descriptions of them as “beautiful people,” and as “simple, pleasant, and child like” (Wilkinson et al., 2012; Wilkinson et al., 2013). When asked about PWID, it is not uncommon for HCPs to

categorize their behaviors as disruptive, problematic and embarrassing (Lennox & Kerr, 1997). It is not likely that HCPs intentionally segregate PWID as an “out group.” Rather, this categorization is likely an effort to reduce HCPs’ uncertainty about this population of patients by attempting to predict and explain how they are most likely to behave in a given interaction (Berger & Calabrese, 1975; Giles et al., 2007; Gudykunst, 1985). However, because of the varying degrees of severity of intellectual disabilities (Special Olympics, 2016), it can be difficult to predict how PWID as a whole are most likely to behave (Chew et al., 2009).

Instead, HCPs should attempt to manage their uncertainty patient by patient, through adopting patient-centered care practices to get to know their patients on a deeper level (Chew et al., 2009; Iezzoni, 2006). HCPs who are able to understand PWID as whole people who experience life in similar ways to them, should feel more certain about their ability to care for them and in turn should experience less anxiety than HCPs who continue to view PWID as a segregated group of individuals (Gudykunst, 1985). Learning how to manage uncertainty about caring for PWID is essential for HCPs because they are increasingly being confronted with PWID who are in need of quality healthcare (Vrijmoeth et al., 2016).

Anxiety. HCPs who possess increased uncertainty about PWID are likely to experience feelings of uneasiness, worry, or even apprehension when interacting with this population of patients. Although minimal amounts of anxiety are normal in any uncertain situation, heightened amounts can lead to a variety of troublesome communicative behaviors (Gudykunst, 1985). For example, HCPs may unintentionally communicate

feelings of anxiety through their actions, which may explain negative interactions they've experienced with PWID in the past. The biopsychosocial model of healthcare recognizes that patients' experiences of health are tied to the interaction between their physical symptoms and social, emotional, and relational aspects of their everyday lives. Therefore, it is important for HCPs to discuss and understand how each patient's disability impacts their experience of health rather than ignore it. However, Duggan, Bradshaw, and Altman (2010) warn that simply asking about a disability but not integrating the disclosure into the care process can come across as offensive and limit further communication.

Communicating about any type of disability requires HCPs to address the "elephant in the room," which is not always a comfortable experience (Iezzoni, 2006). It is not uncommon for HCPs to unintentionally communicate their discomfort through what they say or topics they avoid during the provider-patient interaction (Brillhart, Jay, & Wyers, 1990). For example, HCPs may be visibly more at ease in communicating with a caregiver as opposed to the patient (Wilkinson et al., 2013), or may redirect the conversation away from the patient's disability (Duggan et al., 2010). HCPs may also communicate their discomfort through exaggerated empathy including over-accommodating behaviors, affirmative language, or third-person language (Duggan et al., 2010; Thomas et al., 2003), or by not offering PWID access to resources like alternative communication aids (e.g., picture boards) that they are used to (Chew et al., 2009; Tervo, Azuma, Palmer, & Redinius, 2002). HCPs can reduce feelings of anxiety that cause these unintentional divergent behaviors, by managing their levels of uncertainty and

accommodating their communicative behaviors with PWID accordingly (Giles et al., 1991; Giles et al., 1987; Gudykunst, 1985).

Overall, for many HCPs who lack experience and proper training, providing care to PWID poses significant challenges. From their perspectives, they are trying to provide care to patients about whom they do not feel knowledgeable, whom they perceive as different and somewhat intimidating, and whom they lack appropriate resources to support (Wilkinson et al., 2012). Taken together, it is not surprising that they often experience heightened levels of anxiety when caring for PWID. Thus, while all patients can experience barriers to receiving patient-centered care, the heightened anxiety that HCPs experience in caring for PWID leaves them especially vulnerable to a lack of patient-centeredness during the provider-patient interaction.

Patient-Centered Healthcare for PWID

To ensure effective communication with PWID, HCPs should demonstrate respect for their patients, accommodate their behaviors to meet their patients' unique needs, follow-up with patients to establish strong interpersonal relationships, and maximize time spent with PWID (Baumbusch, Phinney, & Baumbusch, 2014; Spassiani et al., 2016; Wullink, Veldhuijzen, van Schroyen Lantman-de Vak, Metsemakers, & Dinant, 2009). Specific strategies for achieving these patient-centered competencies are reviewed next.

Respect. HCPs must understand that PWID are able to understand and assign meaning to more than they might think, and HCPs' verbal and nonverbal behaviors can either communicate respect for patients, or a lack thereof (Olney, 2001). PWID like

HCPs who know them on a deeper level (Spassiani et al., 2016), yet HCPs and patients agree that they tend to acknowledge caregivers more directly than PWID (Wilkinson et al., 2013). When patients feel ignored by their HCPs they report feeling like they do not matter, and explain frustration when, “My doctor did not ask permission to talk to my social worker about me” (Wullink et al., 2009). HCPs should acknowledge and actively involve PWID in all communication about their health and healthcare, even if a caregiver is present (Chew et al., 2009). For example, patients should be acknowledged first (Jain, 2006), and if the caregiver is talking, HCPs should shift eye contact between caregivers and patients to continually acknowledge their presence, and direct follow-up questions directly to the patient (Chew et al., 2009).

Communicating respect is not limited to the clinical interaction, but instead begins much earlier in the patients’ healthcare experience. Menzies, Herron, Scott, Freeman, and Waller (2013) explain that it is important for HCPs to build rapport with PWID as soon as they arrive at the office. Developing rapport can be accomplished by interacting with PWID directly and engaging them in conversation at admission and intake, which may serve the dual purpose of cuing HCPs to their likes, dislikes, and preferences.

Accommodate. To achieve effective communication HCPs must converge or accommodate their behaviors to communicate their messages in ways that their PWID can understand (Giles & Ogay, 2007). Because every patient’s needs and level of understanding is different, HCPs must allow the patient to explain their own health experience. Solicitation of PWID’s perspectives involves asking open-ended questions or asking them to share a story, which allows patients to express their concerns (Robinson &

Heritage, 2006; Young & Rodriguez, 2006). This type of communication allows HCPs to identify potential barriers to prevention and treatment methods (Hahn, 2009), and to gain important insights into their beliefs and attitudes toward illness, medicine, and health behaviors (Young & Rodriguez, 2006). HCPs should listen (and watch) attentively and ask questions to clarify their understanding, and refrain from interrupting the patient or redirecting remarks back to the traditional interview script (Sparks & Villagran, 2010). Rather than make assumptions, HCPs should ask patients what they are most comfortable with and what works best for them and their caregivers, and integrate those wishes into their care (Iezzoni, 2006; Wilkinson et al., 2013). Surprisingly, none of the HCPs in a recent study reported that they would consult PWID directly about how best to support them (Flynn et al., 2015).

If HCPs focus on their patients' experiences for the first 60 seconds of the provider-patient interaction, research suggests that their patients will be more satisfied (Rea, 2010). Conversely, when HCPs dominate the provider-patient interaction to collect only necessary information needed to diagnose problems, order tests, or make a referral, a breakdown in communication is likely to occur (Sparks & Villagran, 2010). Sharing control of the provider-patient interaction with PWID is essential, as it can lead to better health outcomes for patients, as well as demonstrate respect by showing them that their opinions matter (Sparks & Villagran, 2010; Street, 2007).

Follow-Up. Patients explain that they like to see the same HCPs when they have an established relationship with them (Baumbusch et al., 2014). The development of these relationships is largely related to how HCPs follow-up with their patients to provide

continuous care, both during and after the clinical interaction (Hemm et al., 2015). HCPs can follow-up with patients by referring to a past story or experience that patients have shared, checking on them in the waiting room, reviewing patient charts to avoid redundant questions, checking to see if there are remaining questions before dismissing the patient, and checking-in with the patient at home to inquire how they are responding to treatment (Jain, 2006). Additionally, HCPs can distribute opinion surveys to PWID following their appointment to allow patients and caregivers to express their concerns and issues and evaluate how well they were addressed (Jain, 2006). Following-up with patients allows HCPs to ensure that patients' needs are being met, while simultaneously co-constructing shared meanings to develop a trusting relationship with them (Kilroy et al., 2015).

Time. HCPs can maximize limited time with PWID by providing complete and simple explanations that PWID can understand, to avoid having to re-explain information multiple times. One patient explains, "If you use long words or don't explain what's going on, we don't understand it and it's hard for us to figure out what you're doing and it upsets us and we get concerned" (Baumbusch et al., 2014, p. 359). However, it is realistic to assume that the ability to comprehend even the most plain and simple language may not be achievable for all PWID. In these cases, HCPs can support the use of augmentative and alternative forms of communication and check for understanding regularly (Baumbusch et al, 2014; Menzies et al., 2013). In doing so, HCPs can help PWID understand health-related information the first time to improve the efficiency of the interaction. HCPs agree that PWID often receive lower quality healthcare due to

limited time in these interactions (Lennox et al., 2000), so the uptake of these strategies is essential not only to save time, but also to allow for more preventative screening during these interactions.

Due to limitations in their cognitive and communicative abilities, communication with PWID is not likely to fit a traditional script of how the provider-patient interaction should evolve (Heslop et al, 2013; Wilkinson et al., 2013). Additionally, HCPs may not see these patients frequently or may have no experience caring for this population at all (Brown et al., 2016; McManus et al., 2010). Research suggests that HCPs also do not receive comprehensive training about providing patient-centered care to PWID during their formal education and training (Mencap, 2011). To combat these issues standing in the way of providing patient-centered healthcare to PWID, research and training need to be expanded to help HCPs successfully navigate these interactions. Specifically, training interventions that focus on provider-patient communication and relationship building and that are solidly anchored in the current standards of patient-centered care are needed to address the gaps related to providing quality care to PWID (Lezure, 2014).

Communication Skills Training Interventions

Communication skills training for HCPs is not a novel concept. Because HCPs spend a vast majority of their time communicating with patients (Epstein & Street, 2007), medical schools have largely recognized its importance and many have integrated communication training into their education programs (Bennett & Lyons, 2011; Cegala & Broz, 2002; Norgaard, Ammentorp, Kyvik, & Kofoed, 2012). However, these programs tend to focus on general communication strategies that are presumed to apply to all

provider-patient interactions (Jain, 2006). Unfortunately, because of this many PWID receive care from HCPs who have not had any specialized training or are unaware of the many challenges facing PWID (Siasoco, 2014). Admittedly, patient-centered communication is an important practice for all types of patients, but the implementation of such practices should differ based on the audience of patients they are intended for (Craig et al., 2008).

Complex health interventions such as communication skills trainings work best when they are designed for local audiences and contexts versus being overly standardized (Craig et al., 2008). Additionally, communication skills training interventions that include as much realism as possible are most effective (Ross, 2012). Therefore, a training program specifically focused on patient-centered communication in provider-PWID interactions will ensure that the training is most effective in contexts with PWID. An issue regarding existing communication skills training programs in medical schools is that HCPs who are not physicians – nurses, nurse practitioners, lab technicians, social workers, and other essential staff – are likely exposed to different information about communication skills in their respective degree programs and subsequent training. Because the provider-patient relationship is the fundamental starting point for patient-centered care delivery (Murray & McCrone, 2015), it is important that all HCPs are exposed to similar information regarding communication with PWID, suggesting the need for comprehensive interventions that are applicable to a variety of different HCP specialties.

Although communication skills training interventions can successfully alter HCPs' behaviors (Brown et al., 2010), HCPs who are able to practice their skills regularly are three times more likely to maintain such behaviors in the long run (Gaffney et al., 2016). It is widely accepted that effective communication skills need to be practiced over time to be mastered (Kreps & Thornton, 1992). However, it is not uncommon for patient-centered communication practices to take a backseat for HCPs who perceive communication as a "soft skill" that is less important than other aspects of the medical agenda (Cary & Kurtz, 2013). HCPs may already view themselves as competent communicators (Quintanilla & Mallard, 2008), or it is possible these opinions are shaped in part by feelings of inadequacy or a fear of potential failure in enacting such practices. Although HCPs may be reluctant to admit that they need help navigating interactions with PWID, achieving patient-centered care requires HCPs to adopt a complex set of communication skills and behaviors so they should not frown upon needing some assistance in order to achieve those benchmarks (Brown et al., 2010). Even HCPs who choose to focus their practice on PWID often feel inadequately prepared to care for PWID (Wilkinson et al., 2012). Clearly, due to the uniqueness of provider-PWID interactions, HCPs need additional training and experience with this population of patients (Wilkinson et al., 2012).

Research suggests that HCPs who attend communication skills training programs express higher self-efficacy, and their patients are significantly more satisfied with their overall care (Norgaard et al., 2012). HCPs in Brown et al.'s (2010) study reported an increase in confidence to address communication challenges presented in the training

modules, and indicated that they intended to utilize their new skills. In practice, these HCPs noted that the training had enhanced their clinical interactions with patients as well as their ability to provide quality care to patients. HCPs who participated in training about specifically providing care to PWID reported similar outcomes – they were more likely to retain feelings of confidence and preparedness, and recognize communication as a vital component in this process (Hahn & Cadogan, 2011). The success of these communication skills training interventions, among others, attests to their value in enhancing provider-patient interactions. Researchers continue to push for the development of more specialized interventions that focus specifically on interactions with PWID (ODPHO, 2016b; Ryan & Scoir, 2014; Snell et al., 2010; Tuffrey-Wijne et al., 2005; Wilkinson et al., 2013). However, these interventions will only be successful if careful consideration is given to evaluation processes during program development and implementation (Brown et al., 2010).

Rationale for Study

The current study answers calls for a specialized patient-centered communication training intervention focused on provider-PWID interactions that is developed and tested under rigorous evaluation protocols. The RAFT training program (Appendix A) utilized in this study is evidence-based – informed by formative interviews that obtained patients,’ caregivers,’ and HCPs’ perspectives – and theoretically-grounded in behavior change and interpersonal communication theories (Keeley et al., 2015). Specific information regarding the training intervention is presented in the next chapter.

This dissertation proposes six hypotheses and one research question. They are arranged in two sections – one to test the validity of the theoretical model, and the other to test the impact of the intervention in changing HCPs’ attitudes, PBC, uncertainty, anxiety, and intentions to provide patient-centered care to PWID by engaging in patient-centered communication. The first set of hypotheses predicts behavioral intention through explaining theoretical linkages between key behavioral and relational variables cited in the body of literature on provider-PWID interactions. First, research suggests that HCPs hold both favorable and unfavorable attitudes toward interactions with PWID (Flynn et al., 2015; Hemsley & Balandin, 2014), which likely explains their varying levels of uncertainty and anxiety in caring for this population of patients. HCPs with more negative attitudes perceive PWID to be “different” and perceive them to possess a host of burdensome needs. Conversely, HCPs with more positive attitudes tend to have more experience with PWID (McManus et al., 2010) and are more likely to attempt communication with them (Hemsley & Balandin, 2014). AUM posits that attitudes serve as background variables that impact individuals’ levels of uncertainty and anxiety (Gudykunst, 1985). Hence:

H1: HCPs’ attitudes toward providing patient-centered care to PWID will be negatively associated with uncertainty and anxiety.

HCPs who have established relationships with PWID typically know what to expect from them, yet still report increased feelings of anxiety and inadequacy due to a lack of necessary resources to provide quality care (Emold et al., 2011; Wilkinson et al., 2013).

TPB explains HCPs' experiences of anxiety that are unrelated to uncertain thoughts, but can be attributed to a perceived lack of resources and opportunity. Hence:

H2: Greater PBC will be associated with less uncertainty and anxiety.

Conversely, TPB may also reduce anxiety even if there is high uncertainty because HCPs believe that they are resourceful enough to deal with the uncertainty. Hence:

H3: HCPs' PBC will moderate the relationship between their uncertainty and anxiety.

As a way to manage their uncertainty, HCPs tend to categorize PWID as an "out group" which results in heightened anxiety (Berger & Calabrese, 1975; Giles et al., 2007). In an effort to conceal this anxiety, HCPs may unintentionally communicate their discomfort to patients through diverging their verbal and nonverbal behaviors (Duggan et al., 2010; Tervo et al., 2002; Thomas et al., 2003; Wilkinson et al., 2013). CAT explains that diverging behaviors will increase social distance between HCPs and PWID, in turn making them more uncertain and more anxious about interacting with PWID and less inclined to provide patient-centered care. On the other hand, considering CAT and AUM together, they explain that converging behaviors to meet PWID where they are (i.e., mindfulness or patient-centered communication) functions to decrease social distance between HCPs and PWID thereby reducing uncertainty and anxiety. In this way, if HCPs experience high uncertainty and anxiety but believe that patient-centeredness will help reduce them, they should have stronger intentions toward doing so. Hence:

H4: HCPs' uncertainty and anxiety will be negatively associated with their intentions to provide patient-centered care to PWID.

Oncology HCPs in Flynn et al.'s (2015) study explained that they were generally in favor of providing PWID with quality healthcare, yet felt so physically and emotionally overwhelmed themselves, that they were not always able to follow through. TPB explains that favorable attitudes toward providing patient-centered care to PWID, as well as a perceived ability to do so predicts behavioral intention (Ajzen, 1985). Hence:

H5: HCPs' attitudes toward providing patient-centered care to PWID and PBC will be positively associated with their intentions to provide patient-centered care to PWID.

The second set, comprised of one hypothesis and one research question, represents core outcomes of the training intervention. Previous studies have demonstrated the effectiveness of communication skills training interventions in altering participants' behaviors (Brown et al., 2010; Hahn & Cadogan, 2011; Norgaard et al., 2012). Additionally, TPB suggests that creating favorable attitudes toward behaviors and increasing PBC predicts increased intention (Ajzen, 1985). Hence, after completing RAFT, HCPs' increased knowledge about the importance of providing patient-centered care to PWID and strategies for doing so, should account for increased behavioral intentions related to each of the four patient-centered competencies addressed in the training:

H6: After completing RAFT training, HCPs will report greater intentions to perform behaviors that embody the four patient-centered communication competencies targeted in the training.

In an effort to understand the contributions of RAFT in creating more favorable attitudes, increasing PBC, and reducing uncertainty and anxiety related to providing patient-centered care to PWID, the following research question is proposed:

RQ1: How does RAFT training impact predictors of intention?

CHAPTER THREE: METHOD

The previous chapter proposed six hypotheses and one research question. The purpose of this chapter is to describe the methods and procedures used to test these hypotheses. The chapter is divided into five sections. In the first section, participants are defined and characteristics about them are presented. In the second section, procedures relating to the manipulation (i.e., RAFT training intervention) are described. The third section focuses on data collection. The fourth section focuses on how the variables were measured. The fifth section focuses on how the learning objectives were assessed. Finally, the sixth section describes how the data were analyzed.

Participants

Participants included 109 HCPs. Participant characteristics are summarized in Table 1. Males represented 15.7% of the sample ($n = 17$) and females represented 84.3% of the sample ($n = 91$). One participant did not report his or her sex. Participants ranged in age from 20 years to 72 years, with an average of 33.63 years ($SD = 12.32$). The majority of the sample self-identified their ethnicity as either Hispanic/Latino or Caucasian. Other ethnicities reported in the sample were Asian, African-American, and Native Hawaiian/Pacific Islander. Two participants did not report their ethnicity.

Table 1. Sample Characteristics

Demographics (n = 108)		n	%
Sex:	Male	17	15.7
	Female	91	84.3
Age:	18-30 years	58	53.7
	31-44 years	30	27.8
	45-58 years	14	13.0
	59-72 years	6	5.6
Ethnicity:	Hispanic/Latino	57	52.8
	White	36	33.3
	African-American	4	3.7
	Asian	9	8.3
	Pacific Islander	1	0.9
	Other (not specified)	1	0.9
Provider Type (n = 108)		n	%
	Nursing Student	66	61.2
	Nurse	21	19.4
	Physician	8	7.4
	Other	13	12.0
Healthcare Organization (n = 94)		n	%
	Hospital	40	42.6
	Public Clinic	22	23.4
	Other: Healthcare	11	11.7
	Other: Non-Healthcare	10	10.6
	Unemployed	11	11.7
Years Seeing Patients (n = 109)		n	%
	0 years	21	19.3
	< 5 years	41	37.6
	5-24 years	37	33.9
	25-52 years	10	9.2
Years Seeing PWID (n = 106)		n	%
	0 years	61	57.5
	< 5 years	20	18.9
	5-24 years	16	15.1
	25-52 years	6	5.7
	Years Not Specified	3	2.8
Prior Training PWID (n = 108)		n	%
	Yes	4	3.7
	No	104	96.3

The sample represented a variety of HCP types, although most highly represented were Nursing students and Nurses. Other HCPs represented in the sample included, Physician, Office/Reception Staff, Patient Care Technician, EMT, Physician Assistant, ER Technician, Medical Assistant, and Social Worker. One participant did not report their profession. On average, the HCPs reported seeing patients for an average of 9.34 years ($SD = 10.74$) ranging anywhere from no experience to 52 years. The majority of HCPs had no experience working with PWID ($n = 61$; 57.5%), while some reported prior experience with PWID ($n = 45$; 42.5%). Three participants did not answer the question about experience with PWID. Participants who indicated prior experience with PWID reported servicing that population of patients for an average of 9.58 years ($SD = 11.20$), ranging anywhere from 6 months to 52 years. Three HCPs who indicated prior experience with PWID did not specify the number of years of experience. Of the HCPs who reported having prior experience working with PWID, only 3.7% ($n = 4$) reported receiving any type of training on such interactions, while 96.3% ($n = 104$) indicated no prior training on the topic. HCPs worked in a variety of healthcare organizations including hospital, public clinic, telephone triage, medical education, pharmacy, mental health center, assisted living or nursing home, rehab facility, and private practice. Fifteen HCPs did not report where they worked. Many HCPs were full time students that held employment in locations unrelated to health, or were unemployed.

Procedure

HCPs were recruited through the Special Olympics Texas network of HCPs, as well as the College of Health Professions at Texas State University. First, HCPs already

enrolled in a multi-day training seminar offered through Special Olympics Texas were invited to take part in RAFT training. Second, Special Olympics Texas contacted HCPs who currently service PWID through the Healthy Athletes program and/or who have expressed a prior interest in trainings about PWID, and invited them to participate. Third, faculty from the College of Health Professions were contacted and invited to participate as well as share information about the training with eligible colleagues that may be interested in participating. To be eligible to participate participants had to be at least 18 years of age and be a HCP. Participants were not required to have prior experience working with PWID.

An experienced training and development specialist with a background in training HCPs conducted the face-to-face training sessions using the RAFT Instructor Manual as a guide (Appendix B). The training sessions took place at various locations around south central Texas in October and December of 2016, and January of 2017. Each training session lasted for approximately 2 hours, which included lecture, discussion, role-play, and the completion and unpacking of a case study where HCPs applied RAFT content to an actual provider-patient interaction. Participants were provided with all necessary materials, which included the training booklet and bonus insert for emergency care HCPs. Details and locations of the training sessions are provided below:

Friday, October 28th 2016: Conducted with students and faculty at Baptist Health System in San Antonio, TX (n = 95). The training was conducted during the students' mental health unit.

Monday, December 5th 2016: Conducted with internal medicine physicians at the University of Texas Health Science Center (n = 11). The physicians also practice at University Hospital and the VA.

Friday, January 27th 2017: Conducted with a variety of HCPs and non-medical staff members at University Health System – Robert B. Green Campus in San Antonio, TX (n = 38).

The RAFT communication skills training intervention was utilized in this study. RAFT is an evidence-based training program focused on training HCPs about patient-centered healthcare for PWID. RAFT operationalizes patient-centeredness through four behavior categories – Respect, Accommodation, Follow-Up, and Time. In an effort to preserve efficiency and obtain quality data from participants for evaluation purposes, outcome assessment focused on only one key behavior or competency from each category. They are: (1) Respect – address PWID directly, (2) Accommodation – listen and ask questions, (3) Follow-Up – check for understanding, and (4) Time – explain health information completely using simple terms. Developed in 2015, RAFT can be distinguished from existing training curriculums (see AADMD, 2012, Vanderbilt Kennedy Center, 2011) based on the following four criteria:

RAFT is a true evidence-based program based on actual experiences of PWID, their caregivers, and HCPs. Where many existing training programs are founded on the expertise of the authors, RAFT is based on what key stakeholders expressed are vital missing components in provider-PWID interactions based on their experiences. Interview data from formative research (see Keeley et al., 2015) produced themes that were continuously noted as barriers to effective interactions between HCPs and PWID. These themes were used to design the four core competencies (respect, accommodation, follow-up, and time) addressed in the training.

RAFT is focused on training HCPs communication skills that can be directly applied to a very specific population of patients. Because complex health interventions work best when they are designed for local audiences and contexts versus being overly standardized (Craig et al., 2008), RAFT is designed to be most effective in promoting behavior change among HCPs in provider-patient interactions with PWID.

RAFT focuses on quality communication as a core outcome of the program. Whereas existing training programs tend to include communication as one topic within a larger training curriculum, each module in RAFT is designed to elicit quality communication. RAFT uses a logic model that mirrors the continuum of the patient experience to expand the context of the provider-patient interaction beyond just the clinical interaction. The intervention addresses each of the four patient-centered communication competencies as they function within each stage of the following patient experience: (1) Scheduling and Intake, (2) Initial Assessment, (3) Examination, and (4) Clarification Before Leaving. Because the program focuses on different aspects of the patient experience, RAFT is focused on training all HCPs as opposed to solely physicians.

RAFT facilitates higher levels of learning through interactive modules. Activities built into each module require HCPs to not only understand and apply information but also to analyze and evaluate it. Hands on activities require HCPs to draw from experience rather than hypothetical situations, which allow them to apply what they've learned to their actual work environments as opposed to hypothetical examples. Such activities allow HCPs to express themselves while teaching them how to effectively

communicate with others on a professional level (Jones & Sanford, 2003). This hands-on experience increases learning and motivation, and helps HCPs feel more confident in their interactions with PWID and improve the quality and continuity of care for PWID (Johnson, 2009; Mazer & Hunt, 2008; Sidelinger & Booth-Butterfield, 2010).

Data Collection

A pre-test post-test design was used to assess the overall effectiveness of the RAFT intervention and to detect changes in HCPs' attitudes, PBC, uncertainty, anxiety, and behavioral intention following the intervention. IRB waived the requirement for participants to sign an informed consent to participate in the study. Instead, upon arrival each participant received an informational handout detailing the nature of the study, the approximate time commitment, the benefits of participating, and their right to opt out of the training and/or pre- and post-test at any time. Before beginning the training, participants completed a pre-test on paper, which contained quantitative measures for each of the variables, as well as demographic items such as sex, age, ethnicity, profession, location of employment (e.g., hospital, private practice, etc.), and whether they had experience working with PWID or prior training on the topic. No identifying information about the participants was collected, but participants were assigned unique identification codes used to match pre-test and post-test data. Upon completion of RAFT training, participants completed a post-test that contained the same measures as the pre-test (less demographic items), in addition to learning assessment items, and open-ended qualitative items that solicited HCPs' feedback about the training itself, such as what they believed to be the most valuable aspect of RAFT, recommendations for improvement,

and any skills or competencies that may be missing from the training. Although the recommendations were not assessed as a part of this study, they provided feedback for quality improvement to RAFT for future training sessions. In total, participants completed 54 Likert-type items measuring theoretical concepts, 8 demographic items, 6 learning assessment items, and 3 qualitative feedback items. Half of the Likert-type items were reverse scored to enable proper test of scale reliability (Keyton, 2015).

A total of 144 HCPs participated in RAFT training. However, only participants with completed pre- and post-test measures were included in the final analysis ($n = 109$). Some HCPs did not complete the pre- and post-test in their entirety for a variety of reasons: (1) they were paged out of the training midway through and did not complete the post-test, (2) they arrived late and did not complete the pre-test, (3) they only completed parts of the pre- or post-test and left the majority of items blank, or (4) they chose not to participate in the pre- and post-test.

Instrumentation

The primary variables in the study included attitude, PBC, uncertainty, anxiety, and intention, each measured with a multi-item scale. Descriptive statistics and correlations between variables are presented in Table 2 (pre-test) and Table 3 (post-test). The following section describes each measure.

Attitude. HCPs' attitudes toward providing patient-centered healthcare to PWID were operationalized using the 20-item Attitudes Towards Patients with Disabilities Measure (Lewis & Stenfert-Kroese, 2010; Appendix C). This measure was utilized because of its specific focus on patient-centered care as it has been defined in this study,

specifically with the inclusion of items that denote *Respect, Accommodation, Follow-Up,* and *Time*. Participants were asked to rate their levels of agreement on a 7-point Likert scale ranging from 1 = “strongly disagree” to 7 = “strongly agree.” Sample items include, “It is worthwhile to talk directly to PWID as well as consult with their family/caregivers” and “I would not spend too much time explaining information to PWID, because it is hard for them to understand.” A total of 9 items were reverse scored. For this scale, a higher score indicated more favorable attitudes, while a lower score indicated less favorable attitudes. To shorten the questionnaire and lower demand on participants, items that were not directly relevant to the context being studied were not included in this study. For the attitudes scale, four items were not included: (1) I would not object to PWID being present in the same common areas with other patients. (2) I would avoid, where possible, undertaking invasive procedures with PWID. (3) I am not any more likely to get abuse from PWID compared with other patients. (4) I do not feel that my training and skills are adequate to properly care for PWID. These items were removed because the researcher believed them to focus mainly on attitudes toward PWID rather than the behavior of engaging in patient-centered communication with PWID.

The attitude instrument was reliable (pre-test $\alpha = .70$; post-test $\alpha = .71$). During the cleaning process two items were determined to be unreliable and thus were deleted before analysis. By deleting these items the pre-test reliability increased from $\alpha = .66$ to $\alpha = .70$, and the post-test reliability increased from $\alpha = .65$ to $\alpha = .70$. The first item removed was “The health needs of PWID can be adequately met within mainstream healthcare services.” It is possible that this item was unreliable because participants were

confused about what healthcare services were considered “mainstream” or because this item focused more on administrative protocol than the actual provider-patient interaction. The second item removed was “I would want relatives/caregivers to stay and help out during my interaction with PWID.” This item may have been unreliable because of the phrase “help out” that may have held different connotations for different HCPs.

Perceived Behavioral Control. The items used to measure PBC were designed based on recommendations for creating TPB questionnaires (Ajzen 2006). On a 7-point Likert scale, HCPs were asked to rate the extent to which, if they wanted to, (1) they could perform the behavior of interest, (2) how difficult it would be for them to perform the behavior, and (3) the extent to which it would be possible for them to do so (Appendix D). These items were used for each of the four patient-centered behaviors of particular focus in this study, resulting in a 12-item measure. Sample items include, “I am confident that I can take the time to listen to PWID explain their personal experiences” and “Even if I want to speak to PWID directly, there are factors that prevent me from doing so.” A total of 7 items were reverse scored. For this scale, a higher score indicated higher PBC, while a lower score indicated lower PBC. The PBC instrument was reliable across all four patient-centered behavior categories (pre-test $\alpha = .83$; post-test $\alpha = .82$). During the cleaning process one item was determined to be unreliable and was deleted before analysis. By deleting this item the post-test reliability increased from $\alpha = .61$ to $\alpha = .82$. The item was “I feel comfortable asking PWID to explain their understanding of information.” This item may have been unreliable because it is the only item in the measure that uses the term “comfortable.” The other items in this measure focus on

whether performing a behavior is easy or difficult, and whether the HCP is confident. The term “comfortable” seems to suggest a more personal opinion rather than ability, which may have confused some participants or led to socially desirable responses.

Uncertainty. Uncertainty was measured using the 7-item Clatterbuck Uncertainty Evaluation Scale (CLUES; Clatterbuck, 1979; Appendix E). This scale measures participants’ confidence to predict the outcomes of interactions with strangers. This measure was selected based on the present study’s conceptualization of uncertainty as HCPs’ cognitive perceptions of doubt in terms of their ability to predict how PWID are most likely to behave in the provider-patient interaction. Participants were asked to rate their levels of agreement on a 7-point Likert scale ranging from 1 = “strongly disagree” to 7 = “strongly agree.” Sample items include, “I feel confident in my general ability to predict how PWID will behave” and “It is hard for me to empathize with the way PWID feel about themselves.” A total of 3 items were reverse scored. For this scale, a higher score indicated increased uncertainty, while a lower score indicated decreased uncertainty. The following item was not included in this study: (1) In general, I am confident in my ability to accurately predict PWID’s values. The researcher determined that predicting values deviated from the main focus of the instrument, which was intended to measure HCPs’ perceptions about patients’ behavior. The uncertainty instrument was reliable (pre-test $\alpha = .76$; post-test $\alpha = .70$). No items were found to be unreliable or deleted before analysis.

Anxiety. Anxiety was measured using the 9-item anxiety subscale derived from the Brief Patient Health Questionnaire (Spitzer, Kroenke, & Williams, 1999; Appendix

F). Although it was originally designed to measure patients' anxiety levels, Acosta, Verma, and Anzisi (2007) validated its use to also measure emergency HCPs' anxiety. Participants were asked to rate their levels of agreement on a 7-point Likert scale ranging from 1 = "strongly disagree" to 7 = "strongly agree." Sample items include, "The most pleasurable part of my job is getting to work with PWID" and "I feel fidgety or restless around PWID." A total of 3 items were reverse scored. For this scale, a higher score indicated more anxiety, while a lower score indicated less anxiety. The following item was not included in this study: (1) I notice changes in my mood when caring for PWID. The researcher concluded that this item deviated from the other items included in the measure that focus on immediate "feeling" rather than "mood" which could be related to a combination of other factors. The anxiety instrument was reliable (pre-test $\alpha = .83$; post-test $\alpha = .82$). No items were found to be unreliable or deleted before analysis.

Intention. The items used to measure behavioral intention were designed based on recommendations for creating TPB questionnaires (Ajzen 2006). On a 7-point Likert scale, HCPs were asked to rate the extent to which they (1) plan to execute the behavior, (2) think it is likely that they will execute the behavior, and (3) agree that they will execute the behavior (Appendix G). These items were used for each of the four patient-centered behaviors of particular focus in this study, resulting in a 12-item measure. Participants were asked to rate their levels of agreement on a 7-point Likert scale ranging from 1 = "strongly disagree" to 7 = "strongly agree." Sample items include, "I plan to address PWID directly" and "It is likely that I will simplify complex information for

PWID.” A total of 4 items were reverse scored. A higher intention score indicated greater intentions, while a lower score indicated lesser intentions.

The intention instrument was reliable across all four patient-centered behavior categories (pre-test $\alpha = .72$; post-test $\alpha = .81$). During the cleaning process two items were determined to be unreliable and thus were deleted before analysis. By deleting these items the overall reliability increased from $\alpha = .59$ to $\alpha = .72$. The first item removed was “It is highly likely that I will solicit PWID’s perspectives.” Here, the term “solicit” may have held negative connotations for some HCPs. It is also possible that some HCPs were confused because the item did not specifically state which patient perspectives were to be solicited. The second item that was removed was “I will not exclude medical terminology when I explain complex information to PWID.” It is possible that the double negative used to reverse code this item confused some participants.

Background Variables. In addition to the five scales, participants also responded to 8 demographic items. Basic demographic items included, sex, age, and ethnicity. HCP-specific items included, HCP type (e.g., physician, nurse, student), location of employment (e.g., hospital, private practice, public clinic), years seeing patients, and whether or not they had any prior experience servicing PWID, and/or any prior training on the topic.

Assessment of Learning Objectives

RAFT training contained six learning objectives:

1. Develop effective communication interactions with patients using RAFT.
2. Explain how RAFT can be integrated into each stage of the clinical experience.
3. Demonstrate communication behaviors representing *respect*.
4. Demonstrate communication behaviors representing *accommodation*.

5. Demonstrate communication behaviors representing *follow-up*.
6. Demonstrate communication behaviors representing *time*.

During the training session the trainer engaged in formative assessment techniques to ensure participant understanding. During the interactive portion of the training, participants engaged in: (1) group discussions where they were asked to relate the curriculum to personal experience, (2) role-play activities where participants acted out provider-patient interactions modeling RAFT behaviors by taking on the roles of HCPs, patients, and caregivers, and (3) a case study where participants were provided a testimony of an actual provider-patient interaction and asked to identify RAFT behaviors as well as areas where RAFT could have been implemented to improve the interaction. Through these activities the trainer was able to identify portions of the curriculum that were clearly understood as well as areas where additional clarification was necessary.

In addition to the formative assessment, summative assessment measures were also used to formally assess each learning objective (Appendix H). These items were included at the end of the post-test. The first learning objective was measured using a dichotomous item that asked participants, “Do you feel more prepared to service PWID after completing RAFT training?” Potential responses included: (a) yes and (b) no. The second learning objective was measured with a multiple-choice item that asked, “At what point in the patient experience would you use RAFT?” Potential responses included: (a) when examining the patient, (b) when checking the patient in at the front desk, (c) during a follow-up appointment, (d) a and b, or (e) all of the above. The correct response was (e).

The third learning objective was measured with a multiple-choice item that asked, “A PWID comes in for a routine checkup. Which of the following would be the best way to

communicate with them based on RAFT?” Potential responses included: (a) smile at them while talking with their caregiver, (b) address the patient but get important information from the caregiver, (c) speak directly to the patient and acknowledge the caregiver’s insights, (d) ask the caregiver to make sure the patient understands, or (e) none of the above. The correct response was (c).

The fourth learning objective was measured with a multiple-choice item that read, “If you see that the PWID is having a hard time understanding you, the best thing to do is:” Potential responses included: (a) slow down and explain the information in a different way, maybe with pictures, (b) slow down and repeat yourself until the patient understands, (c) ask the caregiver to explain the information to the patient later, (d) b and c, or (e) all of the above. The correct response was (a).

The fifth learning objective was measured with a multiple-choice item that asked, “Why is it important to follow-up with PWID both during and after their appointment?” Potential responses included: (a) you want to make sure that they come back, (b) to ensure understanding while the patient is still present or to avoid emergency visits, (c) it is only important to follow up with patients after they leave the office, (d) to develop a lasting relationship with them, or (e) b and d. The correct response was (e).

The sixth learning objective was measured with a multiple-choice item that asked, “How can you maximize time during interactions with PWID?” Potential responses included: (a) skip questions that the patient/caregiver asks and leave them for the end, (b) take the time to answer patient’s questions fully and consult the patient’s chart, (c)

schedule longer appointment times for PWID, (d) a and b, or (e) b and c. The correct response was (e).

Data Analysis

All questionnaire data was entered and processed using SPSS. Once data entry was complete, the spreadsheet was cleaned and variable names were added. After the recoding process, descriptive statistics were calculated for demographic items and each of the included scales. Reliability analysis was conducted for each scale and unreliable items were deleted. Composite variables were then created by adding together all items and dividing by the number of items in each measure. A total of 10 composite variables were created: PreAttitude, PrePBC, PreUncertainty, PreAnxiety, PreIntention, PostAttitude, PostPBC, PostUncertainty, PostAnxiety, PostIntention.

To address the hypotheses and research question, Pearson correlations were first used to examine general relationships between variables. Next regression analyses were used to examine the predictive power of the proposed theoretical model. Paired samples t-tests were conducted to examine the effectiveness of the RAFT training intervention. The theoretical model was primarily tested using pre-test data to avoid any contributing effects resulting from exposure to the RAFT intervention. The researcher did run the same analysis on the post-test data to ensure that the patterns were consistent, and to determine the potential impact of RAFT on the model, but those results are not provided in text. Statistical significance was determined at $\alpha = .05$. To assess the learning objectives, frequency counts were used to determine the percentage of participants that selected each of the multiple-choice items.

CHAPTER FOUR: RESULTS

This chapter reports the results of this dissertation for the study's six hypotheses and one research question. The chapter is broken down into six sections. First, correlations between variables are provided. Second, the six hypotheses are tested. The third section examines the research question. The fourth section reports the results of additional analyses performed on the data, including the predictive power of the proposed theoretical model and subgroup differences on the variables. Fifth, RAFT training learning objectives are assessed. Finally, a summary of the results is provided before moving on to the discussion of results.

Correlations Among Variables

Before testing the hypotheses, correlations were calculated to examine the general relationships between variables – primarily the predictors (attitude, PBC, uncertainty, and anxiety) and criterion variable (intention). Attitude at pre-test was positively related to intention ($r = .38, p < .0001$). This relationship maintained at the post-test ($r = .44, p < .0001$). PBC at pre-test was positively related to intention ($r = .61, p < .0001$). This relationship also maintained at the post-test ($r = .70, p < .0001$). Uncertainty at pre-test was negatively related to intention ($r = -.25, p < .01$). At post-test, the relationship maintained ($r = -.32, p < .0001$). Anxiety at pre-test was negatively related to intention ($r = -.41, p < .0001$). This relationship continued at the post-test ($r = -.43, p < .0001$).

Correlations among the predictor variables were also examined before performing regression analyses. All variables were significantly correlated with one another at a moderate to high level, with no coefficient size below .32 (see Tables 2 and 3).

Table 2. Descriptive Statistics and Correlations -- Pre-test

	Intention	Attitude	PBC	Uncertainty	Anxiety
Intention		.38**	.61**	-.25**	-.41**
Attitude			.63**	-.38**	-.47**
PBC				-.51**	-.58**
Uncertainty					.62**
Anxiety					
<i>M</i>	5.50	4.67	5.33	3.59	3.01
<i>SD</i>	.64	.69	.78	.90	.85
<i>α</i>	.72	.70	.83	.76	.83

Note: * $p < .05$, ** $p < .01$

Table 3. Descriptive Statistics and Correlations -- Post-test

	Intention	Attitude	PBC	Uncertainty	Anxiety
Intention		.44**	.70**	-.32**	-.43**
Attitude			.47**	-.32**	-.40**
PBC				-.49**	-.55**
Uncertainty					.75**
Anxiety					
<i>M</i>	5.61	4.80	5.41	3.43	3.01
<i>SD</i>	.80	.66	.82	.91	.93
<i>α</i>	.81	.71	.82	.70	.82

Note: * $p < .05$, ** $p < .01$

Hypothesis Testing

Hypothesis one predicted that HCPs' attitudes toward providing patient-centered care to PWID would be negatively associated with uncertainty and anxiety. This hypothesis was supported. A linear regression performed on the pre-test data controlling for sex, age, ethnicity, experience with PWID, and HCP type, indicated that more favorable attitudes toward PWID predicted decreased uncertainty: ($\beta = -.42, p < .0001$; Model $R^2 = .24, F(8, 92) = 3.60, p < .001$). None of the demographic items were significant predictors of uncertainty. More favorable attitudes also predicted decreased anxiety about communication with PWID among HCPs in this study, when controlling for the same demographic variables: ($\beta = -.48, p < .0001$; Model $R^2 = .35, F(8, 93) = 6.30, p < .0001$). In this model, HCP age also predicted anxiety ($\beta = .27, p < .05$).

Hypothesis two predicted that PBC would be negatively associated with uncertainty and anxiety. This hypothesis was supported. A linear regression performed on the pre-test data controlling for sex, age, ethnicity, experience with PWID, and HCP type indicated that higher PBC predicted less uncertainty: ($\beta = -.60, p < .0001$; Model $R^2 = .36, F(8, 96) = 6.76, p < .0001$). None of the demographic variables were significant predictors of uncertainty. Higher PBC also predicted less anxiety among HCPs in this study, when controlling for the same demographic variables: ($\beta = -.65, p < .0001$; Model $R^2 = .47, F(8, 97) = 10.70, p < .0001$). In this model, experience with PWID was a significant negative predictor of anxiety ($\beta = -.22, p < .05$).

Hypothesis three predicted that PBC would moderate the relationship between uncertainty and anxiety. This hypothesis was not supported. A moderated regression

analysis performed on the pre-test data indicated that PBC did not mitigate the effects of uncertainty on anxiety. The regression models predicting anxiety at pre-test and post-test are summarized in Table 4 (pre-test) and Table 5 (post-test). The first regression equation which included uncertainty and PBC, and controlled for sex, age, ethnicity, experience with PWID, and HCP type (block 1), was significant: $R^2 = .57$, $F(9, 95) = 14.07$, $p < .0001$. Uncertainty, PBC, and experience with PWID were significant predictors of anxiety. The second regression model added the interaction term (block 2), which was calculated by centering the two predictor variables and multiplying them together. The second model was also significant: Adjusted $R^2 = .53$, $F(10, 94) = 12.57$, $p < .0001$. Although uncertainty, PBC, and experience with PWID remained significant predictors of anxiety, the moderator variable did not contribute significant variance to the model.

Table 4. Regression Models Predicting Anxiety (H3) -- Pre-test

	Model 1	Model 2
Uncertainty	.39**	.38**
PBC	-.42**	-.42**
Uncertainty X PBC	--	.03
Sex: Male vs. Female	-.09	-.10
Age	.15	.15
Ethnicity: Hispanic	-.01	-.01
Ethnicity: White	-.07	-.08
Type: Nurse	-.10	-.10
Type: Student vs. Practicing	-.14	-.13
Experience w/ PWID (years)	-.21**	-.21**
R^2	.57	.53

Note: * $p < .05$, ** $p < .01$

Table 5. Regression Models Predicting Anxiety (H3) -- Post-test

	Model 1	Model 2
Uncertainty	.58**	.57**
PBC	-.26**	-.26**
Uncertainty X PBC	--	.05
Sex: Male vs. Female	-.10	-.11
Age	.02	.02
Ethnicity: Hispanic	-.03	-.04
Ethnicity: White	.15	.14
Type: Nurse	.04	.05
Type: Student vs. Practicing	-.12	-.12
Experience w/ PWID (years)	-.05	-.05
R^2	.63	.59

Note: * $p < .05$, ** $p < .01$

Hypothesis four predicted that HCPs' uncertainty and anxiety would be negatively associated with their intentions to provide patient-centered care to PWID. This hypothesis was partially supported (see Table 6, Models 1, 2, and 3). A multiple regression performed on the pre-test data indicated that, when controlling for sex, age, ethnicity, experience with PWID, and HCP type, uncertainty negatively predicted intention (Model 1). The model was significant: $R^2 = .27$, $F(8, 96) = 4.47$, $p < .0001$. In this model, uncertainty, age, and being White were significant predictors of intention. A second multiple regression performed on the pre-test data indicated that, when controlling for sex, age, ethnicity, experience with PWID, and HCP type, anxiety also negatively predicted intention (Model 2). The model was significant: $R^2 = .33$, $F(8, 97) = 5.94$, $p < .0001$. In this model, anxiety and being white were significant predictors of intention. To examine the combined influence of uncertainty and anxiety in predicting intention a third

multiple regression was performed on the pre-test data. Uncertainty, anxiety, and the demographic control variables were entered into the model (Model 3). Anxiety negatively predicted intention, but uncertainty did not. The overall model was significant: $R^2 = .35$, $F(9, 95) = 5.69$, $p < .0001$. Anxiety and being White were significant predictors of intention, but uncertainty no longer contributed significant variance to the model. Results of the same analyses with post-test data are summarized in Table 7, Models 1, 2, and 3, respectively.

Table 6. Regression Models Predicting Intention -- Pre-test

	Model 1	Model 2	Model 3	Model 4	Model 5
Attitude	--	--	--	-.04	-.08
PBC	--	--	--	.54**	.45**
Uncertainty	-.26**	--	-.03	--	.05
Anxiety	--	-.39**	-.39**	--	-.21
Sex: Male vs. Female	.05	-.01	.01	.02	.01
Age	-.26*	-.15	-.16	-.11	-.08
Ethnicity: Hispanic	.15	.12	.12	.02	.01
Ethnicity: White	.38**	.33*	.35**	.19	.22
Type: Nurse	.01	-.03	-.03	.04	-.02
Type: Student vs. Practicing	-.25	-.25	-.27	-.18	-.21
Experience w/ PWID (years)	.12	.03	.03	.12	.08
R^2	.27	.33	.35	.41	.43

Note: * $p < .05$, ** $p < .01$

Table 7. Regression Models Predicting Intention -- Post-test

	Model 1	Model 2	Model 3	Model 4	Model 5
Attitude	--	--	--	.12	.16
PBC	--	--	--	.59**	.56**
Uncertainty	-.23*	--	-.01	--	.12

Anxiety	--	-.39**	-.33*	--	-.05
Sex: Male vs. Female	-.01	-.06	-.05	-.02	-.02
Age	-.19	-.13	-.14	.06	.03
Ethnicity: Hispanic	.43**	.38**	.41**	.23*	.27*
Ethnicity: White	.55**	.51**	.56**	.23*	.30*
Type: Nurse	-.01	-.01	-.01	-.01	.01
Type: Student vs. Practicing	-.12	-.14	-.16	-.12	-.15
Experience w/ PWID (years)	.18	.13	.15	.09	.12
R^2	.24	.29	.28	.51	.53

Note: * $p < .05$, ** $p < .01$

Hypothesis five predicted that HCPs' attitudes toward providing patient-centered care to PWID and PBC would be positively associated with their intentions to engage in patient-centered communication with PWID. This hypothesis was partially supported (see Table 6, Model 4). A multiple regression performed on the pre-test data indicated that, when controlling for sex, age, ethnicity, experience with PWID, and HCP type, PBC positively predicted intention, but attitudes did not. The overall model was significant: $R^2 = .40$, $F(9, 90) = 6.65$, $p < .0001$). PBC was a significant predictor of intention, but attitude did not contribute significant variance to the model. Results of the same analysis with post-test data are summarized in Table 7, Model 4.

Hypothesis six predicted that after completing RAFT training, HCPs would report greater intentions to perform patient-centered communication competencies targeted in the training. This hypothesis was supported (Table 8). A paired samples t-test indicated that HCPs in this study reported significantly greater intentions to perform RAFT patient-centered behaviors after participating in the training than before exposure to the training: $t(103) = 2.08$, $p < .05$. Of the four core RAFT behaviors, participants reported the

greatest increase in intentions to perform *respect* behaviors, such as speaking directly to the patient and addressing the patient before the caregiver. Participants also reported significant increases in intention to *follow-up* with patients by checking for understanding, and intention to maximize *time* by using simple terminology and providing complete explanations. Interestingly, participants did not report an increase in intention to *accommodate* PWID by listening to their experiences.

Table 8. Pre-Post Change in Primary Outcomes

	Pre-test	Post-test
Intention	5.48*	5.61*
Respect	5.34*	5.58*
Accommodation	5.85	5.85
Follow-Up	5.14*	5.28*
Time	5.81*	5.92*
Attitude	4.66**	4.81**
PBC	5.32	5.40
Uncertainty	3.60*	3.43*
Anxiety	3.01	3.00

Note: *p < .05, **p < .01

Examination of Research Question

The research question asked how RAFT impacted the predictors of intention (Table 8). A paired samples t-test indicated that overall, HCPs in this study reported a significant improvement in attitudes after participating in the training than before beginning the training: $t(96) = -3.23$, $p < .01$. A paired samples t-test also indicated an overall significant decrease in HCPs' feelings of uncertainty following completion of the training: $t(105) = 2.04$, $p < .05$. Although a similar pattern was noted for anxiety, the

change in mean scores from pre-test to post-test among all HCPs in the sample was not significant: $t(108) = 0.37, p > .05$. Similarly, there was no significant change in PBC from pre-test to post-test, among all HCPs in the sample: $t(102) = -1.25, p > .05$.

Additional Analyses

Predictive Power of Theoretical Model. To test the predictive power of the proposed theoretical model combining interpersonal and behavior change theories to predict intention, a multiple regression analysis was performed on the pre-test data (Table 6, Model 5). The first regression equation included attitude and PBC, and controlled for sex, age, ethnicity, experience with PWID, and HCP type (block 1). This equation was significant: $R^2 = .41, F(9, 89) = 6.92, p < .0001$. PBC was the only significant predictor of intention. The second regression model added uncertainty and anxiety (block 2). The second model was also significant: $R^2 = .43, F(11, 87) = 5.98, p < .0001$. Again, PBC remained the only significant predictor of intention. Interestingly, after attitude and PBC were entered into the model, anxiety was no longer a significant predictor of intention.

The same analysis was performed on the post-test data collected after exposure to RAFT training (Table 7, Model 5). In this analysis the first equation was significant: $R^2 = .52, F(9, 84) = 10.16, p < .0001$. PBC and ethnicity (Hispanic vs. non-Hispanic; White vs. non-White) were significant predictors of intention. The second equation, which added uncertainty and anxiety was also significant: $R^2 = .53, F(11, 82) = 8.28, p < .0001$. Again, PBC and ethnicity were the only significant predictors of intention. Attitude, uncertainty, and anxiety did not contribute significant variance to the model.

Subgroup Differences. To further explore HCPs' intentions to engage in patient-centered communication with PWID, differences in HCP type and ethnicity were examined at pre-test (Table 9) and post-test (Table 10). Specifically, differences between practicing HCPs vs. nursing/medical students, Hispanic vs. non-Hispanic, and White vs. non-White were examined for each variable. An independent samples t-test discovered a significant difference in levels of intention at pre-test, between practicing HCPs and students: $t(105) = 3.02, p < .01$. Students reported greater intention to engage in patient-centered communication with PWID than practicing HCPs. An independent samples t-test also found a significant difference in PBC at pre-test between these HCPs: $t(105) = 3.14, p < .01$. Students reported higher PBC than practicing HCPs. No differences were found for attitude, uncertainty, or anxiety at pre-test. No differences between practicing HCPs and students were discovered at post-test for any of the variables in the study.

Table 9. Subgroup Differences in Variables -- Pre-test

	Provider Type		Ethnicity			
	Comparison # 1		Comparison # 2		Comparison # 3	
	Practicing Provider	Student	Hispanic	Non-Hispanic	White	Non-White
Intention	5.28**	5.65**	5.44	5.57	5.62	5.44
Attitude	4.51	4.77	4.63	4.72	4.81	4.60
PBC	5.04**	5.51**	5.33	5.33	5.42	5.29
Uncertainty	5.57	3.61	3.45	3.76	3.79	3.50
Anxiety	3.00	3.05	2.91	3.16	3.18	2.96

Note: * $p < .05$, ** $p < .01$

Table 10. Subgroup Differences in Variables -- Post-test

	Provider Type		Ethnicity			
	Comparison # 1		Comparison # 2		Comparison # 3	
	Practicing Provider	Student	Hispanic	Non-Hispanic	White	Non-White
Intention	5.56	5.65	5.67	5.54	5.71	5.56
Attitude	4.67	4.89	4.72	4.88	4.97	4.71
PBC	5.35	5.45	4.47	5.34	5.54	5.35
Uncertainty	3.38	3.47	3.36*	3.62*	3.60	3.35
Anxiety	2.94	3.05	2.77**	3.27**	3.32*	2.85*

Note: * $p < .05$, ** $p < .01$

Because the sample predominantly identified as Hispanic or White, these ethnicities were examined. Independent samples t-tests found significant differences between HCPs who identified as Hispanic vs. those who identified as non-Hispanic on uncertainty $t(105) = 2.10$, $p < .01$ and anxiety $t(107) = 2.95$, $p < .01$ at post-test. HCPs who identified as Hispanic reported less uncertainty and anxiety after exposure to RAFT than HCPs who identified as non-Hispanic. No other differences were detected on any of the other variables at pre- or post-test. An independent samples t-test found a significant difference in anxiety between HCPs who identified as White vs. those who identified as non-White at post-test: $t(107) = -2.54$, $p < .05$. HCPs who identified as White reported more anxiety after exposure to RAFT than HCPs who identified as non-White. No other differences were found between White and non-White HCPs at pre- or post-test.

Analysis of Learning Objectives

The standardized summative assessment of learning objectives was examined using frequency counts to determine the percentage of HCPs that responded to each item correctly. Following completion of RAFT training, 96.3% of HCPs ($n = 105$) indicated

that they felt more prepared to develop effective communication in interactions with PWID. Only 3.7% of HCPs (n = 4) indicated that they did not feel more prepared to service PWID after completing training. Also following completion of training, 96.3% of HCPs (n = 105) correctly identified when the RAFT model can be integrated into each stage of the patient's clinical experience.

Assessment of the effectiveness of RAFT's core modules are provided next. With regard to *Respect*, 71.6% of HCPs (n = 78) correctly identified that the best way to communicate with PWID is to *speak directly to the patient and acknowledge the caregiver's insights*. In terms of *Accommodation*, 58.3% of HCPs (n = 63) correctly identified that the best course of action when PWID are having a hard time understanding, is to *slow down and explain the information in a different way, maybe with pictures*.

With regard to *Follow-Up*, 92.7% of HCPs recognized appropriate behaviors. The breakdown is as follows: 66.1% of HCPs (n = 72) correctly identified that it is important to follow-up with PWID both during and after their appointment to (a) *ensure understanding while the patient is still present to avoid emergency room visits, and (b) develop a lasting relationship with them*. An additional 26.6% of HCPs (n = 29) correctly identified one of the two follow-up behaviors.

With regard to *Time*, 100% of HCPs recognized appropriate behaviors to maximize time. The breakdown is as follows: 64.2% of HCPs (n = 70) correctly identified that to maximize time in interactions with PWID, HCPs can (a) *take the time to answer the patient's questions fully and consult the patient's chart to prepare, and (b)*

schedule longer appointment times with PWID if possible. An additional 35.7% of HCPs (n = 39) correctly identified one of the two time behaviors. No HCPs acknowledged that skipping patient questions and saving them for the end of the interaction was an appropriate way to maximize time.

Summary of Results

This chapter reported the results for six hypotheses and one research question. In summary, the results suggest that RAFT training intervention has the potential for success and contributes to HCPs' increased intentions to employ patient-centered communicative behaviors in interactions with PWID (H6). RAFT is successful in achieving its intended learning objectives, as well as improving HCPs' attitudes toward communicating with PWID, and reducing their uncertainty about such interactions (RQ1).

Improving HCPs' attitudes towards communicating with PWID and providing them with additional strategies to be successful in such interactions (PBC) was associated with decreased uncertainty and anxiety about communicating with PWID (H1; H2). In this study, decreased anxiety directly predicted greater intentions, while uncertainty did not directly impact intention (H4). HCPs' perceptions about the ease or difficulty of employing patient-centered behaviors in interactions with PWID (PBC) played a strong role in predicting intention (H5). Although PBC was a strong predictor of intention, it did not moderate the relationship between uncertainty and anxiety. In other words, when HCPs felt uncertain about communicating with PWID, they still experienced heightened feelings of anxiety, even if they felt as though they had the skills and resources to

perform the behavior (H3). In considering all predictor variables and demographic items together, the variables included in the theoretical model accounted for approximately 43% of the variance in intention at pre-test, and 53% of the variance in intention after exposure to RAFT.

CHAPTER FIVE: DISCUSSION

This chapter discusses the results of hypothesis testing and exploratory analyses of this dissertation. The chapter is organized into nine sections. The first section reviews the argument set forth in this dissertation. The second section offers interpretations for the supported hypotheses. The third section offers interpretations for the partially supported hypotheses. The fourth section discusses and interprets the research question. The fifth section provides possible explanations for the unsupported hypothesis. The sixth section discusses implications of the study. The seventh section addresses the study's limitations. The eighth section provides an overview of the future plans for RAFT training and avenues for future research. Finally, a summary of the chapter is provided.

Review of Argument

The purpose of this dissertation was to implement and evaluate RAFT – an evidence-based, theoretically-grounded communication skills training program for HCPs servicing PWID. RAFT was developed with patients, caregivers, and HCPs in mind (Vrijmoeth et al., 2016), and utilized rigorous formative evaluation measures to ensure that the training accurately addressed the complexity of the provider-PWID interaction (Lipsey, 1993; Kreps, 2014; Sidani & Braden, 1998; Sidani & Sechrest, 1999). The modules included in RAFT not only emerged during formative evaluation research, but

they were also conceptually tied to variables in the theoretical framework, which offered additional rationale for the potential effectiveness of the training.

Specifically, HCPs report increased feelings of **uncertainty** and **anxiety** in interactions with PWID. Research suggests that the valence of HCPs' **attitudes** toward PWID is a direct predictor of both uncertainty and anxiety (Gudykunst, 1985). Many HCPs who service PWID regularly and have established relationships with their patients still report increased anxiety in these interactions even though uncertainty is low (Emold et al., 2011; Wilkinson et al., 2013), which is likely explained by low **PBC** (Ajzen, 1985). HCPs may try to manage heightened levels of uncertainty and anxiety by categorizing PWID as an out-group and diverging their communicative behaviors, rather than converging their behaviors in the form of **patient-centered communication** (Berger & Calabrese, 1975; Giles et al., 2007). While many HCPs recognize the value of engaging in patient-centered communication with PWID and have positive attitudes toward doing so, many feel so overwhelmed that they are not able to follow through (Flynn et al., 2015), which explains how **intention** to engage in patient-centeredness is likely predicted by a combination of HCPs' attitudes and PBC (Ajzen, 1985).

This dissertation answers calls to increase the quality of healthcare for PWID through the development of targeted communication skills training curriculums that teach specialized skills that HCPs can apply in a variety interactions with PWID (Ryan & Scoir, 2014; Snell et al., 2010; Tuffrey-Wijne, Hollins, & Curfs, 2005; Wilkinson, Dreyfus, Bowen, & Bokhour, 2013). This dissertation also answers calls for health communication interventions to employ evidence-based and theoretically-grounded

curriculum (Brown & Bylund, 2008; Faes et al., 2010; Kreps, 2014; Lipsey, 1997; McGilton et al., 2005). In addition to testing the effectiveness of RAFT, this dissertation also tested the predictive power of a theoretical model that combines elements of interpersonal communication (AUM, CAT) and behavior change (TPB) theories to better understand HCPs' motivations for engaging in patient-centered communication in highly specialized interactions with PWID.

Supported Hypotheses

The first supported hypothesis predicted that HCPs' attitudes toward providing patient-centered care to PWID would be negatively associated with uncertainty and anxiety (H1). In other words, HCPs would be less likely to experience uncertainty and anxiety about providing patient-centered care to PWID if they hold more favorable attitudes toward communicating with PWID, and would be more likely to experience heightened uncertainty and anxiety if they possessed less favorable attitudes toward doing so. Although this prediction was supported, results associated with the re-specification of the proposed theoretical model also provide evidence to suggest that the relationships between attitude and uncertainty, and attitude and anxiety may also hold true in the reverse, where uncertainty and anxiety may lead to attitude. These results confirm a relationship between attitude and uncertainty/anxiety, which provides support for the use of AUM in understanding, explaining, and predicting interpersonal interactions between HCPs and PWID. Given the cross-sectional nature of the regression analyses, the results of this study can be considered as consistent with the AUM postulate that attitudes serve as background variables that shape individuals' perceptions of

uncertainty and anxiety (Gudykunst, 1985). At the same time, this result is also consistent with TPB, which would consider uncertainty and anxiety to be antecedents of attitude. The pattern of associations in this study seems to suggest stronger evidence for the latter, when AUM and TPB variables are considered together.

Given these results, it is important for HCPs to understand that their attitudes can affect their subsequent performance in the provider-patient interaction. While research suggests that many HCPs hold favorable attitudes toward communicating with PWID (Lenox et al., 2000), research also suggests that there is a great majority of HCPs who feel less positive about servicing PWID (Iezzoni, 2006), mainly those with either no experience with PWID (McManus et al., 2010) or those with negative prior experiences (Chew et al., 2009; Gibbs et al., 2008; Wilkinson et al., 2012). This result is perhaps most important for those HCPs that hold more negative attitudes toward interacting with PWID. They should note that their attitudes are related to the level of uncertainty and anxiety they experience, and that improving their perceptions about PWID should help them to also reduce their uncertainty about such interactions, as well as the amount of anxiety they experience. These HCPs can start to improve their attitudes by keeping an open mind when it comes to PWID, recognizing that every patient is different, and avoiding stereotypes that group PWID as one “type” of patient, such as those in Wilkinson et al.’s (2012, 2013) study that described PWID as “beautiful people,” and “simple, pleasant, and child like.” Moreover, HCPs should not be discouraged by a negative experience, since increased exposure to PWID has been found to significantly improve HCPs’ attitudes (McManus et al., 2010). If HCPs do experience a negative

interaction, they should handle it on a patient-by-patient basis, communicating with both the patient and caregiver (if applicable), to understand why the patient reacted in a negative way and what they can do differently next time to make the patient more comfortable (Chew et al., 2009; Iezzoni, 2006). By integrating this information into the care process, HCPs and patients should experience more effective interactions (Duggan et al., 2010). This process is important as varying degrees of severity of intellectual disabilities can make it especially difficult to predict the behavior of PWID as a whole (Chew et al., 2009).

The second supported hypothesis predicted that PBC would be negatively associated with uncertainty and anxiety (H2). In other words, HCPs who felt as though providing patient-centered care to PWID was easier to do would experience less uncertainty and anxiety about such interactions, and HCPs who believed it to be more difficult, would experience heightened uncertainty and anxiety when working with PWID. This result was expected, given that in interactions with PWID it is not uncommon for HCPs to feel like they are trying to provide care to patients about whom they do not feel knowledgeable, whom they perceive as different and somewhat intimidating, and whom they lack appropriate resources to support (Wilkinson et al., 2012). The results of this hypothesis also indicated that more experience (years) servicing PWID predicted less anxiety.

This result offers a way for HCPs to decrease feelings of uncertainty and anxiety not only through improving attitudes (as noted by the first supported hypothesis), but also through decreasing perceptions of difficulty in communicating with PWID. Research

suggests that 80% of HCPs believe it is harder to provide care to PWID than those without disabilities (Lennox, 1997), due to limited time and barriers to communication (Stein, 2000; Vrijmoeth et al., 2016; Wilkinson et al., 2013). Therefore, HCPs should perceive interactions with PWID to be easier and more manageable if they are able to overcome these problems. HCPs can develop ways to maximize time with PWID by getting to know their patients on a deeper level to understand their unique needs, and how to accommodate them for more effective interactions. As a result, HCPs should experience decreased feelings of uncertainty and anxiety with these patients, as evidenced by the result that more experience with PWID predicted less anxiety in this study.

This result also provides support for the argument that HCPs' experiences of anxiety are not only related to uncertainty (as suggested by AUM), but are also predicted in part by PBC. As such, this result helps extend AUM to explain why HCPs who report low uncertainty about PWID still report experiencing increased anxiety in such interactions (Emold et al., 2011; Wilkinson et al., 2013). This study helps us understand that HCPs who still experience heightened anxiety even when uncertainty is low, likely perceive communication with PWID to be difficult because of perceptions of limited resources. HCPs can work to decrease their perceptions of difficulty by seeking out new information and strategies, like those provided in training, to prepare them for interactions with PWID. Many HCPs feel as though they are "operating without a map" in interactions with PWID (Wilkinson et al., 2012), so the more they feel like they have the tools and resources to effectively communicate with PWID, the less anxiety they will experience in those provider-patient interactions.

The third supported hypothesis predicted that after completing RAFT training, HCPs would report greater intentions to perform patient-centered communication competencies targeted in the training (H6). This hypothesis was intended to validate RAFT training as an effective tool to increase HCPs' intentions to provide patient-centered care to PWID. The finding that intentions strengthened after exposure to RAFT confirms that communication skills trainings can be used to successfully alter HCPs' behavior and helps HCPs achieve higher quality patient-centered communication (Brown et al., 2010; Cegala & Broz, 2002). Given that RAFT promotes learning at different levels ranging from knowledge and comprehension to synthesis and evaluation, this result also supports suggestions that a combination of teaching modalities and learning strategies are most effective in changing HCPs' behavior (Bonvicini et al., 2009; Makoul, 2001). It also confirms the important role that formative evaluation research plays in the effectiveness of health communication interventions (Kreps, 2014). The development of RAFT followed Vrijmoeth et al.'s (2016) suggestion that PWID, their caregivers, and HCPs' perspectives be considered in the development of interventions for HCPs on this topic, which likely added to its potential for success. In this study the formative research process provided an evidence-base, which created a strong foundation for a successful intervention. Although the evidence of the intervention's success in this study is limited and short term, it does provide initial support for the continued use of RAFT as a tool to help increase HCPs' intentions to engage in patient-centered communication with PWID.

In addition to the finding that HCPs' intentions strengthened after exposure to RAFT, differences in intention were detected between practicing HCPs and

nursing/medical students in this study. Students came into the training with significantly greater intentions for patient-centered communication with PWID than did practicing HCPs. This difference subsided after exposure to RAFT. The initial difference supports prior research that less experienced HCPs may be more open to adopting new communication skills than their more experienced counterparts (Kramer et al., 2004; Pfeiffer, Madray, Ardonlina, & Willms, 1998). For example, recently Green, Gonzaga, Cohen, and Spagnoletti (2014) found that residents are quick to adopt the use of plain language in clinical practice following patient-centered communication training.

Researchers have cited a recency effect in explaining these types of patterns, pointing out that students generally receive communication skills training in the early years of their medical education, and if such training is not reinforced throughout the continuum of medical education and continuing education, HCPs may “unlearn” such skills (Craig, 1992; Evans, Coman, & Goss, 1996). For this reason, it is important that communication skills continue to be incorporated into continuing education for more experienced HCPs through interventions like RAFT. The results obtained from this study suggest that both students and practicing HCPs who may not have been exposed to communication skills training since earning their degrees, should experience increased intention following exposure to RAFT.

Partially Supported Hypotheses

The first hypothesis that was partially supported predicted that HCPs’ uncertainty and anxiety would be negatively associated with their intentions to provide patient-centered care to PWID (H4). The results suggest that while anxiety negatively predicted

intention, uncertainty did not. This finding was unexpected given that AUM suggests that when individuals experience heightened uncertainty and anxiety levels, they will not be motivated to communicate (Gudykunst, 1985). Based on this information it would make sense that higher levels of uncertainty and anxiety would predict less intention to engage in patient-centered communication with PWID, while lower uncertainty and anxiety would predict greater intention. There are a few possible explanations for why uncertainty did not negatively predict intention.

One possible explanation is that uncertainty does predict intention, but only through its effect on anxiety. Data to support this claim is offered in the presentation of results for H4. It is important to consider when HCPs are most likely to experience uncertainty and anxiety about communication with PWID. Uncertainty refers to HCPs' cognitive perception of doubt in terms of their ability to predict outcomes of interactions with PWID (Berger & Calabrese, 1975). Based on this conceptualization of uncertainty, it would make sense that HCPs experience uncertainty prior to the actual interaction and in preparing for or thinking about how interactions with PWID may evolve. That anticipation of the behavioral engagement could lead to increased anxiety, which in turn may be reinforced or mitigated by actual experience. Research suggests that HCPs may unintentionally communicate anxiety to patients (Brillhart et al., 1990; Duggan et al., 2010; Thomas et al., 2003), leading to negative reactions from patients. When HCPs associate negative valence to actual experiences with PWID, their intentions are likely to be impacted (Ajzen, 1985).

A second possible explanation for why this prediction did not hold true for uncertainty involves a combination of AUM and CAT to explain how identity perceptions may factor in. First, AUM purports that when uncertainty falls within the allowable threshold, HCPs will attempt to reduce uncertainty about PWID by categorizing them as either part of an in-group or out-group. When uncertainty about interactions with PWID is higher, HCPs are likely to categorize these patients as an out-group (Giles et al., 2007; Gudykunst, 1985). Research on HCPs' interactions with PWID supports this claim, suggesting that HCPs often see PWID as different from themselves (Iezzoni, 2006; Siasoco, 2014) and either associate positive or negative valence to describe the out-group as "simple" and "beautiful" (Wilkinson et al., 2013), or as "disruptive," "problematic," and "embarrassing" (Lennox & Kerr, 1997). Second, CAT explains how HCPs can either converge their behaviors to meet their audience's needs (i.e., patient-centered behaviors), or diverge their behaviors to emphasize differences between them and PWID. CAT goes on to explain that HCPs' motivations to converge their behaviors are based on their desire to gain approval or liking from their audience (Giles & Ogay, 2007). Taken together, AUM and CAT may help explain why uncertainty did not predict intention in this study. If HCPs attempt to reduce their uncertainty about PWID by categorizing them as an out-group (AUM), it would make sense that they would not converge their behaviors by engaging in patient-centeredness, because they do not have a desire to gain the approval or liking of individuals that they consider to be part of an out-group (CAT). This explanation is supported by prior research that suggests HCPs tend to be more patient-centered with patients whom they perceive to be more like

them – who are described as better communicators, more satisfied, and more compliant (Street et al., 2007). This possibility would suggest that uncertainty is related to intention, but that the effects are moderated by identity perceptions.

The second hypothesis that was partially supported predicted that HCPs' attitudes toward providing patient-centered care to PWID combined with PBC would be positively associated with their intentions to engage in patient-centered communication with PWID (H5). In other words, HCPs with more favorable attitudes, and who perceived communicating with PWID to be easier, would be more inclined to engage in patient-centered behaviors with PWID. In this study, attitude was not a significant predictor of intention at pre- or post-test. This finding was unexpected since attitude and PBC have emerged as important predictors of behavioral intention in a variety of contexts (Ajzen, 1985). It is important to note that TPB does not suggest that attitude has to be a predictor of intention, but rather draws attention to the relative weights of attitude, subjective norm, and PBC, indicating that they likely vary across contexts. The non-significant result for attitude in this study highlights an important finding with respect to patient-centered behaviors in the context of PWID. It suggests that HCPs' intentions to engage in patient-centered behaviors with PWID are primarily driven by their perceptions about the ease or difficulty of doing so. Therefore, training interventions that teach HCPs necessary skills and focus on specific, targeted strategies for effective interactions with PWID will be most successful in achieving behavior change. Because HCPs cite barriers to communication and lack of time as consistent obstacles in interactions with PWID (Dunkley & Sales, 2014; Holtrop & Jordan, 2010; Stein, 2000; Street et al., 2007;

Wilkinson et al., 2013), interventions should focus on training HCPs how to overcome these perceived barriers and maximize time to feel more confident. Although more favorable attitudes toward communicating with PWID might help HCPs reduce their uncertainty and anxiety in interactions with PWID, the result of this hypothesis clarifies that more or less favorable attitudes provide no direct indication that HCPs will engage or not engage in patient-centered behaviors with PWID.

Research Question

The research question asked how RAFT impacted the predictors of intention. The exploratory analysis in this study found a significant improvement in attitude, and a significant decrease in uncertainty following exposure to RAFT training. However, since attitude did not predict intention in this study, the results pertaining to RAFT's influence on uncertainty, anxiety, and PBC may be more telling. Both the attitude and uncertainty variables were incorporated into the design of RAFT to acknowledge the complexity of the real-world situations where HCPs communicate with PWID, as suggested by research on theory-driven interventions (see Lipsey, 1993; Sidani & Braden, 1998; Sidani & Sechrest, 1999). Caregivers who were interviewed during the formative research process continually noted HCPs' attitudes toward PWID as barriers to effective communication. Similarly, because interactions with PWID are inherently different from those with patients without intellectual disabilities (Vrijmoeth et al., 2016), HCPs often cite feelings of uncertainty about these interactions, and even feel like they need a "map" to guide them (Wilkinson et al., 2012). This type of uncertainty has been cited as a barrier to achieving effective communication (Gudykunst, 1985). Given this information, it is

encouraging that RAFT was successful at improving attitudes and reducing uncertainty among HCPs – as they are two of the main barriers to effective communication in interactions with PWID. Moreover, researchers blame a lack of sufficient training about PWID for HCPs’ negative attitudes toward and uncertainty about communication with PWID (Jain, 2006; Martin et al., 2005; Mencap, 2011; Saketkoo et al., 2004). Therefore, these results are encouraging as they not only provide evidence to support the continued use of RAFT as a targeted curriculum for HCPs servicing PWID, but they also provide evidence that RAFT is successfully targeting two of the key barriers that prior research, as well as formative research in this study identified in communication between HCPs and PWID.

This study found no significant overall change in HCPs’ anxiety as a result of exposure to RAFT. One possible explanation for this result is that RAFT training affected anxiety in two countervailing ways. It is possible that RAFT did reduce HCPs’ anxiety by enhancing their skills, but that those effects were mitigated by the new anxiety created by exposure to information that hadn’t been considered before. This pattern might explain why there was no detectable change in anxiety after exposure to the training. It is possible that the more HCPs learned about communication with PWID and the important role that they play as HCPs, the more pressure they experienced to perform successfully in these interactions. For example, Haskard et al. (2008) found that although communication skills training in their study improved physicians’ communication in the medical visit, the training may have also introduced some added pressures for physicians, as they reported an increase in stress and decrease in satisfaction with the interpersonal aspects of their

professional lives. Stress and satisfaction for physicians who did not participate in their training, remained unchanged. While this interpretation could highlight a potential flaw in the training, it is not an uncommon finding when individuals are exposed to any type of new information previously outside their realm of thought.

Another possible reason why anxiety did not decrease after exposure to RAFT could be due to the length of the training. The session in this study lasted approximately two hours. Although the sessions included time for experiential learning in the form of discussions, role-play, and case studies, participants were not able to practice their skills with PWID. Perhaps HCPs need more time to practice the skills they learn and experience how they function in actual interactions with PWID or even standardized-PWID before they are able to reduce their anxiety. Research on communication skills training suggests that the most effective way for HCPs to learn communication skills is through experiential learning where they practice their skills in actual or simulated interactions with patients and receive feedback on their performance (Aspegren, 1999; Howells, Davies, & Silverman, 2006). Specifically, Gaffney et al. (2016) explains that HCPs who are able to practice their skills regularly are three times more likely to maintain such behaviors in the long run. Similarly, TPB explains that direct behavioral experience impacts intention, and also informs perceptions of PBC (Ajzen, 1985, 1988), so perhaps direct experience plays a greater role in predicting anxiety as well. This is a likely possibility, given that experience (years) servicing PWID negatively predicted anxiety among HCPs in this study.

A final potential explanation for why no change in anxiety was detected could be related to a lack of significant change in PBC from pre- to post-test. Similar to anxiety, the study found no significant overall change in PBC as a result of exposure to RAFT. In other words, after completing RAFT training HCPs did not perceive patient-centered communication with PWID to be any easier or harder, although mean scores do suggest a downward trend. This finding may raise a red flag at first, because RAFT training provides targeted strategies to engage HCPs in patient-centered-communication with PWID – which should increase their PBC. However, it should be noted that the training does not focus on overcoming communication barriers related to policy or organizational norms. It is possible that in addition to their perceptions of control related to personal skillset and ability, HCPs also consider a number of professional and/or organizational factors in their assessments of PBC for communication with PWID. For example, HCPs may heavily weigh their perceptions about barriers influenced by the health context where they work (e.g., oncology, imaging, primary care, etc.). Flynn et al. (2015) found that HCPs in oncology settings were less confident in their ability to communicate with PWID. They explained that HCPs in oncology settings are more likely to experience stress and burnout so it was not surprising that they felt additionally burdened by a cancer-PWID.

It is also possible that in making assessments about PBC, HCPs heavily weigh constraints related to the organizational structure where they work— such as whether administrators and other HCPs will do their part to enact RAFT at other stages of the patient experience. In this study, HCPs were trained in all modules, regardless of their

specialty. For example, physicians and nurses were educated about how they can personally enhance communication with their patients, but also how their front office staff plays an important role in setting the stage for effective interactions, and vice versa. If physicians or nurses, for example, perceived that their reception staff would not respond favorably to making extra accommodations for PWID, they may view this as an additional barrier to successfully implementing RAFT in the environment where they work. Research suggests for example, that HCPs who handle the hospital admission process expected PWID to have increased support needs (Hemsley & Balandin, 2014). Lewis and Stenfort-Kroese (2010) found that HCPs were more likely to separate PWID from other patients by placing them in a separate waiting area. If physicians and nurses in the present study perceived that their office staff would treat PWID in a similar manner, it would suggest that even when HCPs feel confident in their own skillset and abilities to communicate with PWID, they may perceive other communication barriers to be too big or outside of their control. This explanation highlights the fact that RAFT is not a one-stop solution for all problems associated with provider-PWID communication. It only addresses communication problems on the individual level, and should be implemented alongside other structural interventions at higher levels. Regardless of the reason why no change in PBC was detected in this study, it should be noted that previous research found that HCPs who experienced reduced self-efficacy after communication skills training (a concept similar to PBC), actually developed a stronger belief that the course improved their skills (Gulbrandsen, Fosslie Jansen, & Finset, 2009).

While no change in PBC was detected among HCPs as a whole in this study, significant differences in PBC were detected when HCPs were grouped by type. Practicing HCPs with inevitably more experience communicating with patients in general, came into the training with perceptions that communicating with PWID would be easier, while nursing and medical students perceived that communicating with PWID would be more difficult. This difference subsided after exposure to RAFT. The initial difference is not surprising, given that practicing HCPs are likely already comfortable communicating with patients and are just learning more specialized skills to apply to a subpopulation of patients. Similar to physicians in Gulbrandsen, Jensen, Finset and Blanch-Hartigan's (2013) study, it is likely that practicing HCPs in this study were able to relate the training's content to their experiences in practice, thus making the material more realistic and perhaps even validating their pre-course communication skills. For students who may already perceive communicating with patients in general as difficult combined with their other responsibilities, the thought of communicating with PWID may be even more daunting, especially due to their limited experience. TPB research supports this explanation, explaining that perceptions about the ease or difficulty of performing a behavior are formed based on a combination of anticipated barriers and past experience (Ajzen, 1988). Students with little to no experience in this study are likely basing their perceptions of PBC solely on anticipated barriers, which explains why they perceived communicating with PWID to be more difficult than practicing HCPs.

Unsupported Hypothesis

One hypothesis in this study was not supported. It predicted that PBC would moderate the relationship between uncertainty and anxiety (H3). AUM explains when HCPs experience heightened uncertainty they also experience heightened anxiety. The hypothesis predicted that although HCPs may feel uncertain about interactions with PWID, if they also believed that they had access to the necessary tools and resources (PBC), they would be less likely to experience anxiety. The data did not support this prediction. Although PBC was negatively associated with anxiety, there was no interaction between PBC and uncertainty. One possible explanation alluded to in the earlier discussion about anxiety, may be that direct behavioral experience has a greater influence on anxiety than other factors, including PBC. If this were the case, it would be possible that even perceptions of being prepared to communicate with PWID would not reduce anxiety, and that only by experiencing successful interactions with PWID would anxiety be reduced.

Implications for Theory and Practice

This dissertation holds several implications for the communication discipline. First, implications about the predictive power of the theoretical model are discussed. Second, specific implications for the health and instructional contexts are offered.

Theoretical Model. The theoretical model proposed in this dissertation combined elements of interpersonal and behavior change theories to understand, explain, and predict HCPs' patient-centered communication with PWID. The model suggested that in the provider-PWID context, uncertainty and anxiety (AUM) be considered as direct

predictors of intention, in addition to attitude and PBC (TPB). Attitude and PBC were also examined as indirect predictors of intention. The results indicated that PBC was the only significant predictor of intention in the proposed hierarchical model. Upon further examination of the role of AUM variables in predicting patient-centered communication with PWID, the results indicated that uncertainty and anxiety may occur prior to TPB variables, supporting TPB suggestions that variables can only impact intention through attitude, subjective norms, or PBC. Although this possibility challenges the proposed theoretical model it can be explained by TPB, which considers attitude, norm, and PBC as the primary determinants of intention. Examining the model in the way also helps explain how uncertainty and anxiety function with TPB variables to predict intention for patient-centered communication with PWID.

In examining the role of HCP demographics in predicting intention within the proposed theoretical model, three findings were noteworthy. First, the results of the pre- and post-test analyses conclude that HCP type (e.g., physician, nurse, student, social worker, etc.) does not uniquely impact intention when considering AUM and/or TPB variables. This result is encouraging, because it provides initial support for the idea that a variety of HCP types can benefit from training that encompasses the continuum of the patient's experience. RAFT differs from other PWID trainings because it targets all HCPs that provide care to patients along the continuum, from receptionists at check-in, to technicians performing tests, and physicians conducting exams and offering treatment recommendations. It is the first of its kind to bring together a variety of HCP types for training, so discovering that HCP type did not have an impact on HCPs' intentions for

patient-centered communication in this study is promising for the continued use of RAFT. Just because HCP type did predict not intention in the model, it does not mean that HCPs do not differ on their reasons for intending or not intending to engage in patient-centered communication with PWID. Trainers who administer RAFT should acknowledge that specific modules may be more applicable and beneficial to HCPs, based on their specific role in the continuum of the patient's experience.

Second, the results of the pre- and post-test analyses conclude that HCPs' ethnicities did have a unique impact on intention, but these results differed from pre- to post-test. In the pre-test, Caucasian/White ethnicity predicted increased intention in models where AUM variables (uncertainty and anxiety) were present. When TPB variables (attitude and PBC) were present in the model, even when accompanied by uncertainty and anxiety, ethnicity was no longer a significant predictor of intention. In the post-test, Caucasian/White ethnicity predicted intention in all models where AUM variables were present, even when TPB variables were also present. These results suggest that in the context of provider-PWID communication, when examining the effects of uncertainty and anxiety on intention, ethnicity may also be an important variable to consider. In this study, compared to other ethnicities, Caucasian/White HCPs indicated stronger intentions than HCPs who identified as any ethnicity other than Caucasian/White. Taken together, it suggests that Caucasian/White HCPs may weigh uncertainty and anxiety more heavily than those of other non-Hispanic ethnicities in decisions about communication with PWID.

Additionally, Hispanic/Latino ethnicity predicted intention in all models where AUM and variables were present even when TPB variables were introduced, but only in the post-test analysis. This result strengthens the possibility that in the presence of uncertainty and anxiety, ethnicity plays an important role in predicting intention. Given that this result is only true for the post-test, it also suggests that RAFT impacts Hispanic/Latino HCPs' perceptions of intention (or predictors of intention) differently than those who do not identify as Hispanic/Latino. Results of the subgroup analyses support this explanation. HCPs who identified as Hispanic/Latino reported lower uncertainty and anxiety levels after exposure to RAFT than HCPs who identified as any non-Hispanic ethnicity. Given their lower uncertainty and anxiety levels, it makes sense that these HCPs also reported greater intentions than HCPs who did not identify as Hispanic/Latino.

Third, prior experience with PWID did not predict intention in any of the models in the pre- or post-test analyses. However, prior experience with PWID was a strong predictor of anxiety, which may have indirectly predicted intention. Regardless of the years of experience that a HCP has servicing PWID, HCPs' perceptions about the ease or difficulty of such communication plays an important role in predicting their intentions for patient-centered communication with PWID. These results are encouraging, because they suggest HCPs are no more or less likely to engage in patient-centered communication with PWID based on prior experience with PWID. These results also suggest that patient-centered communication with PWID is a skill that can be taught to HCPs, regardless of prior experience with this population of patients.

Overall, the results obtained in testing the theoretical model provide important implications for the continued use of RAFT training. Before exposure to RAFT (pre-test), the combined theoretical model accounted for 43% of the variance in intention. Following exposure to RAFT (post-test), the same model accounted for 53% of the variance in intention. Ethnicity emerged as a significant predictor of intention, and PBC strengthened as a predictor of intention after exposure to RAFT. This result suggests that RAFT may impact HCPs of different ethnicities differently. It also suggests that RAFT successfully trained HCPs in targeted strategies to reduce the perceived difficulty of patient-centered communication with PWID. Although the AUM variables uncertainty and anxiety did not directly predict intention in the combined theoretical model, there is evidence to suggest that they may indirectly impact intention through TPB variables, and should continue to be considered in training curriculums on this topic.

Health Communication Implications. The results of this dissertation confirm that HCPs experience unique challenges in interactions with PWID, which impact the quality of care that these patients receive. Specifically, HCPs' perceptions about their PBC and experience of anxiety have direct implications for whether or not they engage in patient-centered communication with PWID. HCPs can reduce their anxiety by developing more favorable attitudes toward interactions with PWID, mainly through avoiding stereotypes (Wilkinson et al., 2012, 2013), not basing their overall opinions on a negative experience (Chew et al., 2009; Wilkinson et al., 2012), and increasing their exposure to PWID (McManus et al., 2010). HCPs can also reduce their anxiety by

learning about targeted strategies to help them improve communication with PWID, for more effective interactions.

Although feelings of uncertainty about interactions with PWID were not directly linked to intention, they were strongly associated with HCPs' anxiety in this study. HCPs should recognize that it is not uncommon to experience increased uncertainty in interactions with PWID, because such interactions are inherently different from typical provider-patient interactions that they likely experience on a day-to-day basis. For example, PWID may be accompanied by a caregiver (Vrijmoeth et al., 2016; Wilkinson et al., 2013), or require augmentative or alternative communication strategies in these interactions (Chew et al., 2009). The more HCPs can learn about PWID and their unique needs, as well as how to include caregivers in the traditionally dyadic provider-patient interaction (Epstein & Street, 2007; Street & DeHaes, 2013), the less uncertain they should feel about how such interactions will evolve in the future.

This dissertation found that overall, HCPs' intentions to engage in patient-centered communication with PWID can be increased in part, through targeted communication skills training interventions. Researchers have continually cited the importance of increasing the quality of healthcare for PWID through the development of evidence-based interventions aimed at HCPs (Snell et al., 2010; Ryan & Scoir, 2014; Tuffrey-Wijne et al., 2005; Wilkinson et al., 2013). Researchers suggested that such interventions should focus on topics like improving attitudes, developing effective communication with PWID, and increasing awareness of PWID's unique needs. Yet, few of these suggestions were accompanied by concrete ways to address these issues

(Hemsley & Balandin, 2014). This dissertation showed that RAFT training can be an effective tool to tackle these issues to improve HCPs' attitudes, decrease their uncertainty, and increase their intentions to provide quality healthcare to PWID. With regard to health communication researchers' concerns about the proper evaluation of such interventions, the results of this dissertation suggest that recommendations to consider rigorous formative evaluation and theoretical linkages in the development of interventions (Brown & Bylund, 2008; Kreps, 2014) are useful, and taking such measures can produce a more comprehensive set of results.

Instructional Communication Implications. The results of this dissertation suggest that medical education focus on training HCPs about different populations of patients, to help them understand that common processes like obtaining a medical history or performing a physical exam require different communication strategies with different patients. Medical education should also teach HCPs that personal factors and opinions such as how they think about patients can have direct implications for the quality of care they provide to them. In this study, HCPs who had less favorable attitudes, less confidence in their abilities, and increased uncertainty and anxiety about interactions with PWID, were less likely to engage in patient-centered communication. This finding is unsettling, given that patient-centered communication allows HCPs to more fully understand their patients' experiences of health (Dean & Street, 2016), and has been associated with improved health outcomes and more positive provider-patient relationships (DiBlasi et al., 2001; Epstein & Street, 2007; Schneider et al., 2004). Thus it

is important that education curriculums focus on improving attitudes and PBC, and decreasing uncertainty and anxiety among HCPs in the context of PWID.

This study also provided evidence to support Keir and Wilkinson's (2013) claim that, "communication skills training is not only about addressing communication problems, but also assisting experienced, high-level communicators to further extend and refine their skills" (p. 624). Although HCPs in this study were no more or less predisposed to engage in patient-centered communication with PWID based on their experience, this study highlighted the positive effects of RAFT communication skills training for HCPs of all experience levels. These results support the need for HCPs to take part in continued education focused not just on the biomedical and technical aspects of healthcare (Cegala & Broz, 2002), but also on communication, to ensure quality healthcare for their patients.

Finally, with regard to the assessment of RAFT's learning objectives, this dissertation found that HCPs that completed RAFT training felt more prepared to communicate with PWID. Participants' responses to assessment items pertaining to each of the core modules indicated that RAFT effectively taught participants how to incorporate each of the patient-centered competencies into interactions with PWID. These results provide evidence to support the use of scaffolding in the development of application-based activities in instructional curriculums. In this study, formative assessment methods such as personal reflections, group-based discussion, role-play, and case-study analysis included in the RAFT curriculum were successful at teaching HCPs how to apply RAFT competencies in practice. The mastery of such competencies was

evident by participants' correct responses to summative assessment items included in the post-test. Additionally, feedback from HCPs suggested adding components that further target experiential learning such as video-taped provider-PWID interactions, or testimony from patients and their caregivers.

Limitations of the Study

In interpreting the results of this dissertation, it is important to note some limitations. First, the small sample size should be noted. Although 144 HCPs participated in RAFT training, only 109 produced usable data that was included in the analyses. Out of these 109, some participants skipped a question or two on some of the measures, resulting in the list-wise deletion of those cases in some analyses. Non-significant results should be interpreted with caution. It is possible that proposed predictors of intention (other than PBC) are significant in the proposed theoretical model, but that they were not detected in this study due to the small sample.

Second, although the sample included a range of HCP types, nurses and nursing students comprised a majority of the sample. Thus, it is possible that the findings are not generalizable to other HCP types who are trained in different educational environments. For example, while nurses receive more training in bedside manner and communication with patients (Flicek, 2012; Koven, 2012; Wittenberg-Lyles et al., 2010), physicians are trained more like soldiers in that they learn how to suppress their emotions so that they can perform their jobs objectively (Groopman, 2007; Korsch & Harding, 1997). These varying degrees of thinking may have impacted how HCPs viewed patient-centered communication.

Third, although the trainings and subsequent data collection occurred at various locations, all data was collected in the south central part of Texas. Because this dissertation was funded in part by Special Olympics Texas, the organization preferred that all pilot testing of the training curriculum occur within Texas. This is likely why the sample was most highly represented by HCPs who identified as Hispanic/Latino. Significant results for this demographic should be approached with caution.

Fourth, this study employed a non-traditional measure of attitude, which may have impacted the lack of significant results detected for attitude in predicting intention. This study utilized an existing attitude measure specifically designed for attitudes as they relate to PWID. Because the original measure had been validated for use with HCPs the measure was deemed appropriate for use with the sample in the current study. Although TPB suggests that attitude instruments measure attitudes toward specific behaviors, the existing items were determined to fit within the four patient-centered behavior categories in this study – respect, accommodation, follow-up, and time. Additionally, the measure was adapted to focus on attitude toward the behavior of engaging in patient-centered communication with PWID, rather than attitude towards the patient. Still, the results surrounding the relationship between attitude and intention should be approached with caution.

Fifth, the reliability and validity of the measures should be taken into consideration when interpreting the results. Although the alphas were adequately reliable ($\geq .70$), none of the measures were highly reliable ($\geq .90$) in this study. Although various items were reverse coded throughout the pre- and post-tests to ensure consistency in

participant responses, it is possible that participants experienced fatigue while completing the measures causing inconsistencies in their responses. It is also important to consider whether the measures adequately measured the variables in the model. Specifically, it is possible that there was not enough differentiation between the measure of uncertainty and PBC. Uncertainty was measured in terms of confidence in one's ability to predict how PWID will behave or react, as suggested by the conceptual definition utilized in this dissertation. However, the argument could be made that confidence is too closely related to PBC to make any distinction between the two. This issue could have impacted the results obtained in connection with these variables.

Sixth, due to the short amount of time between pre-and post-test data collection, it is possible that social desirability bias influenced significant changes that were detected in the variables. Because participants completed the pre-test immediately prior to the intervention and the post-test immediately following the intervention, participants may have remembered how they responded to the items in the pre-test and adjusted their responses accordingly in the post-test, based on what they thought the trainer hoped to accomplish with the intervention.

Seventh, due to time constraints and the amount of time that participants had available to participate in this training during the workday, summative assessment measures only represented lower levels of learning as opposed to higher levels. Although the post-evaluation measures clearly assessed each of the core modules in the training, they were formatted as multiple-choice questions rather than open response or behavior-based measures. However, it should be noted that each question was focused on the

application of each module rather than definitions. Additionally, although summative assessment in this study did not reflect higher levels of learning such as synthesis and evaluation, formative assessment that occurred throughout the training did require participants to demonstrate this type of learning. For example, discussions, role-play activities, and a case study required participants to enact patient-centered behaviors in hypothetical situations, identify areas where RAFT is applied or could be applied, and combine different elements of RAFT to describe an effective interaction between HCPs and PWID. Including the case study in the post-test as an added assessment method could have solved this limitation, but the researcher concluded that it was important for the trainer to unpack the case study with participants during training to ensure that the activity was most effective.

Eighth, although this study measured behavioral intention, which is the strongest predictor of behavior, there was a lack of behavioral follow-up included in these results. The results of the present study seem to suggest that RAFT has the potential to promote behavior change among HCPs in the sample, but cannot confirm it. Until HCPs are able to implement patient-centered communication with PWID and their behaviors are evaluated, evidence of behavior change is not available.

Future Directions

Special Olympics Texas and United Healthcare provided funding for this dissertation as a pilot study to: (1) test the effectiveness of RAFT with HCPs and (2) receive expert feedback on the curriculum. The results of this dissertation will be immediately utilized to perform quality improvement to RAFT before it is accredited

(CME, CE, and ACPE) and converted to an online platform through OptumHealth Education. RAFT training will be offered to HCPs nationwide in the form of two live webinars in June and August 2017. The webinars will be available to the public on the OptumHealth Education website for two years thereafter.

To earn their certificate, all participants registered for the training through OptumHealth Education will be required to complete a pre-test approximately 3 days prior to the training, and a post-test at two points in time – the first immediately following training and the second approximately three months post training. The measures will include the same measures used in this study (attitude, PBC, uncertainty, anxiety, intention), but will also extend the efforts of this dissertation by including: (1) a measure of self-reported behavior at three months post training, and (2) the case study as an additional form of summative assessment. Moreover, HCPs who earn a continuing education certificate by completing the training will be asked to provide their patients with a link to a patient satisfaction survey – independently housed and managed by Special Olympics Texas – which will allow PWID and their caregivers to rate their HCPs on a number of RAFT competencies. This survey will provide data to measure HCPs' actual behavior as opposed to their personal perceptions about their behavior in these interactions. This measure of actual behavior is important, given that most communication skills training programs are not well informed about the influences on the audiences they are designed to help (Kreps, 2014). This information will also be made available to HCPs as a way to receive feedback from their patients, as researchers suggest that the ultimate test of whether communication skills training is useful in improving

communication in provider-patient interactions, is the impact on the patients themselves (Keir & Wilkinson, 2013).

Future provider-patient health communication intervention research should continue to utilize a combination of interpersonal and behavior change theories. Integrating elements of these theories should more accurately predict behavior change, by accounting for the complexity of these real-world interactions. Future research should also examine additional predictors of anxiety to determine if direct behavioral experience plays a key role in determining HCPs' anxiety levels in interactions with PWID, as the results of this study may suggest. Research that seeks to validate and expand TPB should continue to examine the relationship between the three predictors of intention to determine if one has the power to cancel out the other two in extreme situations. Finally, health communication researchers interested in the provider-patient interaction should focus their efforts on different types of specialized provider-patient interactions, because as this dissertation suggests, all provider-patient interactions are not the same.

Summary of Dissertation

This dissertation (1) evaluated the effectiveness of RAFT – a communication skills training intervention for HCPs servicing PWID, and (2) examined predictors of HCPs' patient-centered communication in interactions with PWID. Specifically, this study sought to determine if HCPs' attitudes, PBC, uncertainty, and anxiety predicted intention to engage in patient-centered communication. Results indicated that RAFT significantly increased HCPs' intentions to engage in patient-centered communication, improved their attitudes toward interactions with PWID, and reduced their uncertainty

about such interactions. Although RAFT did not change HCPs' PBC or anxiety levels as a whole, significant differences were identified among subgroups of the sample.

With regard to the proposed theoretical model, PBC was found to be the strongest predictor of intention. Uncertainty and anxiety predicted intention, but were not significant predictors when TPB variables were introduced into the model. Uncertainty predicted intention on its own, but was not a significant predictor when anxiety, attitude, or PBC were present. These results provide support for the integration of interpersonal and behavior change theories when developing health communication interventions, to directly target specific factors known to influence a particular communication interaction. These results also hold implications for TPB and the unique role that PBC plays in predicting HCPs' behaviors in interactions with PWID.

APPENDIX A: RAFT TRAINING

Fall 2016

R.A.F.T.

For Healthcare Providers Servicing Patients with Intellectual Disabilities

Providing Clarity in Uncharted Territory
Informed by patients, caregivers, and healthcare providers, and backed by health communication theory, RAFT provides an evidence-based model for effective communication between healthcare providers and patients with intellectual disabilities.



Delivering Comprehensive Healthcare Beyond the Clinical Interaction

They spoke. We listened. Special Olympics Texas partnered with a team of health communication researchers to ask patients, caregivers, and healthcare providers what they believed were vital missing components in their own experiences of receiving and providing healthcare. **Respect, Accommodation, Follow-Up, and Time** emerged as key themes in their responses, which lay the foundation for this training program.

RAFT utilizes a logic model that mirrors the continuum of the patient experience to expand the context of the provider-patient interaction beyond just the clinical examination. It is intentionally designed to educate anyone involved in providing care to patients from the time there is a call to schedule an appointment, to the time the patient leaves the office and beyond. This includes but is not limited to: physicians, nurses, nurse practitioners, physician's assistants, reception staff, medical students, technicians, and physical therapists.

RAFT prepares providers to deliver comprehensive healthcare to patients with intellectual disabilities. Providers learn how to: (1) decrease communication barriers with their patients, (2) increase the delivery of meaningful, targeted healthcare, and (3) increase their patients' perceived quality of care.

Training Modules

- Module 1 Introduction to RAFT
- Module 2 Scheduling and Intake
- Module 3 Initial Assessment
- Module 4 Clinical Examination
- Module 5 Clarification and Discharge
- Module 6 RAFT Case Study
- Module 7 Conclusions and Feedback



"There was a communication barrier...I wish I would have received more hands on training [to strategize] different ways you can communicate if you run into an issue." ~Healthcare Provider

R.A.F.T. Training at a Glance

Page	Topic
3	Module 1 An Introduction: Getting Familiar with R.A.F.T.
4	Learning Objectives
5	Module 2 Scheduling and Intake
6	Module 3 Initial Assessment
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RAFT Training was created by health communication researcher, Brenda L. MacArthur, Ph.D.(c), in conjunction with Special Olympics Texas.

United Healthcare provided funding for this project.

An Introduction: Getting Familiar with R.A.F.T.

It is not about what the experts think. It is about what patients, caregivers, and healthcare providers experience as barriers to effective communication. RAFT targets these problem areas head on, offering strategies to overcome them.

That is what sets RAFT apart from other training programs.



"They are human beings and they need compassion and they need to be treated like they are important."

Respect: Patients should be acknowledged and actively involved in communication about their health and healthcare¹. Too often, patients and caregivers feel like their providers do not treat them *like people* because they *appear different*. A patient explained, "I could tell the way he was acting...the reactions." Providers must show respect for patients by acknowledging their presence and allowing them to play a role in their care.

Accommodation: Patients possess varying communication abilities and utilize different verbal/nonverbal strategies when interacting with providers¹. Often, their disabilities and limited communication abilities are viewed as challenging and off-putting, rather than an expression of a need that should be met². One provider explained, "Even though I'm trying to speak as simple as I can, they still may not understand what I am saying. And so that's definitely challenging." To maximize effective communication, providers must make accommodations to meet patients where they are and on a level that they can understand.

Follow-Up: Establishing sustained relationships is fundamental in providing quality healthcare and achieving continuity of care³. Caregivers reported retaining the same provider for extended periods. One parent explained, "To go through the history, have to explain everything. It's the hardest thing." A provider also alluded to concerns over not knowing the patient, "Communicating with the individual [is most difficult], especially when we don't know them." Providers who are able to show a genuine interest in patients' experiences and concerns can build rapport and a trusting relationship⁴. As providers and patients become more familiar with one another, the clinical experience should be more beneficial for both parties.

Time: Caregivers and providers cite limited time as a major challenge in providing quality care to patients. One caregiver mentioned, "Just slow down, we know you are busy, we know you've got tons of patients to look at, we've waited in the waiting room for that hour, hour and a half, so we want more than just 10 minutes to get a proper diagnosis." Time is a limited resource and this challenge puts strain on appointments that require increased involvement⁵. Providers must maximize the amount of time they spend with patients with intellectual disabilities.

R.A.F.T Learning Objectives

Upon completion, healthcare providers will:

1. Develop effective communication interactions with patients using the RAFT model.
2. Explain how the RAFT model can be integrated into each stage of the patient's clinical experience.
3. Demonstrate communication behaviors representing the ***Respect*** component of the RAFT model*.
4. Demonstrate communication behaviors representing the ***Accommodation*** component of the RAFT model*.
5. Demonstrate communication behaviors representing the ***Follow-Up*** component of the RAFT model*.
6. Demonstrate communication behaviors representing the ***Time*** component of the RAFT model*.

* Specific behaviors will vary based on provider type and specialty.



Brenda L. MacArthur
George Mason University

A Note From the Developer

I would like to thank you for your interest in RAFT Training. As a researcher, I recognize the value of translational work that directly applies research findings to practice to promote health. RAFT brings together an expert team of health communication researchers, industry experts, healthcare providers, and most importantly patients and their families/caregivers to create an evidence-based, and theoretically sound curriculum.

RAFT was designed with you in mind. Regardless of your specialty, you should be able to directly apply these concepts to your everyday work environment – whether that is a hospital, private practice, public clinic, or other establishment. The goal is to enhance the quality and continuity of healthcare your patients receive, by involving your entire team, department, or unit, in this training. I hope that you will collaborate with one another as you work through each module, and apply the concepts to *your* patients and *their* unique needs.

I would like to thank Dr. Maureen Keeley, Dr. Michael Burns, Ms. Lauren Cafferty, and Dr. Melinda Villagran for conducting the initial interviews used to inform the development of RAFT. I would also like to thank the patients, parents, caregivers, and providers who provided insights about communication challenges and barriers in provider-patient interactions.

Module 2 Scheduling and Intake

A positive patient experience begins before the patient arrives at the office for their appointment. It begins when the patient schedules an appointment and continues through the check-in process.



Respect

Communicate in a respectful manner at all times. Respect all patients equally, recognizing that it may be necessary to show respect differently for different patients.

- **Interact with the patient first.** Realize the difference between *talking to* the patient, and *talking about* the patient.
- **Know and use the patient's name.**
- **Demonstrate nonverbal immediacy** – wave, smile, and use a positive tone of voice.

Accommodation

Patients arrive with different health problems, concerns, experiences, and expectations, so how you interact with them will vary. To meet their needs/expectations you may need to be more detailed in initial conversations. Effective communication requires a shared understanding and co-creation of meaning, and may require multiple attempts and various strategies to achieve. Be patient, and if at first you don't succeed, try again.

- **Provide additional information about the visit** – approximate wait times, who they will interact with, and any planned procedures.
- **Ask about special circumstances/requests, before the patient arrives** and use that information to personalize the experience.
- **Provide clear instructions beforehand.**

Follow-Up

You will likely spend additional time providing information about the appointment to patients and caregivers. Follow-up with or check-in with patients throughout this process to check for understanding. This will help them reduce anxiety about the visit.

- **Be direct.** Ask if there are questions about specific pieces of information. Ask open-ended questions and have patients summarize instructions.
- **Check in with patients in the waiting area.** Alert them of approximate wait times, offer water, or change the TV station.
- **Remind patients about information you provided over the phone.**

Time

Time is valuable for patients and providers alike. Being time conscious involves paying enough attention to patients so that they do not feel rushed, but also being respectful of their time. Extended waiting can make some patients more anxious.

- **Be proactive and alert patients before they arrive** if you are running significantly behind schedule.
- **Do not rush patients through paperwork during the check-in process.** Spend time answering questions and ensuring understanding when completing paperwork.

Module 3

Initial Assessment



The initial assessment can be confusing as patients often see one provider who collects their vitals before another arrives to examine them. Continuity in providers' communicative behaviors is extremely important. By the time patients are called into an examination room, they have already formed expectations for the remainder of their clinical visit based on their experience with the providers who greeted them. Their expectations should be met as they transition to the next phase of their visit.

Respect

Behaviors that communicate respect are pivotal to ensuring a smooth transition from the waiting area to the examination room. Being aware of how your behaviors communicate respect for patients will help you develop a rapport with them.

- **Maintain focus on the patient by allowing them to recount their own experiences.**
- **Demonstrate immediacy – establish eye contact, shake hands, keep an open posture, and avoid physical barriers.**
- **Explain the procedure before performing it.**

Accommodation

All patients are not the same, and should not be grouped into categories. They have different levels of anxiety related to different procedures and require varied accommodations to ensure comfort.

- **If the patient does not understand, change the explanation. Do not “dumb down” material. Simply avoid medical jargon and terminology.**
- **Notify other providers of noteworthy patient behaviors so they can prepare beforehand.**
- **Ensure that the caregiver is invited into the exam room. Caregivers help patients stick to prevention/treatment regimens and even act as translators at times, so their presence can be helpful.**

Follow-Up

In the initial assessment, we discussed the importance asking direct questions to patients and caregivers. During the initial assessment it is likely that caregivers will provide some, if not all of the patient's health information to providers – which is why it becomes important to follow-up with the patient to see if he/she has anything to add or has any questions.

- **Review the patient's chart to avoid redundant questions. Talk with other providers to know what they have already discussed with the patient.**
- **Engage in small talk. Find common ground where you may share similar interests/experiences with patients.**

Time

Although there is a limited amount of time to collect a medical history and vitals, patients need to feel like their providers value their time with them.

- **Plan ahead and allow additional time for appointments.**
- **Provide complete responses to questions as they arise. This will save time during the examination phase and avoid more complex and time-consuming responses at the end of the visit.**

Module 4

Clinical Examination



The physical examination stage of the patient experience often produces the most anxiety for patients. They are typically in yet another new space, perhaps in a vulnerable physical position, and surrounded by intimidating tools and noises. This is the most crucial stage of the patient experience and if RAFT is properly implemented in the previous stages, the examination has a stronger likelihood of success.

Respect

If patients do not feel respected by the providers performing the examination and prescribing prevention/treatment regimens, the entire patient experience is likely to suffer. Reception and nursing staff tends rotate so different staff may greet the patient and take their vitals at each visit. The patient typically sees the same provider for their exam, so it is not uncommon for them to place greater importance on feeling respected by these providers.

- Recognize the patient's ability to know how their symptoms make them feel.
- Trust caregivers' insights and knowledge.
- Utilize nonverbal behaviors – slow down, repeat info, and use gestures for emphasis.
- Connect with patients by *listening to understand* rather than simply to respond.

Accommodation

Flexibility and willingness to adapt your exam routine to meet patients' unique needs will create a positive clinical experience. Providers must continue to emulate the level of accommodations provided during scheduling, intake, and initial assessment to ensure consistency.

- Utilize resources to ensure comfort. Incorporate books/toys/games from the waiting area, and offer stuffed animals during painful/invasive procedures.

- Use multiple modalities to explain procedures – visuals, augmentative and alternative communication strategies.

Follow-Up

Check on patients while they are still present and immediate adjustments can be made. In addition to explaining procedures fully, check in with patients throughout to ensure comfort.

- Ask about biomedical and biopsychosocial aspects of the patient's experience. Allow them to share experiences and emotions.
- Let patients see you as a real person.

Time

Patients should not feel rushed through an exam. If RAFT is properly implemented in the early stages, the reception staff should have already accounted for a longer appointment time.

- Summarize information and provide simple comparisons.
- Offering patients clarification is linked to determinants of health outcomes such as treatment/medication adherence.
- Be prepared with supplemental info that will help patients/caregivers understand/remember complex information.

Module 5

Clarification and Discharge



Upon completion of the examination, the patient should feel confident about the next steps, and leave with the necessary information to successfully follow the prevention and/or treatment regimen. Providing additional clarification before the patient is discharged ensures that the experience ends positively, leaving the patient feeling fulfilled. Just as providers must implement RAFT at the start of a clinical visit, they must continue to implement it at the conclusion of the visit and beyond.

Respect

Regardless of how the examination transpired, patients should leave their appointments feeling positive. Patients will return to, or pass by the reception area on their way out. It is important to acknowledge the patient's presence and at a minimum, wish them a good day.

- Greet the patient when they return to reception.
- Re-explain or clarify instructions for the patient and caregiver.
- Display positive nonverbal behaviors to communicate that you are proud – smile, wave, perhaps pat on the shoulder.

Accommodation

Patients typically emerge from the examination with a plethora of information, resources, and recommendations. It may take them a moment to process the information or they may need assistance synthesizing the information. Providers must help patients and caregivers decode the information.

- Provide spoken *and* written instructions.
- Re-explain prevention/treatment recommendations.
- Provide additional resources for caregivers.

Follow-Up

Following-up with patients before they leave the office is important because it is the final opportunity to clarify information and address any remaining concerns. Following-up after they leave shows that you care. Remember that follow-up refers to both informational and relational factors. These behaviors have a lasting impact on the patient's experience, perception, and relationship with healthcare providers.

- Use the teach-back technique to check for understanding and accuracy.
- Address remaining concerns by asking direct questions.
- Follow-up via phone/email within 1 week.

Time

Patients should not feel rushed out of the door once the examination is complete. Take the appropriate amount of time to ensure that patients leave feeling confident in their course of action and feel supported by their providers.

- Slow down and think carefully about referrals. Consider the patient's needs and challenges to determine the best fit.
- Follow-up with patients before their next appointment – provide clarification and recommendations to save time during the next visit or prevent an emergency visit.

Module 6

R.A.F.T. Case Study

Let's put your R.A.F.T. knowledge to the test!

The following is a testimonial provided by a physician. Read the testimonial carefully. In the space provided below, make note of any RAFT behaviors that you notice. Also note any areas for improvement. You may find more than one example for some of the RAFT behaviors.

I had a patient with Down syndrome who came to our clinic because he couldn't talk. He was socially subdued most of the time. Yet the nurses noticed that he was particularly entertained by the books that had pop ups. They made sure to keep these on hand for him. We even had a note in his file so that the new nurses would know how to get him engaged or regain his attention if he got distracted. His inability to talk was an ongoing issue. He had seen multiple providers who all suggested that he needed to develop his social skills. This answer was not enough for me. I made a list of medical conditions that could have potentially been contributing to the issue. I looked into his medical history and asked his parents many questions. As it turned out, he had failed his newborn hearing test and no action had been taken since that time. He also had a history of recurring ear infections but no one had connected the issue to his newborn hearing test.

After multiple appointments and discussions with his family, we went ahead with testing. It took a lot of tests and a lot of trial and error, but when we received his hearing test results it was evident that he had severe to profound hearing loss. After further testing and follow up, we confirmed that he was not hearing anything at all. I concluded that his speaking issue was most likely a result of his hearing impairment and not a result of social issues related to his intellectual disability. We started working with the family to get him the help that he needed. We connected him with a specialist who could provide more targeted treatment for the ear infections he was experiencing. We identified a great ENT who had experience working with patients with intellectual disabilities. As a result, the ear infections were finally taken care of and he even received hearing aids. However, at that point he was already seven, and we'd missed the window for language development. So we had to start thinking through other possibilities. Although he wasn't benefitting too much from his hearing aids, he was at least hearing a little more, and learning more about the sounds around his environment. Within a few months we saw a quick shift in his demeanor. We have routine check-ins with him and he is definitely more connected to what's going on around him. It is upsetting that it took that long for anything to happen because previous doctors did not spend the time with him and his family. It could have been a better situation if testing happened sooner.

R:

A:

F:

T:

Module 7

Conclusions and Feedback

Please take a few moments to respond to the following questions.

1. **At what point in the patient's experience would you use RAFT?**
 - (a) when examining the patient
 - (b) when checking the patient in at the front desk
 - (c) during a follow-up appointment
 - (d) a and b
 - (e) all of the above
2. **Which of the following is the best way to communicate with PWID based on RAFT?**
 - (a) smile at them while talking with their caregiver
 - (b) address the patient but get important information from the caregiver
 - (c) speak directly to the patient and acknowledge the caregiver's insights
 - (d) ask the caregiver to make sure the patient understands
 - (e) none of the above
3. **If you see that the PWID is having a hard time understanding you, the best thing for you to do is:**
 - (a) slow down and explain the information in a different way, maybe with pictures
 - (b) slow down and repeat yourself until the patient understands
 - (c) ask the caregiver to explain the information to the patient later
 - (d) b and c
 - (e) all of the above
4. **Why is it important to follow-up with PWID both during and after their appointment?**
 - (a) you want to make sure that they come back
 - (b) to ensure understanding while the patient is still present or to avoid emergency room visits
 - (c) it is only important to follow up with patients after they leave the office
 - (d) to develop a lasting relationship with them
 - (e) b and d
5. **How can you maximize time during interactions with PWID?**
 - (a) skip questions that the patient/caregiver asks and leave it for the end
 - (b) take the time to answer patient's questions fully and consult the patient's chart to prepare
 - (c) schedule longer appointment times for PWID
 - (d) a and b
 - (e) b and c
6. **What do you consider the *most valuable* aspect of RAFT? Why?**

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Notes

R.A.F.T.

FOR EMERGENCY CARE PROVIDERS

*SPECIAL ISSUE
FALL 2016



ABOUT THE TRAINING

RAFT Training prepares providers to deliver comprehensive healthcare to patients with intellectual disabilities. In this insert, RAFT is modified for direct application in emergency care settings.

Emergency care providers learn how to: (1) decrease communication barriers with their patients, (2) increase the delivery of meaningful, targeted healthcare, and (3) increase their patients' perceived quality of care.

CLARITY AMIDST THE CHAOS: WHEN PATIENTS WITH INTELLECTUAL DISABILITIES PRESENT IN THE EMERGENCY ROOM

In the world of emergency medicine communication strategies may very well be the last thing on your mind. After all, you are responsible for each patient's physical wellbeing. You are hit with a rush of patients who all need your attention – and at the same time you are faced with an abundance of important decisions regarding your patients' care. In each moment, you must prioritize where to place your focus. It is not surprising that those decisions typically lie within the realm of hands-on patient care. Although not ideal, sometimes communication

takes a backseat to more pressing health issues that need immediate attention. But – this does not have to be your reality.

Communication is all around us and it does not happen in a vacuum. It is present in what we say, how we say it, what our body language suggests, and even in what we fail to say. There is no off switch and patients will pick up on it – even in the midst of a significant health crisis. Think about the famous quote that suggests, *"People may not remember what you did or what you said, but they*

will always remember how you made them feel."

RAFT works with you to integrate effective communication strategies into your everyday interactions with patients with intellectual disabilities. Gone are the days of prioritizing communication and hands-on patient care. RAFT offers targeted strategies to help you find the right balance for you. And it is easier than you think! Try them out and soon they will become second nature to you – even in the most challenging and stressful emergency situations.

INSIDE THIS SPECIAL ISSUE

A Brief Overview. We unpack the RAFT acronym and explain the relevance in the unique emergency room setting.

RAFT in the ER. We take you through each RAFT component and offer strategies for practical application in fast-paced, high-stress, emergency situations.



Special
Olympics
Texas



UnitedHealthcare

RAFT. A BRIEF OVERVIEW

The quality of healthcare that patients with intellectual disabilities receive is largely dependent on their experiences with providers. Providers can employ RAFT principles to ensure effective communication with patients and their caregivers, even during emergency situations. To enhance quality and continuity of care, RAFT suggests that providers employ four principles: **Respect, Accommodation, Follow-Up, and Time.**

Respect. Patients understand more than would seem apparent from their expressive ability. Providers can demonstrate respect by acknowledging patients directly, and allowing them to play as much or as little of a role in their care as they can or wish.

Accommodation. Patients possess varying communication abilities and utilize different verbal/nonverbal strategies to communicate their needs. Successful communication is rooted in the ability to recognize each patient's needs and adapt to meet patients where they are and on a level they understand.

Follow-Up. Providers can check on patients for informational and relational purposes. Ensuring an accurate exchange of information is crucial, as is establishing rapport. Such relationships ensure more comfortable interactions for patients and providers during this stressful time.

Time. Time is a limited resource, especially in the ER. The ability to maximize time with both patients and their caregivers can help providers to accomplish multiple competing goals. The ability to work in sync with other providers will ensure continuity in patient care.



TARGETED STRATEGIES USING R.A.F.T.

RESPECT

- Briefly introduce yourself to the patient and summarize your role.
- Maintain eye contact upon arrival, during explanations, and when providing reassurances.
- Solicit the patient's perspective if he/she is physically able.
- Include the patient in dialogue with other providers. Avoid talking *about* patients as if they are not present.

ACCOMMODATION

- Explain each procedure fully, regardless of the severity – from checking oxygen levels, to taking blood, or weaving stitches.
- Use simple language and avoid medical jargon and terminology.
- If caregivers cannot be present while you work, reassure the patient that they are close by and will return soon.
- Record noteworthy patient behaviors/information in the file so other providers can prepare.
- Utilize resources such as calming music or a personal possession to ensure comfort.

FOLLOW-UP

- Ask direct questions about the patient's symptoms.
- Check on patients throughout each procedure.
- If caregivers cannot be present, provide regular updates on the patient's status.
- Ask patients to summarize instructions even if they insist that they understand.
- Find common ground or relate to their feelings of uncertainty or anxiety about the situation.
- When the patient's condition stabilizes, ask about biopsychosocial aspects of the patient's experience.

TIME

- Read the patient forms and avoid redundant questions.
- Speak slowly and clearly to avoid having to repeat yourself.
- Provide complete responses to questions as they arise.
- Offer supplemental materials that further break down and repeat information you previously explained to them.

APPENDIX B: RAFT INSTRUCTOR MANUAL

R.A.F.T. Training

For Healthcare Providers Servicing Patients with Intellectual Disabilities

Instructor Training Manual

Developed by Brenda L. MacArthur, Ph.D.(c)
In conjunction with Special Olympics of Texas.

Training Synopsis and Background

The RAFT (Respect, Accommodation, Follow-Up, Time) training provides an evidence-based model for effective communication interactions between office/reception staff, healthcare providers, patients with intellectual disabilities (PWID), and their caregivers. Based on hours of interview data from healthcare providers, PWID, and caregivers, the RAFT model provides evidence-based practices for healthcare providers and office/reception staff regarding communication with PWID and their caregivers. This training also serves an advocacy role for PWID to ensure a beneficial patient experience.

The RAFT training curriculum includes seven modules, which can be delivered in two-hour time blocks. RAFT can easily be adapted to provide shorter or more detailed training sessions as needed. More detailed training could include the use of standardized patients, role-playing, and other skill-based experiential learning activities to allow trainees additional time to practice the concepts outlined in RAFT. The modules provide information about how to utilize RAFT throughout the entire patient experience from the time the patient arrives and checks in to the time he/she leaves the office. Also included in the modules is a case study based on an actual interaction between a physician and PWID.

RAFT training is based on the experiences of healthcare providers who regularly work with PWID, caregivers, and most importantly, PWID themselves. The RAFT model was established through a research partnership between Special Olympics Texas and the Department of Communication Studies at Texas State University. Texas State's team of researchers worked with Special Olympics Texas to obtain a comprehensive view of the communication that occurs between healthcare providers, PWID, and their caregivers. Four main themes emerged from the interview data that created the RAFT model:

- **Respect:** Showing respect for PWID is a common theme that emerges among patients and caregivers. Respect can be communicated simply by treating a PWID like a human, and like an individual who has his/her own attitudes, beliefs, and values. Many PWID and their caregivers note that healthcare providers do not treat PWID "like people" because they "appear different." Unfortunately, individuals often perceive that people with intellectual disabilities have "communication problems," and locate the problem solely in the individual with the intellectual disability (Northway, 2014). Although it may be necessary for caregivers to assist during clinical visits, patients should have the opportunity to actively participate as much as they are comfortable doing so.
- **Accommodation:** At the core of every communication interaction is the need to understand one's audience and be able to adapt communicative behaviors to accommodate the needs of that audience. Through verbal and nonverbal feedback, an effective communicator should adapt their communication to help the receiver understand the message. The importance of accommodation is magnified in any healthcare interaction because of the complexity of such messages. However, being able to adapt your messages to reach your audience becomes even more important when communicating about health information with PWID. A major challenge for PWID is that their disabilities and limited communication abilities

are sometimes viewed as challenging and off-putting, rather than an expression of a need that should be met (Northway, 2014).

- **Follow-Up:** Continuous care is fundamental in caring for PWID (Hemm, Dagnan, & Meyer, 2015). Providing adequate care is complex when the patient has limited cognitive capacity and communicative function. Caregivers can assist in providing vital health information, but co-constructed communication wherein a mutual understanding is achieved is essential, especially with PWID. Showing a genuine interest in patients' experiences and concerns can help build rapport, which can eventually lead to the development of a trusting relationship. As you get to know PWID and they become more comfortable with you, the clinical experience should be more beneficial for both PWID and healthcare providers.
- **Time:** Because of PWID limited cognitive and communicative ability, time is frequently cited as concern in healthcare interactions (Wilkinson, Dreyfus, Bowen, & Bokhour, 2013). Time is a limited resource and often healthcare providers are limited in the amount of time allotted to each patient. This challenge puts strain on appointments that require increased involvement. Healthcare providers' ability to maximize the amount of time they do have with PWID is an extremely beneficial skill.

The following modules include statements from the research that informed the development of RAFT. These statements serve as examples for teaching the communication skills associated with each component of the model and provide powerful insight into the clinical experience for PWID and their caregivers.

Training Objectives

After completing this training participants will be able to:

1. Develop effective interactions with PWID using the RAFT model.
2. Explain how the RAFT model can be integrated into each stage of the patient's clinical experience.
3. Demonstrate communication behaviors representing the *Respect* component of the RAFT model.
4. Demonstrate communication behaviors representing the *Accommodation* component of the RAFT model.
5. Demonstrate communication behaviors representing the *Follow-up* component of the RAFT model.
6. Demonstrate communication behaviors representing the *Time* component of the RAFT model.

Module 1: Introduction to RAFT

Trainer Introductions

Begin by introducing yourself and all participants. It may be helpful to ask what each participant hopes to gain from attending this training so that you can tailor various explanations or examples to best fit the needs of your audience. Encourage participants to ask questions and share their own experiences and examples as they relate to the curriculum.

Rationale for Training

Over 6.5 million individuals in the United States are currently diagnosed with an intellectual disability (ID; Special Olympics, 2015). By definition, these individuals experience limitations in cognitive functioning, communication, and sometimes self-care (Special Olympics, 2015). Individuals diagnosed with an ID possess an IQ below 70-75, experience significant limitations in adaptive functioning such as communication or self-care, and were diagnosed before the age of 18 (Special Olympics, 2015). Limitations in cognitive functioning distinguish IDs from other developmental disabilities that can include physical limitations. However, intellectual disabilities often co-occur so it is not uncommon for individuals to experience both cognitive and physical disabilities (AAIDD, 2015).

The limited communicative abilities of individuals with ID restrict their independence and pose challenges when it comes to participating in decisions regarding their health (Ogletree, Bruce, Finch, Fahey, & McLean, 2011). Unfortunately, the majority of individuals with ID struggle to communicate medical needs or medical information to their healthcare providers (Blackstone, Beukelman, & Yorkston, 2015). Barriers to communication can result in a host of adverse health effects including misdiagnoses, medication dosage errors, and other medical errors. Researchers cite the importance of communication labeling it as the leading cause of medical errors (Starmer et al., 2014).

To address the concerns that PWID experience, Special Olympics has developed targeted programming. Programs such as the Healthy Athletes Initiative, Project UNIFY, and the R-Word Campaign aim to reduce social stigma and promote advocacy (Siperstein, Pociaks, & Collins, 2010). The next step to promote advocacy for PWID is training healthcare providers outside of the Special Olympics network to improve patients' experiences and reduce medical errors through effective communication.

Shortfalls in Healthcare

Healthcare providers, PWID, and caregivers must be able to elicit and understand one another's perspective, reconcile differences, and achieve some degree of agreement on the status of the PWID's health, along with the best course(s) of action (Street & DeHaes, 2013). Unfortunately, healthcare providers often cite a lack of confidence and awareness in caring for PWID, barriers to communication, and difficulty in obtaining the PWID's perspective (Dunkley & Sales, 2014). To illustrate these issues, the following statements were obtained from interviews conducted with healthcare providers and caregivers:

"I wished I would have received more hands on training because in our class we learned the best ways to communicate with people, and ... the first time we went it was super busy and we couldn't – there was a communication barrier. And I think it would have been a lot easier if someone would have a conference and maybe [strategize] different ways you can communicate with these people if you run into an issue." ~Healthcare Provider

"We've had discussions about how to interact with different populations but I wouldn't say that there was a comprehensive training or anything like that." ~Healthcare Provider

"I just talk to [the physicians] a lot. And I tell them about people. I have my own fear of doctors. I think I go in and explain more than most people because I don't want them afraid of our children, or of our adult children especially." ~Caregiver

There are a variety of explanations for why healthcare providers may experience a lack of confidence and awareness in servicing PWID. Perhaps the simplest explanation is "fear of the unknown." As human beings, we accommodate our behaviors when interacting with individuals from different social groups (Giles, Coupland & Coupland, 1991; Giles, Mulac, Bradac, & Johnson, 1987.) We evaluate and assess others on a variety of factors (e.g., race, age, education, socioeconomic status, hobbies, career, medical classifications, etc.). When we make distinctions between groups, we categorize people as a member of an in-group (group whom with we identify) or an out-group (group whom with we disidentify) (Giles, Willemyns, Gallois, & Anderson, 2007). This dis-identification with an out-group causes us to feel uncomfortable and sometimes this discomfort is unintentionally communicated through our actions, which may be the case with healthcare providers who service PWID.

For more than a decade, researchers have cited the importance of developing evidence-based interventions (i.e., integrating high quality research with practitioner expertise and client preferences) for healthcare providers on this topic (Snell et al., 2010). Healthcare providers who have participated in training about providing care to PWID in the past, have cited retaining feelings of confidence and preparedness, and recognized communication as a vital component in this process (Hahn & Cadogan, 2011). The following communication skills training program suggests ways in which healthcare providers as well as office/reception staff can accommodate their behaviors to better meet the needs of PWID who may be viewed as an out-group. Simple yet strategic communication behaviors can improve the entire clinical experience for PWID, as well as providers' experiences with PWID.

Communication Skills Training

Communication skills training for healthcare providers is not a novel concept. In recent years, medical schools have recognized its importance and integrated communication training into their education programs (Bennett & Lyons, 2011). Many reputable websites provide free information about provider-patient communication or advertise face-to-face sessions for a high cost (see UC San Diego PACE Program).

The training proposed here differs from others like it because it is a true evidence-based program based on “real life” experiences from PWID, their caregivers, and healthcare providers. Throughout the training participants will experience real stories that support the tenets proposed in the training model. Unlike other training programs that simply fill websites with pages of information where healthcare providers can passively learn “what to do and not do” when caring for patients, participants in this program will learn the content through interactive modules that stimulate higher levels of learning. The interactive nature of this training requires them to not only understand and apply information but also to analyze and evaluate it. As a result, providers will feel more confident in their interactions with PWID, thereby improving the quality and continuity of healthcare for PWID.

This program can be conducted in face-to-face sessions, or self-directed through online learning modules. To ensure that the training is as realistic as possible, and to maintain consistency, the program follows the patient experience through four stages: (1) Scheduling and Intake, (2) Initial Assessment, (3) Clinical Examination, and (4) Clarification and Discharge.

That is, RAFT should be adopted for each stage of the patient experience from scheduling an appointment to the conclusion of the clinical visit and beyond. Before walking you through how the RAFT model can be implemented in each stage, let’s begin by introducing the RAFT Model.

Introduction to RAFT

- **Respect:** It is important that all patients feel respected and feel as though they are the main focus in all clinical interactions. All patients, regardless of their physical or cognitive ability should be acknowledged and actively involved in all communication about their health and healthcare (Chew, Iacono, & Tracy, 2009). While some healthcare providers may feel uncomfortable communicating with PWID out of concern that the information will not be properly understood, people with intellectual disabilities often have stronger receptive than expressive communication skills and are likely to understand more than would seem apparent from their expressive ability (Olney, 2001). Unfortunately however, many caregivers expressed concerns about healthcare providers’ lack of respect for PWID.

One caregiver mentioned, *“They may have some abnormalities in a sense, but they are human beings and they need compassion and they need to be treated like they are important.”*

- **Accommodation:** The key to successful communication is rooted in the ability to recognize the important role your audience plays in a given interaction. It is unlikely that you would interact with your boss or employees in the same ways that you interact with your family or friends. Patients can be viewed in much the same way. Some patients will be able to comprehend health information more quickly and easily than others who may need to additional clarification or explanations in simpler terms. Regardless, it is important for you to be audience-centered and make accommodations to meet each patient’s needs. This accommodation may require you to adapt your communicative behaviors when interacting with them. Paying close attention to verbal and nonverbal feedback cues will

help alert you to instances where it is necessary to make these accommodations. However, it is important to recognize that PWID often have varying communication abilities and may utilize a number of different verbal and nonverbal strategies (Chew et al., 2009). Accommodation is of utmost importance, especially when interacting with PWID because these patients experience distinctive communication barriers such as physical and/or sensory impairment that further add to the complexity of communicating about health information.

A provider describes her experience realizing she might need to accommodate her message to meet the needs of her PWID, *“Even though I’m trying to speak as simple as I can, they still may not understand what I am saying. And so that’s definitely challenging.”* Another provider explains the need to modify her message to ensure understanding, *“Sometimes I just have to realize that if I ask the same question of every patient, not every patient is going to understand that question. Sometimes I need to restate it or rephrase it.”*

- **Follow-Up Medically and Relationally:** Providing adequate care is complex when the patient has limited cognitive capacity and communication function. To ensure that PWID receive the best care, it may be necessary to follow-up with them more often. These follow-ups may occur in the form of subsequent visits, or simply checking in with the patient throughout their visit. As you begin to develop a relationship with your patients, you will likely be able to anticipate where these instances are needed. However, over time the goal is that your patients will establish a level of comfort with you that will enable them to be more open with you.

Establishing sustained relationships with patients is fundamental in providing high quality healthcare and achieving long-term continuity of care (Hemm et al., 2015). These relationships are especially important in dealing with PWID. Healthcare providers have specifically cited difficulty in accomplishing clinical tasks with PWID such as attempting to gain a medical history (Lennox, Green, Diggins, & Ugoni, 2001). PWID with severe intellectual disabilities and limited communication skills often rely on caregivers to optimize their communication opportunities and interpret behaviors that may indicate specific wants, needs, and emotions (Chew et al., 2009). Any time a third party is introduced into an interaction the communication immediately becomes more complex, which may be intimidating for patients and healthcare providers. Thus, to reduce the anxiety that may accompany such interactions, it is important for healthcare providers to establish relationships with patients and their caregivers (if applicable). Such relationships should ensure a level of trust and comfort for both the patient and provider, which should help all parties better manage their uncertainty about these complex communication interactions.

One provider explains the importance of developing a relationship with patients, *“A lot of time it’s communicating with the actual individual [that is most difficult], especially when we don’t know them.”*

- **Time:** Healthcare providers' and patients' time is valuable, and often providers are under immense pressure to see as many patients as possible each day. However, the complexity that accompanies clinical interactions with PWID often results in extended visits (Wilkinson et al., 2013), which then backs up the remaining patients scheduled for that day. Unfortunately, one of the main reasons why PWID often fail to receive the best care is due to limited time (Murphy, 2006). It is estimated that interactions with PWID generally take at least 6 minutes longer than other visits (Lennox, Diggins, & Ugoni, 1997).

A family caregiver mentions, *"Just slow down, we know you are busy, we know you've got tons of patients to look at, we've waited in the waiting room for that hour, hour and a half, so we want more than just 10 minutes to get a proper diagnosis instead of, 'Let's try this and if it doesn't work try this.' Just take the time, that's all we're asking for."*

Activity: Ask participants to take out a pen and paper, and reflect on a time they experienced with a challenging interaction with a patient. Explain that the interaction does not necessarily have to involve a PWID. Ask them to (1) describe the situation, (2) explain how the situation made them feel, (3) explain in detail how they dealt with this situation, and (4) discuss how RAFT could have been applied.

For **medical students**, ask them to think about how they think an interaction with a PWID may unfold. Ask them to (1) describe the situation, (2) explain their main concerns, (3) explain how they may deal with these concerns using RAFT.

Once all participants have finished, allow them to share their experiences. However, do not require all to share. Ask for volunteers. As the trainer, you want to establish a judgment-free environment where participants feel comfortable sharing their experiences.

This activity should help participants begin to think about RAFT in terms of their own experiences and situations. Establishing this way of thinking early on will help participants recognize the value of RAFT in their own practices, and will help them to integrate it into their lives. Be sure to unpack this activity and stress the importance of applying the content of the training to their own jobs/roles as healthcare providers.

Now that you have an understanding of each component of the RAFT model, we will examine how RAFT can be implemented at each stage of the patient experience. We will begin by considering the scheduling and intake process.

Module 2: Scheduling and Intake

A positive patient experience begins before the patient even arrives at the office for their appointment. Ideally, the implementation of RAFT should begin when the patient (new or returning) schedules an appointment. The communication behaviors described below are based on responses from PWID and caregivers who described both positive and negative clinical experiences. We have provided quotations to help trainees visualize and understand a PWID's experience.

Respect

PWID may be viewed as different because of their needs. During the scheduling process and welcoming PWID into the office, communicate in a respectful manner at all times. While it is not suggested that you show more respect to these patients over other patients, or treat these patients in a child-like manner, it is important to respect all patients equally, recognizing the fact that it may be necessary to show respect for these patients in different ways. Here are some ways to communicate respect:

Interact with the Patient First

"First and foremost, I always interact with the person with ID...If I can't get all the information I need or they can't provide me with, then I turn to the caregiver."

Greet the patient before greeting the caregiver. The patient is your focus and as many of the PWID and caregivers who participated in the study noted, the patient is often treated as "less than" because they are seen as different. The conversations you have when checking-in and completing paperwork should be addressed to both the patient and his or her caregiver (if applicable). Acknowledging the patient as your focus from the moment they enter the office will set the tone for a positive experience. While acknowledging the patient directly is not something that typically requires a lot of effort, when PWID arrive with caregivers who are responsible for their care, it is easy to lose sight of the fact that the patient is still present. Acknowledge the difference between talking *to* the patient, and talking *about* the patient when he/she is still present. This simple distinction can help the patient feel as though you care about them and are taking their perspective into account. Although the caretaker may ultimately be responsible for making health related decisions on behalf of the PWID, caregivers are likely to view you in a more positive light if your behaviors communicate that your main concern lies with the patient's best interests.

Know the Patient's Name (Verbal Immediacy)

"They all know him by name."

Take a moment at the beginning of the day to note whether any of the scheduled appointments are with PWID. Take note of their name and greet them using their name. Referring to the patient by name will communicate that you respect them as an individual, which is likely to relieve some of the anxiety they may be feeling associated with their visit. Immediately relieving some of the anxiety that patients may be experiencing as they enter the office should help

patients feel welcomed and more relaxed. While acknowledging all patients by name is ideal, it is especially beneficial for PWID who likely experience increased uncertainty about being in a new environment coupled with the invasiveness of undergoing a clinical exam.

Demonstrate Nonverbal Immediacy

“...they [office staff] all wave at him from where they are at in the waiting room.”

Be aware of your nonverbal behaviors. Nonverbal immediacy refers to expressing liking through body language. Nonverbal behaviors are important when communicating with PWID, as these individuals are more likely to communicate informally using nonverbal behaviors such as gesturing, eye contact, shaking hands, and pointing, to name a few (Chew et al., 2009). Simple waves, smiles, and a positive tone of voice go a long way and complement acknowledging the patients by name to help reduce anxiety almost immediately upon arrival. Although these simple behaviors may appear to be common sense, we often forget to take the time to nonverbally acknowledge others when we are busy or stressed. Take the time to remind yourself of the importance of these mundane behaviors.

Accommodation

Each patient arrives to clinical appointments with different problems, concerns, experiences, and expectations. One size certainly does not fit all, especially with PWID. For communication to be successful, a shared understanding and co-creation of meaning must first be achieved. Communication is a process that may require multiple attempts and various strategies in order to achieve mutual understanding. How you greet one patient may be very different from how you greet another. This may depend on their reaction to your initial greeting or simply what their body language communicates to you when they first enter the office. To meet the needs and expectations of PWID you may need to be more detailed in your initial conversation with them to make these accommodations. For example, providing additional information about what they can expect during their visit such as approximate wait time, who they will interact with, and any planned procedures may help them to feel more welcomed. The path to understanding is likely to be different for each and every patient. Be patient, and if at first you don't succeed, try again. Consider the following behaviors when communicating with PWID when they first arrive to the office:

Ask About Special Circumstances, Requests, or Accommodations

When scheduling a new or returning patient ask if there are any special circumstances, requests, or accommodations that would help the patient to feel more comfortable during their visit. Asking these questions before the patient arrives will give you an opportunity to take note of ways you can personalize the patient's experience based on their specific needs. For example, if the patient experiences limited mobility, you may need to make minor adjustments to the waiting area to maximize the space for that patient as well as others. Or, if the patient enjoys a certain TV show you may tune the office TV to that program prior to their arrival. This is also an opportunity for you to get to know your patients on a deeper level, while also communicating to them that you care about them. These details will help lay the foundation for the development of

a trusting relationship later on. Ensuring that the office/reception staff are prepared will help the patient's visit run smoothly, which will ultimately create a more comfortable experience for the patient.

Provide Clear Instructions

"I really try to prep my son before we get there so he knows what to expect, like when we are in the waiting room, or when we are waiting for the doctor to come in."

Caregivers typically spend more time preparing a PWID for a clinical visit than the average person. Providing them with clear instructions prior to the visit will help them to adequately prepare both themselves and the patients for the visit. These instructions may include any dietary restrictions leading up to the appointment, what to bring to the appointment, or even sample questions the physician may ask about medical history or symptoms to help better treat the patient. Having this information prior to the visit will help to save time during the appointment because the caregiver will be more prepared to help answer questions and the patient will already be prepped on what they can expect, thus saving the physician from spending a lot of time on these tasks. Taking some extra time to reduce the patient's uncertainty that accompanies a clinical visit will also help reduce anxiety for the caregiver and healthcare providers.

Follow-Up

During the scheduling and intake process, you will likely be spending more time providing information about the clinical visit to PWID and their caregivers. Because of this additional complexity, follow-up or check in with these patients throughout this process to check for understanding. This will help them reduce any anxiety they may be experiencing. The following are a few simple ways to understand your patients' needs:

Check for Patient and Caregiver Understanding and Provide Clarification

After presenting information about an appointment over the phone or about paperwork in the office, it is customary that you would tell patients to let you know if they have any questions. However, with PWID you may need to be more direct and ask them if they have a question about a specific piece of information. This may also require you to ask more open-ended rather than closed-ended questions. A PWID or caregiver may be reluctant to volunteer that they do not understand something, but asking them to *summarize* what you told them, for example, will help you to pinpoint where any misunderstanding occurs. If this happens, do not simply restate what you said previously. Try to explain the same information in a different way.

Check-In with Patient in the Waiting Area

Sometimes examinations take longer than expected and you can get behind, which increases wait times. If you are experiencing longer wait times, check in with the PWID and their caregiver periodically. Perhaps offer them a cup of water, ask if they would like to watch something specific on the TV, or alert them to where the restrooms are located. Checking in reminds the patient that you have not forgotten about them and allows you to fulfill any immediate needs that

they may have while they are waiting.

State Expectations for the Visit When Patient Arrives

We already know that many caregivers like to prep their PWID both prior to and during their visit. By reiterating expectations for the visit that may have been explained over the phone will help remind the patient and caregiver what they can expect. Additionally, if this information is already familiar to the patients, it will help them to further reduce their uncertainty and anxiety about the visit. Helping the patients to remain calm throughout the duration of their visit will make the visit run more efficiently for the patients and providers.

Time

Time is valuable for patients, caregivers, and healthcare providers. Unfortunately, time is a limited resource for many, if not all healthcare providers. Being time conscious is related to paying enough attention to patients so that they do not feel rushed, but also being respectful of their time. Extended waiting can make some patients more anxious than they would normally be. The following behaviors can help you best manage your time with PWID:

Be Respectful of Time

Waiting can cause stress for any patient but can be especially taxing on PWID. If you notice that appointment times are running significantly behind schedule, it would be helpful to call PWID to inform them of the situation so their caregivers can prepare them for the increased wait time. You could even suggest that they arrive a bit later if possible, to reduce the amount of time they have to wait. Taking the time to review which patients have appointments on a given day will allow you to be aware of when these types of services may be necessary.

Don't Rush! Spend Time Answering Questions and Ensuring Understanding

"They may take a little more understand and a lot more patience and a little bit more of your time but they are just people. Just like you and me. They are just slower. "

Due to PWID cognitive or sensory impairments, it is likely that it will take them additional time to process what you say and anything you ask them to do. Additionally it will likely take them more time to communicate information back to you (Chew et al., 2009). Spending the time answering their questions, asking open-ended follow-up questions, and ensuring understanding saves time in the long run while also creating a more positive clinical experience for the patient. Accounting for this added time to fill out paperwork when scheduling appointments will allow the physician to spend adequate time engaged with the patient, while also not increasing the wait times for other patients.

Activity: Count off by fours and assign participants different roles including, (1) PWID, (2) caregiver, (3) office/reception staff, and (4) healthcare provider. Each group should have one PWID, one caregiver, 1-2 office/reception staff, and 1-2 healthcare providers (depending on the

size of the training group). In each group, pair the patient with the caregiver and the office/reception staff with the healthcare provider. Give each group their corresponding scenario (provided below) and allow them a few minutes to discuss among themselves. Ask all groups to read the scenario and be prepared to act it out. The patient and caregiver groups will be provided with a list of unexpected challenges that could actually arise during the scheduling and intake process. This group can choose which challenge they would like to act out, and the office/reception staff and healthcare provider group will have to respond in the moment by applying RAFT.

Allow each group to act out the scenario in different areas of the room, or surrounding rooms. The goal of this exercise is for office/reception staff and healthcare providers to be put on the spot to enact RAFT, so they should not be watching other groups. They should be employing RAFT in their own way. Once all groups have finished, allow each group to share their experience.

Scenarios

PWID and Caregiver: The patient is experiencing headaches, loss of appetite, and seems to be depressed. You call the office to schedule an appointment with your primary care provider. You are given an appointment within the next week. Over that time period, the symptoms have worsened. When you arrive at the office you are given a form to fill out and are directed to the waiting room. Below is a list of possible challenges that could occur in this situation. Pick 1-3 from this list that you would like to act out.

- The PWID is uncomfortable in the waiting room. The noise is bothersome.
- The PWID is scared of the doctor's office and does not want to enter.
- The wait is longer than expected and the PWID is anxious.
- The PWID is scared of needles and hears another patient talking about a finger stick.

Office/Reception Staff and Healthcare Provider: You see that one of your regular PWID is scheduled for an appointment this week. The patient is experiencing headaches, loss of appetite, and seems to be depressed. You recognize this patient as one who is anxious when he/she arrives at the office. You know that he/she always brings a parent along. Work together to make a plan for this visit. How should the office/reception staff and healthcare providers work together to prepare for this visit? What will you do before the visit? What will happen when the patient arrives? What if something unexpected happens? How will you deal with it?

Module 3: Initial Assessment

To ensure a continued positive patient experience as the patient transitions from the reception/waiting area to examination room, it is important to maintain use of RAFT behaviors. The initial assessment can be confusing for PWID as they often see a nurse who collects their vitals before the physician arrives. This module represents the next stage of the patient experience where patients first encounter the medical staff, whether it is a nurse, physician, or other healthcare provider. This transition is where continuity in healthcare providers' communicative behaviors is extremely important. By the time patients are called into an examination room, they have already formed expectations for the remainder of their clinical visit based on their experience with the office/reception staff. Therefore, it is important for their expectations to be met as they transition to the next phase of their visit.

Respect

As described in the previous module, behaviors that communicate respect are pivotal to providing a positive experience for PWID and their caregivers. Being aware of how your behaviors can communicate respect for your patients is critical. The following behaviors can communicate respect during the initial assessment:

Acknowledge All Parties But Maintain Focus on the Patient

"My biggest thing that I've learned is ...they are a lot more interactive than I thought they would be. I thought there might be a communication barrier or it might be difficult to have a conversation with them, but most of the athletes are super open and they talk about everything..."

It is typical for caregivers to not only accompany PWID to their clinical visits, but also for them to be present in the examination room. Just as it is important for the reception staff to make contact with the patient first and acknowledge them by name, it is even more important for healthcare providers to maintain the focus of their communication on the patient rather than the caregiver. Chew et al. (2009) suggest that a best practice is to assume competence because PWID may understand more than they can demonstrate, and still feel included when spoken to. However, we also know that PWID often rely on caregivers to provide medical information, so it is also important to include them in the conversation. It is in this way that a triadic conversation occurs. While PWID should be given the opportunity to tell their story, caregivers can provide details that PWID may unintentionally leave out. Caregivers should also be referred to by name. If they do not mention their name, be sure to ask.

When obtaining the patient's blood pressure, temperature, and other vitals, you can include both the patient and the caregiver in the conversation by ensuring that you are speaking loudly and clearly so the caregiver can hear what is being said. Provide the opportunity for the patients and their caregivers to ask questions. This helps caregivers obtain the information they need to help provide clarity to the PWID and assist you in adapting your message, if necessary.

Demonstrate Verbal and Nonverbal Immediacy

"I don't just say, oh I'm screening you, they're just another subject. I always get personal with them, and I always – I'm pretty good at remembering their names when they come by because I have to fill out all their information."

We have noted that communicating with PWID is complex and at times, requires more effort than normal. Although PWID may or may not respond verbally, you can still demonstrate verbal immediacy by referring to them by name. Additionally, nonverbal communication is still possible, and is essential to building rapport with these patients. For example, upon entering the examination room, be sure that your nonverbal behaviors suggest that you are open to communication. You can convey this message through establishing eye contact with the patient, shaking their hand, and smiling. Moreover, be sure to maintain an open posture. In other words, do not place a physical barrier such as a computer or counter between you and the patient. Make sure that your face is visible at all times. You should also refrain from crossing your arms – instead you might roll up your sleeves so that your forearms are exposed. These simple behaviors should help the patient relax and see you as a "regular" person, thus making it easier for you to do your job.

Explain the Procedure Before Performing It

"She [the nurse] talks to him. You know, she says Charlie, I am going to look in your ears... Charlie I'm going to press on your belly... You know, she is talking to him, where the... sorry, I'm going to cry."

Though all healthcare providers are advised to inform their patients what they are going to do before they perform any procedure, this is incredibly important for PWID who may have limited cognitive capabilities. What may seem normal or routine to a non-PWID may create anxiety for an PWID. You can show respect for PWID by using short, simple sentences to help ensure understanding before performing any procedure. Remember, clear messages communicate respect.

Accommodation

PWID do not all fit into one category or another. They each require different accommodations to help reduce anxiety and ensure comfort during clinical visits. The most audience-centered healthcare providers will adapt their communication to ensure that their patients receive the best healthcare experience possible. Consider the following behaviors when communicating with PWID during the initial assessment:

If the Patient Does Not Understand, Change Your Explanation

"We learn a lot about what ways they understand best and since we do like the science part of it, we know that if we start throwing bone density terms at you, you are not going to get it. So we tried to come up with layman's terms, we don't try to dumb it down, ever. But we do like something that they would understand."

Adapting your explanation of any procedure is important. As the statement just quoted says, there is no need to “dumb down” what you are doing but you can use more simplistic terms to explain the purpose and procedure. This is true for PWID and non-PWID alike. Some medical or scientific terms are difficult for any non-medical professional to understand and this can create anxiety. Avoid medical jargon where possible and instead pay attention to the patient’s nonverbal behaviors to gauge whether they are feeling anxious or confused. If you are having trouble adapting your communication to meet the needs of a specific PWID, do not be afraid to consult the caregiver who can often be a helpful “translator” in these cases.

Notify Physician of Noteworthy Patient Behaviors

If the physician does not perform the initial assessment, the nurse or assistant who performed the initial assessment should take note of any patient behaviors that might better prepare the physician prior to examining the patient. For example, if a patient becomes tense when touched on a certain area of the body and reacts negatively, informing the physician prepares him/her to appropriately explain the steps of the examination and prepare in advance for a possible negative reaction. This information will allow the physician to adapt during the examination stage, which is explained in the next module.

Ensure the Caregiver is Present

If a caregiver accompanies a PWID to a clinical visit, ensure that the caregiver is invited to take part in the initial assessment and examination. Caregivers are often the people who ensure that PWID adhere to recommendations and treatment regimens, so it is of utmost importance that they are able to witness exactly what takes place during each clinical interaction. Because every patient is different, some PWID may arrive with a caregiver while others do not. If a caregiver is present, they serve a purpose for being there and should always be included in the experience if both they and the patient are comfortable.

Follow-Up

During the initial assessment, we discussed how it is important to direct questions to both the patient and caregiver. With PWID, it is likely that the caregiver will provide some if not all health information about the patient. Therefore, it becomes extremely important to follow up with the patient to see if they have anything to add, or have any questions. This process not only helps to ensure understanding but it also helps to create that trusting relationship with PWID, which is essential in providing complex healthcare to PWID.

Review Chart to Avoid Redundant Questions

To develop a sustained and trusting relationship, healthcare providers should review their charts and notes to refrain from asking the same personal questions repeatedly. Create a feeling of history through the questions you ask. Caregivers notice when the same questions are asked repeatedly, which ultimately sends the message that provider does not truly know the patient. One caregiver discussed how the medical team repeatedly asks her daughter how old she is and

what her favorite color is. Healthcare providers who see the same patients often should demonstrate that they know this type of information about their patient. It is unrealistic to assume that healthcare providers would be able to memorize this type of personal information about each patient. However, making a note about it in their file will help you remember that information the next time you see them.

Find Common Ground

"I ask how they've been. We talk a lot about sports. Because I'm a big sports person and that's kind of how we have a middle ground."

The initial assessment can be somewhat invasive for PWID who are not used to being poked and prodded. However, you can make the experience a bit more comfortable with them by talking with them and attempting to find common ground. Just because they may not have the same cognitive abilities does not mean they do not share similar interests. For example, if the PWID likes sports, you might share what sports you like. These simple connections can reduce anxiety and allow for a more positive experience and relationship to form.

Time

Although healthcare providers have a limited amount of time to collect a medical history and current vitals before moving on to the examination, communicate that you care about the patient and value your time with them. Even if you are in a rush, taking the time to engage in a short conversation while waiting for them to pull their sleeve up or lay down can help communicate interest and caring. The following behaviors can assist you in maximizing your time during the initial assessment:

Allow Yourself Additional Time

"We have time for them, that if they are going to panic, that's fine. We have time to kind of, reorient them. And kind of calm them down and give them time to realize that this is an okay place, if they need to take a break go and leave and then come back in. We have that time built into it [the appointment] already."

The initial assessment may require more time when working with PWID. Rushing and not appropriately explaining the process creates anxiety for the patient and the caregiver. Taking the time at the beginning of the day to see if any PWID are visiting may allow you to adapt your schedule accordingly. If possible, it may be wise to schedule appointment times longer for PWID so the time is built into your schedule and you can take your time with the patient.

Provide Complete Responses to Questions

If a question arises during the initial assessment, take the time to answer it fully to minimize additional questions about the same thing later on. Information collected during the initial assessment will lay the foundation for questions that are asked during the examination, possible diagnoses, and treatment decisions. So ignoring a question will not make it disappear. The same

question will likely arise again later in the visit, and at that time may require a more complex and time consuming explanation.

Activity: Put participants into groups of 4-5. You may adapt group size based on the size of the training. Ask participants to assign one person as the scribe. Have each group come up with a list of concerns that they think PWID may have during the initial assessment and 1-2 ways they could implement RAFT to deal with those concerns. After each group has finished, ask each group to share their top three.

Module 4: Clinical Examination

The examination stage of the patient experience often produces the most anxiety. This is the most crucial stage of the patient experience and if the RAFT model is properly implemented in the previous stages, the examination has a stronger likelihood of success. As mentioned previously, the continued implementation of RAFT throughout the entire clinical visit is essential in creating a positive experience for PWID.

Respect

While it is important for PWID and their caregivers to feel respected by the office/reception staff, it is of utmost importance that they also feel respected by the healthcare provider responsible for performing the examination and prescribing treatment recommendations as necessary. If RAFT is not implemented during the examination phase, the entire patient experience is likely to suffer. Reception staff and nurses are likely to rotate, so it is possible that different staff greet the patient and take their vitals at each visit. However, the patient typically sees the same physician, so it is likely that PWID and their caregivers place greater importance on feeling respected by the physicians themselves. The following behaviors can be implemented during the examination to communicate respect:

Acknowledge the Role of the Patient and Caregiver

"I'll sit in the room and she'll ask her questions. I don't take over everything. I let her – let them work it out with her. Because sometimes she might tell her something she might not tell me. I'm there to protect her, but by protecting someone, I think you need you make them independent, as independent as you can."

Earlier we discussed the importance of acknowledging the patient before acknowledging the caregiver. The same is true in the examination phase of the clinical interaction. If the physician also performed the initial assessment, there is no need to greet the patient and caregiver again. Continue to refer to both parties by name and direct your conversation to the patient while also allowing the caregiver to provide supplemental information as needed. Just as suggested during the initial assessment stage, project your voice so that all parties in the room can follow along. However, you should encourage the patient to tell their story first, before asking the caregiver if he/she has anything to add. While a caregiver may be able to provide a medical history, or a list of symptoms, the patient is the only one who can explain how those symptoms make them feel. Keeping in mind that the caregiver is present and reminding yourself that they are present to support the patient will help you to maintain your focus on the patient, thereby communicating a sense of respect to both parties.

Trust Caregivers' Insight and Knowledge

"And he has his moods, so you know; we've been with him for 16 years so we understand all of that, and the eye gazes and stuff like that. And people just don't take the time to look for those cues. And we even have family members that don't, so you know it's just one of those things and it's a different world."

Caregivers often know PWID the best because they spend the most time with them. Therefore, they will likely be the ones to quickly spot normal or abnormal behaviors for that patient. This level of knowledge becomes important when dealing with nonverbal PWID. While it may be hard for you to interpret what their hand signals, gestures, and facial expressions actually mean, the caregiver can act as a translator for you. Caregivers note that when physicians trust the caregiver it can “make or break” a clinical visit. Although you want to ensure that you are focused on the patient, you should not be afraid to encourage caregivers to provide insight during the examination. After all, they are there to help both you and the PWID better understand one another.

Explain Each Procedure Before Performing It

“Sometimes there are different tools we pull out and sometimes that can cause fear and “oh are you going to give me a shot” and so showing them the tools we are using and like we will have a light and kind of show them, “okay, this is a light and we are going to look in your ear” and kind of point and gesture to kind of convey, so that it is easier to understand.”

You will remember that we discussed how important it is for healthcare providers to share the details of any procedure using short sentences and simple language, free of medical jargon. During the examination phase is likely where the most invasive procedures occur, so continuing this process is essential. In order to pinpoint the root of any given health issue, the physician may need to touch sensitive areas on the body, run tests with unfamiliar and intimidating equipment, or even give the patient a shot. All of these procedures have the potential to create anxiety or even induce a certain level of pain or discomfort for patients. Notifying patients and caregivers about what to expect prior to performing a given procedure will help them to prepare which should also decrease their anxiety by eliminating any surprises.

Utilize Multiple Nonverbal Behaviors

We have already learned about the importance of nonverbal immediacy when dealing with PWID. We know that behaviors such as eye contact, smiling, and being aware of physical barriers communicate respect for PWID. However, there is another side of nonverbal communication. This step involves slowing down the pace of the conversation, repeating important points regularly, and using gestures to emphasize the more important points. These nonverbal behaviors are beneficial for all patients, but are extremely useful for PWID who may be more comfortable communicating nonverbally. Adding these small details into your usual communicative pattern will not only promote increased understanding, but will also help you to demonstrate respect in different ways in different stages of the clinical experience.

Listen to Understand Rather than to Respond

“If there is an instance where someone asks, “How are you?” she’s going to respond, “I’m fine.” Whether she is or she isn’t. So getting them [the physicians] to understand that what she’s speaking is not necessarily what it means. I think one of the biggest things is take the time. Take the time to listen. Take the time to learn more about these disabilities.”

It is important for providers to understand the difference between hearing and listening. Hearing is the physiological process of perceiving sound, whereas listening requires your brain to process what is being said and assign meaning to the words. Hearing may be more appealing for healthcare providers because it takes less time and allows you to simply nod and smile while completing other tasks such as recording information or thinking about your next course of action. However, taking the time to listen to PWID' stories or concerns will help you to make connections that will allow you to understand your patients on a deeper level. This information will come in handy when introducing possible treatment plans to best fit the needs of the patient and his/her situation. Listening requires respect and empathy for the patient's situation.

Accommodation

Flexibility and a willingness to adapt your usual examination routine to meet the unique needs of your patients will help create a positive clinical experience. PWID may require a level of explanation and adaptation that non-PWID do not require. Again, it is imperative that physicians continue to emulate the same level of accommodations as the other providers and office/reception staff during examinations to ensure consistency. The following RAFT behaviors will help you adapt your behaviors to accommodate the needs of your PWID during the physical exam:

Use Multiple Modalities to Explain a Procedure

Adapting your explanation of any procedure is important. We've already explained why healthcare providers should avoid using medical jargon whenever possible. Although using short sentences and simple terms may be enough during the initial assessment, often times the health information provided during the examination is more complex and may warrant additional modalities to help ensure understanding for PWID. Using a visual representation to accompany your spoken words can make it easier for the patient to follow along. These visual aids may be in the form of a model such as a skeleton that allows you to demonstrate how limbs move, a chart or graph that tracks height and weight percentiles, a picture that depicts what internal systems like the digestive system look like, or even something that you draw out on a sheet of paper. Having these visual aids to complement your spoken words allows the patient to utilize the combination of modalities that works best for them.

Utilize Your Resources to Make Patients Comfortable

Some PWID may be naturally more anxious about a physical exam than others. Recognize that one strategy that works for one PWID may not work with another. Although it is ideal to encourage the patient's engagement in all aspects of the clinical interaction, he/she may prefer to play a less active role in order to calm their nerves. If this is the case, you might consider bringing in books/toys/games from the waiting room to make them more comfortable. Additionally, you might keep some stuffed animals on hand to help comfort patients during painful procedures such as a finger stick or shot. Being open to different options allows you to provide a unique experience for each patient. Make note of what a particular patient likes and dislikes so that you can be prepared to offer similar accommodations in the future.

Follow-Up

While it is important to schedule follow-up appointments with PWID to check in on them periodically, it is also important to check in on patients while they are still in the office, so that immediate adjustments can be made as needed. Although you should have explained the details of a procedure before performing it, it is still important to check in with them throughout to ensure that they remain comfortable. This also communicates that you care about them and are open to making adjustments if needed. The following RAFT behaviors demonstrate how you can follow-up with patients during the examination:

Ask About Biomedical and Biopsychosocial Aspects of the Patient's Experience

Just as it is important for the patient to understand what you are doing, it is important for you to try to understand exactly what the patient is experiencing. This may require you to ask several follow-up questions and actively listen to both the patient and caregiver. Although your main purpose is to check for understanding about medical information, it is also beneficial for you to tap into the patient's emotional experience as well. In some cases, a patient's emotional state may require you to refer them for an additional examination. In other cases, a patient's emotions could lead you to uncover side effects of prescribed medications. Either way, focusing solely on routine medical questions may function to distance the patient from you. In an effort to continue the relational development process with patients and caregivers, it is important for them to see you as a "real" person.

Time

Because of the additional accommodations that PWID require during the physical exam, healthcare providers can expect to spend more time engaged in the examination with these patients. However, if RAFT is properly implemented throughout all stages of the clinical experience, the office/reception staff should have already accounted for a longer appointment time for PWID. This information should be communicated from the office/reception staff to physicians and other healthcare providers so that they do not feel as though they need to rush to their next appointment. The following behaviors will help you maximize your time while providing high quality healthcare to PWID:

Summarize Information and Provide Comparisons

"He [the physician] would go on and talk about your blood pressure and talk about things you needed to do. He was great. He was just great...and he would go through his records. He would say, 'It was this way last year, and this is what you can do to be better.'"

When informing the patient about the results of their exam, provide some context for the information you are providing. Just as it is important to establish consistency as PWID transition through their clinical visit, it is also important for physicians to point out consistencies or inconsistencies in patients' current health status based on past medical records. Providing this information up front and explaining why the results are consistent or inconsistent with prior visits may reduce anxiety as well as reduce the number of patient and/or caregiver questions.

Provide Complete Responses to Questions

"Yeah, I think that there has to be a little more understanding. We're going to go in and we might have, a lot of questions... You know, it is going to require a little more time than your normal patient."

The results of the physical exam will elicit numerous questions. Just as taking the time to answer questions during the initial assessment should minimize questions later on, the same is also true for questions that arise during the examination. However, ensuring that the proper time is spent on questions during the physical exam is also linked to important determinants of health outcomes such as treatment and medication adherence. Taking time during the physical exam to answer questions may prevent a simple misunderstanding.

Activity: The purpose of this activity is to help participants practice listening to understand, rather than listening to respond. Arrange participants into pairs. Have each person take turns describing a situation in which they were a patient. This could be an experience at a hospital, dentist's office, or primary care provider's office. Describe (1) why you were there, (2) how you felt, and (3) what the office/reception staff or healthcare provider did to either make you feel comfortable or more uncomfortable. Note that this story can be fictional, or the details can be changed to maintain confidentiality. The story is not the focus of this exercise. Rather, the listener should practice *listening to understand*, using verbal and nonverbal behaviors. The storyteller will then provide feedback and constructive criticism to the listener. Each person should have a turn as the storyteller and listener.

Module 5: Clarification and Discharge

Upon completion of the physical examination, the patient and the caregiver should feel confident about the next steps, and leave with the necessary information to successfully follow the treatment plan. Providing clarification before the PWID leaves the office ensures that the experience ends positively, leaving the patient and caregiver feeling fulfilled. Just as RAFT behaviors should be implemented by office/reception staff at the start of a clinical visit, they must continue to be implemented until the patient leaves the office. The following behaviors are recommended for healthcare providers and office/reception staff.

Respect

So far, we have discussed the importance of showing respect for patients and caregivers throughout the clinical visit, and this respect should continue even after the conclusion of the examination. The following behaviors could be implemented to communicate respect at the conclusion of a patient's visit:

Greet the Patient When They Return to the Reception Desk

After being examined by a physician or other healthcare provider, PWID and their caregivers will return to the reception area. Even if they do not stop, be sure to acknowledge the patient's presence and wish them a good day. In some cases where you have an established relationship with a patient, it may be appropriate for you to ask how the visit went. Showing a continued interest in the patient and his/her experience will help you to develop rapport with PWID and their caregivers.

Explain Instructions to the Patient and Caregiver

Because caregivers play such a vital role in the continued care of PWID, it is important that they are present for and included in conversations or clarifications about the next steps. Instructions could refer to information about a prescription medication, follow-up appointment, or referral to another healthcare provider. Be sensitive to both the patient and caregiver's needs and requests. For example, if you are scheduling a follow-up appointment ask if a date and time works for both the patient *and* caregiver, since it is ultimately the caregiver who must accompany the PWID to any appointments.

Demonstrate Nonverbal Immediacy

"Well they do like hugs, so when they want a hug, I do like to give them a hug."

Healthcare providers as well as the office/reception staff should continue to display positive nonverbal behaviors such as establishing eye contact, smiling, waving, or perhaps even a pat on the shoulder if appropriate. These behaviors can help communicate to the patient that he/she did a good job, or that you are proud of them. This will ensure that their visit ends on a positive note, and also allows you to continue developing a trusting relationship with the patient.

Adapt

PWID and caregivers typically emerge from the examination phase of the clinical visit with a plethora of information, recommendations, and resources. It may take them a moment to process that information, or they may need assistance in determining which course of action is most pressing. It is important for healthcare providers to help patients and caregivers decode such information. Consider the following behaviors when communicating with an PWID and their caregiver as they leave the office:

Provide Both Spoken and Written Instructions for Treatment Plans

"If there is a coach with them we try to convey [recommendations] to the coach too and we will also have a form so that if there are any recommendations that we have them in written form in a situation where the athlete doesn't understand what we are saying. And that form can be given to someone else who is helping with their care."

All patients leave a clinical visit with recommendations for what they should do next. However, for PWID, their recommendations may be more complex or they may have a harder time processing the information. Therefore, providing the instructions in writing can help patients and caregivers organize their thoughts and develop a course of action. Such materials will provide information for PWID and their caregivers to refer back to once they are home, or provide to other caregivers who may not have accompanied the patient to their clinical visit. Writing information down also helps convert important information from short-term into long-term memory.

Re-explain Treatment Recommendations

Many caregivers expressed how they often feel rushed out of the office and leave without truly understanding the treatment plan or next steps. If the PWID and caregiver do not understand their instructions, try explaining them in a different way. As stated earlier, simply repeating the same thing repeatedly will not create understanding. Think of a new way to explain the information and do not be afraid to use the written material you have provided to help you in this process.

Provide Additional Resources for Caregivers

"I think that [caregivers] all should talk to other people that have children. Doesn't matter what their disabilities are, because that's where I learned the most. Not from my doctors, but getting together with other families and trading stories of school and that. Communicating with other families who have special needs people."

Remember that the caregiver plays a major role in caring for a PWID. You may need to provide additional information to the caregiver about his or her specific role in the patient's recommended prevention/treatment plan. Think of ways the caregiver can provide additional support. You might also consider sharing information about caregiver support resources such as organizations that provide assistance or support groups for caregivers of PWID.

Follow-Up

Continuing to follow-up with patients is incredibly important when the patient exits the office because this is the final opportunity to clarify any information or address any concerns that the patient or caregiver may still have. Remember, the follow-up step refers to both informational and relational factors. Follow-up behaviors have a lasting impact on the patient's experience, perception, and relationship with healthcare providers as well as office/reception staff. Here are a few recommendations for ways to follow-up with patients before they exit the office:

Use the "Teach Back" Technique to Check for Accuracy

Do not be afraid to ask the PWID or the caregiver to repeat instructions or treatment plans back to you. You may say something like, "Tell me about what you will do when you get home to help you stay healthy." This "teach back" message is a way for you to ensure understanding and increase the likelihood that the patient will follow the treatment plan.

Address Any Remaining Concerns

Before the patient leaves, address any remaining concerns. Ask the patient and the caregiver if there are any other concerns or questions they still have. At this point it is still not too late for the healthcare provider to clarify recommendations. Moreover, your availability to PWID and their caregivers at the conclusion of their visit communicates that you care about the patient even after they leave the office.

Time

No patient should be rushed out of the door once the examination is complete. Take an appropriate amount of time to ensure that the PWID and caregiver leave the office feeling confident in their course of action and feel supported by their healthcare provider and office/reception staff. The following behaviors may help you to maximize time in the final minutes of the PWID's visit:

Slow Down and Think Carefully About Referrals

If a referral is necessary, take the time to think carefully about the healthcare provider you choose to refer your PWID to. Additional time should already be built into the appointment so that providers will have adequate time to make quality decisions, including those about any referrals. Think about your patient's unique needs and challenges as well as your colleague to determine the best fit. With any referral, it is imperative that you provide clarifying information about the healthcare provider that you suggested in order to help reduce the anxiety associated with seeing a new unfamiliar provider. If you are having a hard time making a decision, you may lay out some options for PWID and their caregivers with your ideas for why they would be a good match, and let them decide which provider they would prefer.

Follow-Up After Patients Return Home

"I think that's a key thing, just following up with them to make sure things have happened."

Because sometimes families need lots of reminders of things that need to happen.”

Although it may be time consuming to check in on patients between visits, scheduling a short phone call can help ensure that patients are following their treatment regimens. These types of conversations also allow caregivers to receive clarification on specific recommendations. Addressing these issues over the phone can save time during the patient’s next visit, or may even prevent an emergency visit. These phone calls also function to enhance relationships with the PWID and caregiver. Small gestures like this can also communicate credibility and instill confidence in caregivers who often carry a lot of physical and emotional responsibility for PWID.

Taking the time to perform the abovementioned behaviors for each step of RAFT will greatly improve the PWID experience, improve the overall quality of care PWID receive, as well as enhance your experience as a healthcare provider. These simple behaviors do not require much time but will provide beneficial results.

Activity: As the trainer you will facilitate a group discussion. The discussion should focus around the question: How should healthcare providers and office/reception staff provide clarification before leaving? You might ask participants about their reactions to this last module. Below are some prompts you might use to get the participants engaged:

- Is it mainly the healthcare provider’s responsibility to provide clarification?
- Are office/reception staff qualified to provide clarification on medications and treatment?
- Should the healthcare provider escort the patient back to the reception area?
- What if the patient does not want to follow the recommendation?
- What if the patient does not stop at the reception desk on the way out? Should you stop them?

Module 6: RAFT Case Study

Instructions

Note: This module can be used as an exercise or as a final test of participants' knowledge.

Let's put your RAFT knowledge to the test. The following is a testimonial provided by a physician with a Down Syndrome patient. This example serves as an excellent case study for demonstrating the positive effects of implementing RAFT behaviors. Read the testimonial carefully and make note of any behavior that you think resembles RAFT. Also make note of instances where RAFT could have been implemented. Be sure to mark the appropriate letter for each behavior (Respect, Accommodation, Follow-up, Time). You may find more than one example for some of the RAFT behaviors.

Case Study

I had a Down syndrome patient who came to our clinic because he couldn't talk. He was socially subdued most of the time. Yet the nurses noticed that he was particularly entertained by the books that had pop ups. They made sure to keep these on hand for him. We even had a note in his file so that the new nurses would know how to get him engaged or regain his attention if he got distracted. His inability to talk was an ongoing issue. He had seen multiple providers who all suggested that he needed to develop his social skills. This answer was not enough for me. I made a list of medical conditions that could have potentially been contributing to the issue. I looked into his medical history and asked his parents many questions. As it turned out, he had failed his newborn hearing test and no action had been taken since that time. He also had a history of recurring ear infections but no one had connected the issue to his newborn hearing test.

After multiple appointments and discussions with his family, we went ahead with testing. It took a lot of tests and a lot of trial and error, but when we received his hearing test results it was evident that he had severe to profound hearing loss. After further testing and follow up, we confirmed that he was not hearing anything at all. I concluded that his speaking issue was most likely a result of his hearing impairment and not a result of social issues related to his intellectual disability. We started working with the family to get him the help that he needed. We connected him with a specialist who could provide more targeted treatment for the ear infections he was experiencing. We identified a great ENT who had experience working with patients with intellectual disabilities. As a result, the ear infections were finally taken care of and he even received hearing aids. However, at that point he was already seven, and we'd missed the window for language development. So we had had to start thinking through other possibilities. Although he wasn't benefitting too much from his hearing aids, he was at least hearing a little more, and learning more about the sounds around his environment. Within a few months we saw a quick shift in his demeanor. We have routine check-ins with him and he is definitely more connected to what's going on around him. It is upsetting that it took that long for anything to happen because previous doctors did not spend the time with him and his family. It could have been a better situation if testing happened sooner.

R:

A:

F:

T:

Sample Answers

R: The provider listened to the caregiver and considered patient-specific aspects of the situation. This patient, although he was nonverbal, was treated like a human who deserved a proper diagnosis. The provider trusted the caregiver's insights and knowledge about the situation.

A: The nurses kept the pop-up books on hand for the patient and put a note in his file so that other providers would know what he liked. The provider shifted from previous scripts identifying social skills as the reason for the patient's inability to talk and asked the caregiver a number of questions to help him carefully consider the situation. The caregiver was present in all aspects of patient care.

F: The provider asked specific questions about the biopsychosocial aspects of the patient's health experience. The provider offered continued care and follow-up to see what was working. He recommended further testing and checked back in with the patient and caregiver to see if the problem had been resolved. He worked to identify an ENT that would be a good fit for this particular patient. The provider still has routine check-ins with the patient even though he is now seeing a specialist.

T: The provider took the time to invest in the care and diagnosis process despite the complicated situation and the patient's inability to provide any verbal feedback. The provider carefully considered the possibilities before executing treatment, and did not give up despite the continued trial and error.

Trainer Tips for Unpacking the Case Study

- Ask why what the participants point out is representative of the specific RAFT letter. What about that behavior makes it Respect, Accommodation, Follow-up, or Time?
- Ask the participants about Time specifically. In this case do they think the extra time was worth it? Would most healthcare providers take the time to do this?
- What else could the physician have done to improve the PWID experience?
- What stood out as having the biggest impact on this patient?
- Do you have any related stories that you would like to share? Sometimes your training participants are able to provide the best examples.
- Remind the participants that much of the painful experiences for the child and his family could have been avoided if RAFT was properly implemented from the patient's initial visit.
- Discussions related to specific examples and explanations will help participants remember RAFT after the conclusion of the training.

Module 7: Conclusion and Feedback

Before you dismiss participants, be sure to have each participant flip to page 10 of their training packet and answer the following questions. Depending on time and the providers' experience, you may have participants fill this out or just use it as a guide for one final discussion and closeout. Also use this time to answer any questions that participants may have.

1. At what point during the patient experience would you use RAFT? Answer: *At every stage of the patient experience.*
2. What do you consider the most valuable aspect of RAFT? Explain why. Answer: *This will vary depending on the group you are working with and will be opinion based.*
3. Do you have any remaining questions?
4. Based on your expertise and experience, do you have any recommendations for improving RAFT Training? We appreciate your feedback.

APPENDIX C: ATTITUDE INSTRUMENT

Instructions: The following questions focus on your general perceptions about providing care to patients with intellectual disabilities. In these questions, patients with intellectual disabilities are referred to as “PWID.” Please use the following scale to indicate your level of agreement that the item applies to you:

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Somewhat Disagree
- 4 = Neutral
- 5 = Somewhat Agree
- 6 = Agree
- 7 = Strongly Agree

- ☐ 1. *If available, I would request a private waiting area for PWID.
- ☐ 2. *It would be more difficult to carry out procedures with PWID compared to other patients.
- ☐ 3. *PWID are more difficult to care for, because they do not comply with requests.
- ☐ 4. *I would not spend too much time explaining information to PWID, as it is hard for them to understand.
- ☐ 5. *I would not ask PWID if they were in pain as they would not be able to tell me.
- ☐ 6. It is worthwhile to talk directly to PWID as well as consult with their family/caregivers.
- ☐ 7. PWID would not be any more emotional than other patients.
- ☐ 8. *PWID would probably be more easily distressed or upset compared with other patients.
- ☐ 9. *I would be cautious when approaching PWID as they may become aggressive.
- ☐ 10. I would expect PWID to be as willing and cooperative as other patients.
- ☐ 11. *I am reluctant to service PWID because doing so would take up too much time.
- ☐ 12. *Servicing PWID would take up more time than I have available.
- ☐ 13. The health needs of PWID can be adequately met within mainstream hospital services.
- ☐ 14. I feel that I have adequate skills and training to effectively service PWID.
- ☐ 15. I would want relatives/caregivers to stay and help out during my interaction with PWID.
- ☐ 16. I expect PWID to experience discomfort in the same way as other patients.

Note: * indicates that item is reverse-scored.

APPENDIX D: PERCEIVED BEHAVIORAL CONTROL INSTRUMENT

Instructions: The following questions focus on your general ability to accommodate the needs of patients with intellectual disabilities. In these questions, patients with intellectual disabilities are referred to as “PWID.” Please use the following scale to indicate your level of agreement that the item applies to you:

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Somewhat Disagree
- 4 = Neutral
- 5 = Somewhat Agree
- 6 = Agree
- 7 = Strongly Agree

Respect: Speak Directly to PWID

- ☐ 1. I am confident in speaking directly to PWID.
- ☐ 2. *Speaking directly to PWID is difficult.
- ☐ 3. *Even if I want to speak to PWID directly, there are factors that prevent me from doing so.

Accommodation: Listen to PWID Personal Experiences

- ☐ 4. I am confident that I can take the time to listen to PWID explain their personal experiences.
- ☐ 5. *It is hard to take the time to listen to PWID’s personal experiences.
- ☐ 6. *Taking the time to listen to PWID’s personal experiences requires extra time that I do not have.

Follow-Up: Check for Understanding

- ☐ 7. I feel comfortable asking PWID to explain their understanding of information.
- ☐ 8. *Asking PWID to explain their understanding of information complicates things.
- ☐ 9. *Asking PWID to explain their understanding of information requires additional resources that I do not have access to.

Time: Provide Simple and Complete Explanations

- ☐ 10. I am confident in my ability to explain information to PWID in simple terms.
- ☐ 11. It is easy for me to use plain language when explaining information to PWID.
- ☐ 12. *It is impossible to use plain language to explain complex information to PWID.

Note: * indicates that item is reverse-scored.

APPENDIX E: UNCERTAINTY INSTRUMENT

Instructions: The following questions focus on your confidence in knowing how interactions with patients with intellectual disabilities will evolve. In these questions, patients with intellectual disabilities are referred to as “PWID.” Please use the following scale to indicate your level of agreement that the item applies to you:

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Somewhat Disagree
- 4 = Neutral
- 5 = Somewhat Agree
- 6 = Agree
- 7 = Strongly Agree

- ☐ 1. I am confident in my general ability to predict how PWID will behave.
- ☐ 2. *I have a hard time accurately determining how much PWID like/dislike me.
- ☐ 3. Generally, I am confident in my ability to accurately predict PWID’s attitudes.
- ☐ 4. *I do not feel fully confident in my ability to accurately predict PWID’s feelings and emotions.
- ☐ 5. *It is hard for me to empathize with the way PWID feel about themselves.
- ☐ 6. In general, I am able to learn a lot about PWID after I meet them for the first time.

Note: * indicates that item is reverse-scored.

APPENDIX F: ANXIETY INSTRUMENT

Instructions: The following questions focus feelings you experience when caring for patients with intellectual disabilities. In these questions, patients with intellectual disabilities are referred to as “PWID.” Please use the following scale to indicate your level of agreement that the item applies to you:

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Somewhat Disagree
- 4 = Neutral
- 5 = Somewhat Agree
- 6 = Agree
- 7 = Strongly Agree

- ___ 1. The most pleasurable part of my job is caring for PWID.
- ___ 2. *I feel discouraged when communicating with PWID.
- ___ 3. I feel rejuvenated after interacting with PWID.
- ___ 4. *I have little energy when caring for PWID.
- ___ 5. *I feel like a failure when caring for PWID.
- ___ 6. It is easy to concentrate on the task at hand when I am around PWID.
- ___ 7. *I feel fidgety or restless around PWID.
- ___ 8. I am the best person to work with PWID.

Note: * indicates that item is reverse-scored.

APPENDIX G: BEHAVIORAL INTENTION INSTRUMENT

Instructions: The following questions ask you to think about future interactions with patients with intellectual disabilities. In these questions, patients with intellectual disabilities are referred to as “PWID.” Please use the following scale to indicate your level of agreement that the item applies to you:

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Somewhat Disagree
- 4 = Neutral
- 5 = Somewhat Agree
- 6 = Agree
- 7 = Strongly Agree

Respect: Speak Directly to ID Patient

- ☐ 1. I plan to address PWID directly.
- ☐ 2. *It is unlikely that I will speak directly with PWID.
- ☐ 3. I will address PWID before their caregivers.

Accommodation: Listen to PWID’ Personal Experiences

- ☐ 4. I plan to devote extra time to listen to PWID tell me about their experiences.
- ☐ 5. It is highly likely that I will solicit PWID’s perspectives.
- ☐ 6. *To save time I will not encourage PWID to share a personal story.

Follow-Up: Check for Understanding

- ☐ 7. *I will ask family/caregivers for permission before asking PWID if they understand.
- ☐ 8. I plan to ask PWID to explain their understanding about health-related information.
- ☐ 9. It will likely ask patients to explain their understanding about health related information.

Time: Provide Simple and Complete Explanations

- ☐ 10. I plan to use simple language to explain health information to PWID.
- ☐ 11. It is likely that I will simplify complex information for PWID.
- ☐ 12. *I will not exclude medical terminology when I explain complex information to PWID.

Note: * indicates that item is reverse-scored.

APPENDIX H: SUMMATIVE ASSESSMENT OF RAFT

1. Do you feel more prepared to service PWID after completing RAFT Training?
 - (a) Yes
 - (b) No
2. At what point in the patient's experience would you use RAFT?
 - (a) when examining the patient
 - (b) when checking the patient in at the front desk
 - (c) during a follow-up appointment
 - (d) a and b
 - (e) all of the above
3. A PWID comes in for a routine checkup. Which of the following would be the best way to communicate with them based on RAFT?
 - (a) smile at them while talking with their caregiver
 - (b) address the patient but get important information from the caregiver
 - (c) speak directly to the patient and acknowledge the caregiver's insights
 - (d) ask the caregiver to make sure the patient understands
 - (e) none of the above
4. If you see that the PWID is having a hard time understanding you, the best thing to do is:
 - (a) slow down and explain the information in a different way, maybe with pictures
 - (b) slow down and repeat yourself until the patient understands
 - (c) ask the caregiver to explain the information to the patient later
 - (d) b and c
 - (e) all of the above
5. Why is it important to follow-up with PWID both during and after their appointment?
 - (a) you want to make sure that they come back
 - (b) to ensure understanding while the patient is still present or to avoid emergency visits
 - (c) it is only important to follow up with patients after they leave the office
 - (d) to develop a lasting relationship with them
 - (e) b and d
6. How can you maximize time during interactions with PWID?
 - (a) skip questions that the patient/caregiver asks and leave it for the end
 - (b) take the time to answer patient's questions fully and consult the patient's chart
 - (c) schedule longer appointment times for PWID
 - (d) a and b
 - (e) b and c

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