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# Gender as an Occupation: The Role of OT in the Transgender Community

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# **GENDER AS AN OCCUPATION:** THE ROLE OF OT IN THE TRANSGENDER COMMUNITY

A Master's Thesis Presented to the Faculty of the Graduate Program in OT Ithaca College

In partial fulfillment of the requirements for the degree of Master of Science

By

Jamie Kimelstein

October 2019

## Abstract

Gender is a performative act constituted through engagement in many occupations such as dressing, grooming, and communication. The occupations of transgender individuals may be impacted by the transition process and must be fully understood. Occupational therapy practitioners are skilled in analyzing the supports and barriers people experience when engaging in their occupations, thus can be instrumental in facilitating transgender individuals' engagement in the occupation of gender. The purpose of this study is to explore the occupations of transgender people and begin to understand the relationship between occupation and gender performance. The information gathered can help to inform the role of OT in working with the transgender population.

# Acknowledgements

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Dedication For Nanny. molta bella

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# **Chapter 1: Introduction**

# Introduction

Of all the 1,397,150 transgender adults in the United States, 41% have attempted suicide with a total of 287,000 attempted suicides per year (Virupaksha, Muralidhar, & Ramakrishna, 2016). This staggering number would lead us to believe that health care professionals across all disciplines are scrambling to find the most effective way to help an entire population of people. However, the world's largest health organizations currently have little to no publications on the subject of transgender health. For example, the Center for Disease Control has a total of three publications geared for health professionals on how to provide acceptable care for transgender people. This scarcity of research is evident in occupational therapy (OT) literature as well as other allied health professions. To this end, more research is needed to gain an understanding of the occupational needs of transgender people in order to assist OT practitioners in better serving this population.

# Background

When a child is born in the United States, the first thing noted is their sex. This sex assignment is noted on the birth certificate based on the appearance of the individual's genitals. Due to our preconceived notions of gender and sex, it is believed that one's genitalia will determine the way in which the child will interact with their environment and peers. Gender, unlike sex, is a socially conceived notion of the rules and expectations boys and girls are to follow. These preconceived notions represent the concept of gender as a societal construct versus gender as determined by sex. The aforementioned guidelines can include anything from the careers we occupy to the way we sit on the bus. The heralded sociologist,

Judith Butler (1988), proposed the performative gender theory in her essay "Performative Acts and Gender Constitution." In short, this hypothesis outlines the idea that gender is an act that you must 'put on' each day. No individual is born with a gender because the definition of gender is created through the context of society. This is reflected in many non-western cultures in which there are more than two genders, for example, the Hijra of South Asia (Goel, 2016). Using Butler's (1988) widely accepted theory, gender immediately transforms from an innate part of our physical body to an occupation that requires attention and planning. In order to participate in the occupation of gender, one must first complete multiple activities of daily living (ADLs) including, but not limited to dressing, hair styling, make-up, walking, and toileting.

As a child ages and the societal effects of gender make a larger impact on function, they may feel that the gender assigned to them at birth was not accurate. The word coined for this happenstance is transgender. Transgender is an adjective used to describe a person whose gender identity is incongruent with (or does not "match") the biological sex they were assigned at birth. "Transgender" serves an umbrella term to refer to the full range and diversity of identities within transgender communities because it is currently the most widely used and recognized term (Green & Maurer, 2015). Transgender individuals will often implement gender affirming modalities commonly referred to as binding or tucking, amongst others. This process of fulfilling roles, habits, and routines to better match one's gender identity is referred to as transition (Transgender Student Education Resources (TSER), 2016). Most importantly, the way in which these occupations are carried out will have a profound effect on the individual's performance of gender. OT has the distinct value of analyzing a person's occupational performance in a given context and recommending client-centered modifications or adaptations that will aid in the individual's ability to perform their occupations, including those of gender constitution. The American OT Association (AOTA) defines OT in stating, "OT services are provided for habilitation, rehabilitation, and the promotion of health and wellness to those who have or are at risk for developing an illness, injury, disease, disorder, condition, impairment, disability, activity limitation, or participation restriction" (AOTA, 2014, p. S1). According to this definition, OT can help with establishing and adapting new ways to express gender and adapting their current ways of interacting with their contexts.

According to the OT Practice Framework (2014), occupational justice is defined as "a justice that recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class, or other differences" (p. S9). Using this understanding of occupational justice, transgender people are victim to a great deal of injustices. When individuals are unable to engage in occupations due to their gender, they experience occupational injustices which can negatively impact health and wellbeing (AOTA, 2014). This is of significance because research has shown that engagement in meaningful occupations is necessary for health and wellbeing (Wilcock, 2006). Therefore, it is the responsibility of OT practitioners to learn about the occupational needs of transgender individuals in order to ensure they can fully participate in their lives.

# Statement of problem

Currently, there is a scarcity of evidence for OT practitioners for meeting the specific needs of the transgender community. There have been no studies that explore the occupational needs of transgender individuals and this information is important to fully understand the occupation of gender.

#### **Rationale for study**

This study is needed due to the severe lack of evidence that currently exists in the OT literature. This study will help to contribute to the evidence base to which OT practitioners can turn in order to provide the highest level of care to their transgender clients. The progress of transition is without a defined beginning and end, which requires constant adaptation to the individual's context and environment.

# **Purpose of study**

The purpose of this study is to explore the occupations of transgender people during transition to better understand how transgender people carry out the occupation of gender.

# **Research questions**

What occupations do transgender people identify as being impacted during their transition process?

Which occupations do transgender people identify as important?

How satisfied are transgender people with their current performance of occupations?

# **Operational Definitions**

**Sex:** The biological makeup of the individual including appearance of genitals, hormones, and chromosomes (Wu, 2016).

**Gender:** The way which one conducts themselves, often described as masculine and feminine, in personal, social, environment, and virtual contexts, coinciding with personal identity (TSER, 2016).

**Transgender:** An adjective used to describe a person whose gender identity is incongruent with (or does not "match") the biological sex they were assigned at birth. "Transgender" serves an umbrella term to refer to the full range and diversity of identities within transgender communities because it is currently the most widely used and recognized term (Green & Maurer, 2015).

**Transition:** The process of developing and assuming gender expression to match one's gender identity (TSER, 2016).

**Transmasculine:** Those who identify as more masculine, includes transgender men (Human Rights Campaign, 2015).

**Transfeminine**: Those who identify as more feminine, includes transgender women (Human Rights Campaign, 2015).

**Non-binary:** A descriptive term used for those who do not identify as masculine or feminine, or who identify as both, or as outside the gender binary (TSER, 2016).

**Cisgender**: (pronounced /sis-gender/): An adjective to describe a person whose gender identity is congruent with (or "matches") the biological sex they were assigned at birth. It is sometimes abbreviated as 'cis' (Green & Maurer, 2015).

#### **Chapter 2: Literature Review**

# **Gender versus Sex**

The conflation of sex and gender is highly problematic and widespread; the misunderstanding between these concepts is the driving force behind the oppression of transgender individuals in all westernized countries. When it is assumed that gender and sex are synonymous, the possibility of the transgender experience is erased. However, transgender identities are valid, as evidenced through the variance of biology and gender expression that have existed throughout history. Clarification of the differences between the terms gender and sex can assist with building understanding and acceptance.

Sex refers to the biological makeup of the individual and the development of secondary sex characteristics; whereas gender refers to the ways in which we conduct ourselves in personal, social, environmental, and virtual contexts (Wu, 2016). It is important to note that as gender has become more widely understood as a non-binary experience, an increased number of studies have also concluded that sex, too, is on a spectrum. Wu (2016) explains this concept as follows:

Sex determination – the way we are "coded" into a biological sex – is <u>complicated in</u> <u>and of itself</u>. There are far more options than just "male" or "female," and countless instances of species that can actually transition from one sex to another within a single lifetime. With most mammals, however, the majority of individuals are cisgender male or female; transgender individuals are estimated to comprise about <u>0.3% of the adult U.S. population</u> (p. 2). It is important to note, however that this statistic has recently been reported to have risen to 0.58% of the US population, by the Williams Institute at ACLU (Flores, Herman, Gates, & Taylor, 2015).

# **Transgender Identity**

# Etymology of the word transgender.

The term transgender is defined as the experience through which someone identifies outside the gender they were assigned at birth (Green & Maurer, 2015). The term transgender is intentionally used rather than transsexual or transvestite as both of these latter terms have become derogatory and highly offensive to many in the transgender community. The term used today for this group of people is trans or transgender, which evolved over many years after being introduced in a United States based medical textbook in 1965 by Dr. Oliven, M.D.

Dr. John F Oliven was a Psychiatrist at Columbia University where he wrote his reference work *Sexual Hygiene and Pathology*, and coined the term transgenderism (Oliven, 1965). Following this publication, the medical world began to move away from the negative terms "transsexual" and "transvestite." Then in the year 1969, the Stonewall Riots took place. This event began the gay rights movement and was started by the outspoken transgender advocates and trans woman of color, Marsha P. Johnson and Sylvia Rivera (Brady, 2015). These two trans women paved the way for what is known as Lesbian Gay Bisexual Transgender and Queer (LGBTQ+) rights in America today.

Those in the transgender community who present more masculine will be referred to as transmasculine in this paper. This term allows for identification of transgender men as well as non-binary individuals who are more masculine leaning. Similarly, this paper will use the term transfeminine when referring to transgender individuals who present more femininely.

# **Transgender Health**

# Health impacts of stigma.

As with all marginalized groups, the transgender population faces significant stigma and oppression. (Lee, 2017). The impact that stigma and oppression have on health is a relatively new concept in peer-reviewed literature. However, the negative impacts chronic stress has on many aspects of health, including physical, mental, and emotional, are well documented (Hughto, Reisner, & Pachankis, 2015). This understanding of the body's response to stress is used in describing the relationship between oppression and health for the transgender population.

Social isolation, including rejection from family and friend groups, can have a profound impact on the mental and physical well-being of transgender individuals. The disconnect between the client and their peers is described by Hughto et al. (2015) as interpersonal stigma, further described as enacted stigma between persons. Interpersonal stigma can result in not only loss of social support, but also in physical violence. The transgender community faces substantially higher rates of physical assault than their cisgender peers (Hughto et al, 2015.). A review of the violence experienced by transgender people in the United States found that 33-55% of gender minority individuals faced physical assault due to their gender identity (Safer, et al., 2016). Trans women, especially trans women of color, are most harshly targeted in hate crimes and other forms of oppression in the US (Lee, 2017). This high incidence of violence in the transgender community leads to a high rate of mental health needs in this population.

(Stotzer, 2009). Clements-Noelle, Marx, Guzman & Katz (2001) found that 32% of transgender individuals, both transmasculine and transfeminine, have attempted suicide in their lifetime. Furthermore, according to the Epidemiologic Studies Depression Scale, 62% of trans women and 55% of trans men were diagnosed with depression (Clements-Noelle, Marx, Guzman & Katz, 2001).

These societal impacts may also play an integral role on the physical health of transgender people (Downing & Przedworksi, 2018). Unfortunately, public health professionals have not adequately examined this community and little is known about the long-term health implications faced by this population. In fact, the National Institute for Health has only funded 43 studies exploring the health outcomes of transgender individuals, most of which focused on HIV status and tobacco use (Downing & Przedworski, 2018). Regardless, transgender individuals require healthcare for a myriad of reasons other than HIV/AIDS care and tobacco addiction. Downing & Pzerdworski (2018) found that 17.3% of trans women are uninsured compared to 9.6% of cisgender women, 23.1% of trans men are uninsured compared to 12.4% cisgender men, and 13.2% of non-binary individuals are uninsured. Similarly, over 50% of non-binary respondents reported having multiple chronic conditions including chronic heart disease, asthma, arthritis, diabetes, and depression (Downing & Pzerdworski, 2018). This high prevalence of comorbidities may be secondary to lower accessibility of healthcare as 25.3% of trans women, 34.2% of trans men, and 23.3% of non-binary people report not having a primary care practitioner (Downing & Pzerdworski, 2018).

## Access to healthcare.

Transgender individuals encounter a multitude of barriers when accessing necessary healthcare (Safer et al., 2016). According to a recent study, transgender people's largest self-reported barrier in healthcare is finding competent healthcare providers, while others include financial barriers, health system barriers, and socioeconomic barriers (Safer et al., 2016). Insurance coverage acts as a gate-keeper for transgender people attempting to access transition related services (James et al., 2016). According to the National Transgender Discrimination Survey (NTDS), 25% of respondents experienced denial of coverage for hormone replacement therapy whilst more than half (55%) of those who sought coverage for gender affirming surgeries were also denied (James et al., 2016). This denial can be due to a multitude of reasons including, but not limited to a lack of medical necessity as deemed by the provider, inconsistencies with the name on insurance information and the name on their social security card, or inadequate documentation of the impacts of gender dysphoria (Human Rights Campaign, 2015).

The transgender community faces not only barriers when accessing transition related care, such as hormone replacement therapy (HRT) and gender affirming surgeries, but when attempting to access any healthcare providers who are competent in the needs of transgender individuals (James, et al., 2016). An often-overlooked facet of transgender healthcare is the ability for transgender clients to access general practitioners who understand the process of transition and the health impacts of this medical intervention (Safer et al., 2016). One third of respondents to the NTDS reported having "at least one negative experience related to being transgender, such as verbal harassment, refusal of treatment, or having to teach the health care provider about transgender people to receive appropriate care" (James et al., 2016, p. 5).

The fear of this incompetent health care and inability to receive coverage leads transgender patients to avoid seeking medical intervention for illness and injury related care. (James et al., 2016). The NTDS also found that 23% of respondents reported avoiding seeking health care when they needed to because of "fear of being mistreated as a transgender person" (James et al., 2016, p. 10). Furthermore, this avoidance of seeking medical professionals has lead transgender patients to access hormones on their own through unsafe means. The NTDS found that while 91% respondents reported receiving hormone replacement therapy only from licensed medical professionals, "6% received from both medical professionals as well as friends, and 2% reported receiving only from friends, online, or other non-licensed sources" (James et al., 2016 p. 10).

The summation of all these facets have forced transgender patients to avoid necessary medical care or receive it from unsafe means. Health care practitioners are ethically bound to providing services to people in need, including the transgender population. It is clear that there are many aspects of the healthcare system, including the providers themselves, that need to be improved in order to fully meet the needs of this population.

# **Occupation and Occupational Justice**

# **Occupation.**

According to the OT Practice Framework, occupation is defined as "the various kinds of life activities in which individuals, groups, or populations engage" (AOTA, 2014, p. S19). This broad definition is the basis for the domain of OT as the focus of the profession is to facilitate participation in these life activities. A core concept underlying the profession of OT, stemming from the field of occupational science, is that participation in occupation is integral to health and wellbeing (AOTA, 2014). OT practitioners focus on helping optimize

occupational performance to improve health and well-being (AOTA, 2014). OT practitioners are particularly concerned with the contexts and environments in which occupations take place and seek to identify barriers that may be preventing people from engaging in their meaningful occupations. These barriers can be secondary to a multitude of factors such as physical limitations, mental illness, social acceptance, and access to health insurance and services.

Trans individuals face a wide gamut of barriers each day. These barriers can take place on intrapersonal, interpersonal, or structural levels. Intrapersonal stigma refers to that which exists within the individual for example, a transgender person may have internalized negative perceptions of transgender people resulting in a dislike of their own identity. Interpersonal stigma is enacted stigma between persons. (Hughto et al., 2015). A widespread structural barrier is that it is legal in 32 out of 50 states to be fired for being transgender (American Civil Liberties Union (ACLU), 2018). This can lead to economic insecurity, which results in lack of stable housing and access to adequate nutrition. Furthermore, these barriers can prevent trans individuals from engaging in the occupations necessary for their mental, emotional, and physical health.

# **Occupational justice.**

The World Health Organization (WHO) defines health as "a state of complete, physical, mental, and social well-being, and not merely the absence of disease or infirmity" (World Health Association, 2006, p.1). Furthermore, well-being is defined as, "a general term encompassing the total universe of human life domains, including physical, mental, and social aspects" (WHO, 2006, p. 211). In order to fully experience health and well-being, one must participate in their occupations (AOTA, 2014). Participation is defined as "involvement

in a life situation" (WHO, 2006, p. 211). OT focuses on fostering engagement in daily occupations "that lead to participation in desired life situations" (AOTA, 2014, p. S3). When one is not able to access their occupations for whatever reason, whether it be social, physical, or cognitive barriers, occupational injustice occurs. (AOTA, 2014).

Transgender people face occupational injustice when they are not able to engage in meaningful daily occupations for various reasons including oppression and decreased access. Due to the nature of oppression surrounding transness, these individuals will often opt out of engaging in occupations due to fear regarding their physical and emotional safety. Emotional safety refers to one's level of comfort in a given setting (Catherall, 2006.) Fear for one's safety, on all levels, may lead to avoidance of certain occupations. For example, if a transgender person feels unsafe when walking on the sidewalk, out of fear of assault, they will opt for other options such as staying at home or asking for rides from trusted individuals. Furthermore, transgender individuals often become victim to verbal assault, which may not have an immediate impact on the individual's physical health but can later impact one's mental health and subsequently, their physical health in the future.

Kitzinger (1996) writes:

In an oppressive society, it is not necessary, most of the time, to beat us up or to murder or torture us to ensure our silence and invisibility. This is because a climate of terror has been created instead in which most gay people voluntarily, and of our own free will, stay silent and invisible (p. 11).

This excerpt is focused on the lived experience of LGB individuals; however, it is easily generalizable to transgender individuals. Those in the gender minority (i.e. not cisgender) are at an exponentially larger risk for physical and verbal assault (ACLU, 2018). This threat of

violence will, understandably, lead to trans people avoiding occupations to evade harm (Ellis, McNeil & Baily, 2014).

Additionally, transgender individuals have decreased access to occupations. According to the NTDS from the National Center for Transgender Equality, 15% of transgender respondents were living in severe poverty, making less than \$10,000 (U.S.D.) per year, as compared to 4% of the country as a whole (James et al., 2015). This may be attributed to the significant challenges transgender employees face when applying for work. Here, it is reported that transgender workers report unemployment at twice the rate of the entire U.S. population [at 14% versus 7%] (Human Rights Campaign, 2015). Furthermore, transgender individuals are victim to a wage gap. According to a study in 2008, transgender women reported their wages fell by one third after transitioning, regardless of sexual orientation (Schilt & Wiswall, 2008). This statistic shows us that there are financial impacts of transition and significant expenses related to transition services. This decreased economic stability creates a lack of opportunities for transgender individuals to engage in occupations that require financial resources such as shopping, leisure activities, and travel.

# **Theory Development: Gender as an Occupation**

When considering the foundational work, *Performative Acts and Gender Constitution* (Butler, 1988), gender can be conceptualized as an enacted occupation as the presentation of gender is the sum of many occupations such as dressing, grooming, social communication, verbal communication, functional mobility, amongst others. Presentation is the physical manifestation of one's gender (TSER, 2018). Some transgender individuals often need to make decisions about how to engage in the occupation of gender in an attempt to "pass" as the gender with which they identify. *Passing* is a term used in the transgender community to

describe the act of exhibiting one's gender in a way that causes others to see them as their desired gender. In westernized society, we see gender as a dichotomy between male and female. With this dichotomy comes gendering objects and occupations. For example, a typical masculine presentation in the predominant U.S. culture may include short hair, loose pants, and a collared shirt, whereas a feminine presentation may include shaved legs, long hair, and a dress.

Butler (1988) states that "Gender is instituted through the stylization of the body and, hence, must be understood as the mundane way in which bodily gestures, movements, and enactments of various kinds constitute the illusion of an abiding gendered self" (Butler, 1988, p. 519). This understanding of gender is important for OT practitioners to recognize as the profession is concerned with facilitating participation and engagement in meaningful occupations. When gender is understood as an occupation, the role of OT becomes clear. It is imperative that transgender people are able to engage in the occupation of gender to support their overall health and well-being.

Furthermore, the occupation of gender contributes the personal identity of the individual. Christiansen (1999) states that "occupations constitute the mechanism that enables persons to develop and express their identities" (p. 2). It is through this conceptualization that we can begin to appreciate gender as an occupation that contributes to the creation of one's personal identity.

# **Transgender Modalities**

The transgender community has needed to operate without external supports for the majority of its existence. Therefore, they have self-developed and continue to use different adaptive strategies, equipment, and techniques to engage in the occupations of gender. These

adaptive strategies, equipment, and techniques will be referred to as trans modalities in this paper. Within OT, modalities are defined as, "devices and techniques to prepare the client for occupational performance" (AOTA, 2014, S29). It is important to note, however, that within the OT profession, the term modalities is often used in reference to physical agent modalities such as the use of thermal, electromagnetic, and ultrasonic waves to create musculoskeletal and neurological changes in the client (AOTA, 2018). The term trans modalities is distinctly different from physical agent modalities, and refers to preparatory activities to foster occupational performance. This term was chosen because trans modalities not only refers to the adaptive equipment used in the trans community but strategies such as tucking, which as equally important for gender presentation. There are many safety precautions related to these trans modalities that must be considered by healthcare practitioners working with transgender clients. Additionally, trans modalities are part of the occupation of gender and therefore there is a need for OT practitioners to understand these strategies, techniques and equipment in order to enable their trans clients to fully engage in their occupations. Common trans modalities will be further discussed in the context of potential impact on occupational performance and engagement.

# Binding.

There are many common trans modalities used by people who are attempting to masculinize their gender presentation. Binding is the act of using external wraps or commercial binders to flatten and spread breast tissue, thus creating a masculine chest. This technique can be done using multiple approaches. According to a recent survey, 51.5% of trans masculine individuals reported binding 7 days a week (Peitzmeier, Gardner, Weinand, Corbet & Acevedo, 2017). Of this population, 87.2% reported using a commercial binder

and 16.5% reported using elastic or other bandages. This is an important statistic because of the negative health impacts that can be caused by using ACE bandages or some other antiinflammatory wrap. Additionally, commercially available binders come with their own set of precautions as 97.2% of transmasculine individuals reported at least one negative outcome secondary to binding (Peitzmeier et al., 2017). The most often reported issues were back pain at 53.8%, overheating at 53.5 %, chest pain at 48%, shortness of breath (SOB) at 46.6%, itching at 44.9%, bad posture at 40.3%, and shoulder pain at 38.9% (Peitzmeier et al., 2017). This study suggests that the best way to prevent negative health outcomes is to reduce the frequency of binding (Peitzmeier et al., 2017).

# Packing.

Transmasculine individuals may want to create the appearance of the phallus as a form of gender presentation. In order to achieve this, many individuals participate in what is called packing. In the trans community, this is defined as the act of using handmade or storebought prosthetics to create the appearance and feeling of a penis in one's groin. Examples of homemade options to create this prosthetic can include a rolled-up sock or filling a condom with hair gel, amongst others. Store bought prosthetics for transmasculine individuals include soft and hard packers, adhesive prosthetics, and stand to pee devices (STPs). Ultimately, the choice depends on the individual's financial means and access to resources, alongside desired outcomes.

Packers are often made of silicone with a wide range of density, thus the hard and soft identifiers. These pieces of equipment are typically placed in the individual's undergarments. There are undergarments available for purchase that are specifically created for packing so that the silicone is not touching the wearer, in order to minimize hygiene issues and

maximize comfort. However, these items are quite expensive and may not be easily accessible. When working with individuals to choose the appropriate packer, practitioners can educate regarding proper hygiene, regardless of undergarment type. Packers should always be 100% silicone as other commonly used materials can be dangerous due to plastics leaking from the prosthetic and into the wearer. The research is lacking on the safety of packers and penile prosthetics; however, the organization Bad Vibes conducts chemical research to determine the safety of sex toys (Bad Vibes, 2018). The tools that transmasculine individuals use to create a phallus are not sex toys but they do tend to be made from the same materials, thusly similar rules apply. Due to the nature of the products, practitioners should recommend regular washing using an antimicrobial soap or cleanser designated for sex toys (Bad Vibes, 2018). This minimizes the risk for yeast infections and other bacteria that can grow from sweat and skin contact. Additionally, silicone can be uncomfortable when in direct contact with the skin, especially after washing. To combat this, transmasculine people often engage in dusting, which is the act of rubbing cornstarch on the silicone. Cornstarch is used rather than talc powder due to correlational studies that found a link between perineal exposure to talc and incidence of epithelial ovarian cancer (Harlow, Cramer, Bell, & Welch, 1992).

Similar to packers, Stand to Pee Devices (STPs) are phallic prosthetics, but with additional functionality. In addition to creating the look and feel of a phallus, they aid transmasculine people in standing while urinating. STPs have a cup that covers the vulva followed by a shaft, which usually will resemble a penis and a hole where the urethral opening would typically be on a penis to allow for urine to flow out. STPs are often made of the same materials as traditional packers, therefore caring for the prosthetic is similar; the

only difference is that STPs should be cleaned daily due to the presence of bodily fluids inside the shaft of the device. The use of this prosthetic device can have immense psychosocial impacts as it will allow the client to enter a men's restroom and use the urinal which has been widely discussed in transgender online groups such as Youtube or Facebook. Being able to access the restroom that matches one's gender identity is an important means to increasing social participation. Often times, the use of an STP requires practice to minimize spilling from the cup. Trans individuals should be encouraged to practice in a place where cleanup is easy such as a bathtub. Moreover, voiding while standing can be difficult due to the unfamiliar sensation. To combat this uneasiness, clients may benefit from slightly bending their knees to begin the task.

# Tucking.

Transfeminine individuals may want to create the appearance and feeling of a vulva by participating in tucking. Tucking is the practice of concealing the penis and testes (Hastings, 2017). The task of tucking requires multiple steps that, infrequently, can be harmful to the client, so trans individuals should receive education regarding appropriate precautions to use in the daily routine. The first step is to push the testes up into the inguinal canals, which may be uncomfortable but should never hurt. If the individual is in pain, then the process must be restarted after a short break (Dornheim, 2017). The next step is to tuck the penis and scrotum, which can be done with the use of tape or without tape. If tape is being used, the client should use medical tape as this is safe for use on skin and reduces the risk of irritation and pain with removal. Additionally, the individual will want to remove pubic hair through waxing or shaving prior to this step. The client will need to wrap the

empty scrotum around the penis before pushing it back between the buttocks. At this point, the client may add the tape to keep the genitalia secure before donning tight undergarments.

An article of clothing called a gaff may be used in place of underwear. A gaff is an undergarment specially designed for tucking; it is often made from lycra to smooth the genital area. Tucking for long periods of time can cut off blood circulation, therefore breaks should be taken (Hastings, 2017). Moreover, there are some risks to the individual's fertility as the purpose of the scrotum is to hold the testes away from the body for temperature control. Keeping the testes in the inguinal canals can overheat the sperm, however, this effect should reverse within three months of resting from tucking (Hastings, 2017).

When untucking, the individual should slowly "pull the tape away from the scrotum and move the penis back into its resting position" (Dornheim, 2017, page 2). If tape was used and is not coming off, a wet washcloth can be placed over the tape to loosen the adhesive. Conversely, medical adhesive remover may be used to make the process easier. The use of tape rather than a gaff can cause irritation and in rare cases, infection. Because of this risk, practitioners should also address genital hygiene with transfeminine clients who tuck.

# **OT and the Transgender Population**

The OT Practice Framework 3<sup>rd</sup> edition, called the Framework, is the guiding document for the profession that articulates OT's domain and process (2014). The Framework discusses the domain of OT as being comprised of occupations, client factors, performance patterns, performance skills, and context and environment. The Framework recognizes that occupations occur within contexts and are influenced by client specific abilities and characteristics. When analyzing the Framework using the theory of Gender as an Occupation, there are many areas influenced by gender which will be explored in detail.

# Client factors, performance skills, and performance patterns.

Client factors are defined as "specific capacities, characteristics, or beliefs that reside within the person and that influence performance in occupations" (AOTA, 2014, p. S7). Client factors include values, beliefs, and spirituality; body functions (e.g. mental functions, sensory functions, neuromusculoskeletal and movement-related functions, voice functions etc); and body structures (e.g. nervous system, structures involved in voice and speech etc). Individual's values and beliefs are constructed by life experiences, which have likely been affected by their gender and presentation. The display of one's internal identity can be achieved through engaging in occupations such as grooming, dressing, voice, and movement patterns showing the intersection of client factors and occupations. It is important to have the required body structures and functions to engage in the occupation of gender (e.g. movement-related functions needed for tucking, mental functions needed for determining appropriate and safe trans modalities), and adaptations can be made if there are impairments.

Performance skills are closely intertwined with client factors and are defined as "goal-directed actions that are observable as small units of engagement in daily life occupations [...] learned and developed over time and are situated in specific contexts and environments" (AOTA, 2014, p. S7). Performance skills are the observable aspects of behavior or what we can see someone doing when engaging in occupations. This includes motor skills, process skills, and social interaction skills. The acquisition of performance skills is necessary to promote occupational performance in the desired domains (AOTA, 2014).

Trans people need to develop the performance skills of the gender they wish to present- for example, the motor skills required to feminize their gait pattern or to masculinize their posture, and the social skills required to fulfil the gender norms in a given culture. Upon

first look, these actions may not seem integral to gender performance; however, they are closely related when they are examined from a perspective that views gender as an occupation. Using certain mannerisms and postures, defined as "aligns" in the Framework, will impact the gender that others are perceiving (AOTA, 2014, p. S25). A detailed example of performance skills is related to working with a transmasculine person who needs to bind their chest as part of daily dressing. The OT can work with the person to use the performance skills of "chooses", "uses", and "inquires" to understand the positive and negative impacts of each binding option to find the most appropriate (i.e. safe and yields the desired presentation) technique for the client.

Additionally, the performance patterns, such as habits, routines, rituals, and roles, are heavily impacted by one's gender identity, especially within the context of transition. For example, a transmasculine person may add the occupation of binding into their morning ADL routine. OT practitioners can work with trans individuals to establish binding routines that address frequency and duration of binding (e.g. not more than 8-10 hours at a time, take days off, etc.) while also considering the psychosocial aspect of the importance of binding for presentation.

#### Context and environment.

The contexts and environments surrounding occupation are equally important as the client factors, performance skills, and patterns. OT practitioners are trained in understanding the complex, transactional relationship amongst the person, the environment, and the occupation (Law et. Al., 1996). Context is primarily used to refer to elements "within and surrounding the client that are often less tangible than physical and social environments but nonetheless exert a strong influence on performance" (AOTA, 2014, p. S9). Environment

includes the physical and social surroundings while, context includes cultural, personal, temporal, and virtual (AOTA, 2014).

The physical environment "refers to the natural and built surroundings in which daily life occupations occur" (AOTA, 2014, p. S8) including the natural environment and built structures. The social environment is defined as, "the presence of, relationships with, and expectations of persons, groups, and populations with whom the clients have contact" (AOTA, 2014, p. S9). For transgender individuals, physical environmental barriers may play little role in one's ability to present their gender. However, if a physical space is not inclusive, a trans person may not be able to engage in their desired occupations within that space such as a lack of inclusive restrooms. The social environment can heavily impact a trans person's participation in the occupation of gender both positively and negatively. Social interactions and interpersonal relationships can serve to better the life of the person whilst providing support and promoting psychosocial health. However, familial acceptance, connections to peer groups, and workplace interactions can be negatively impacted by stigma and discrimination.

Similarly, the cultural context will heavily impact transgender people's ability to participate in the occupation of gender. The Framework (2014) describes the cultural context as, "customs, beliefs, activity patterns, behavioral standards, and expectations accepted by the society of which the client is a member" (p. S9). Westernized societies operate under the assumption of a binary gender system dichotomized into male and female (Lorber, 2007). Because of the expectation that individuals will be cisgender and binary, transgender individuals must exist outside of what is considered the norm. This act of "othering" will have an impact on the psychosocial health of the individual as it will most often lead to social

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isolation (Hughto et al., 2015). Othering is defined as "transforming difference into otherness so as to create an in-group and an out-group" (Staszak, 2008, p.1).

Personal context refers to the "demographic features of the individual" (AOTA, 2014, p. S9). The personal context of transgender people is not only referring to their gender identity but their sexuality, socioeconomic status, as well as race and ethnicity. The amalgamation of one's many identities is defined as intersectionality. This term was first coined Crenshaw (1989) with a focus on Black Women, but the term has become widely used in LGBTQ+ spaces due to its applicability to the population. Through the lenses of intersectionality, we begin to understand that gender presentation is no longer dependent solely on clothing but is a constant overlap of personal context consisting of race, personal experience, socioeconomic status, and access to supports or services, as evidenced by the occupational injustice experienced by the community (Ellis et al. 2014).

Likewise, the temporal context varies greatly between individuals as it is dependent on the individual's stage of life, time of day, or personal history (AOTA, 2014). This will affect the way the client sees their own gender and the ways in which they would like to present it. One's personal experiences regarding their ability to live their personal gender will shape their level of comfort in participating in the occupation of gender. Likewise, the process of transition seemingly acts as a linear progression, however this is not the case. Transition does not have a set start nor end date as transition can refer to, and is not limited to realizing your gender identity, coming out to friends and family, or seeking medical intervention.

In modern industrialized society, the virtual context has become increasingly important. The Framework (2014) defines the virtual context as, "the interactions 24

that occur in simulated, real-time, or near-time situations absent of physical contact" (p. S9). The internet has a wide range of opportunities for transgender people to interact, thus creating a strong social support system. For many transgender youth and adults alike, internet communities such as Facebook Groups have become integral to survival. These support systems can be used to find affirming healthcare providers, create relationships, and find housing or employment. However, the anonymity of the internet can create hostile environments for transgender people. The American Center for Disease Control found that 34% of LGBTQ+ youth and adolescents experiences online bullying compared to 14% of their cisgender heterosexual peers (Center for Disease Control, 2018).

# **Types of OT Interventions**

# Create and promote.

According to the Framework, there are five intervention approaches OT practitioners may employ when working with a client (AOTA, 2014). *Create and promote* pertains to an approach designed to "enhance performance for all people in the natural contexts of life" (AOTA, 2014, p. S33). This intervention approach does not assume disability of the clients and thus acts to improve health and wellness in a community setting. For example, an OT practitioner may provide an education session to healthcare professionals regarding best practices when working with transgender individuals such as information regarding transgender modalities and the importance of affirmative care.

# Establish and restore.

The intervention approach of *establish or restore* focuses on habilitation or rehabilitation of skills to improve a client's function (AOTA, 2014). Habilitation refers to, "health care services designed to assist people in acquiring, improving [...] or maintaining

skills [...] for participation in occupations and daily life activities" (AOTA, 2014, p. S33). This approach to intervention can include many aspects of a treatment plan. For example, OT practitioners may focus on educating transgender clients on safe and effective use of transgender modalities, self-advocacy skills when finding health care providers, or navigating difficult conversations with peers regarding their gender identity. Moreover, OT practitioners can work to establish a morning ADL routine that includes binding, packing, using hip pads, or donning gender-affirming clothing.

### Maintain.

*Maintain* refers to an intervention approach in which the practitioner and client identify ways to preserve functional capacities gained through previous intervention sessions. This is pertinent to transgender individuals as they continue to improve their engagement in ADLs such as the use of transgender modalities and dressing. The maintain approach assumes that "...without continued maintenance intervention, performance would decrease, occupational needs would not be met, or both, thereby affecting health, well-being, and quality of life" (AOTA, 2014, p. S33). Therefore, without repeated practice of the newly learned skills, transgender individuals may backtrack on progress made toward goals such that their ability to engage in the occupation of gender will decrease, resulting in unsafe use of modalities, decrease in self-advocacy skills, and increase in secondary mental health concerns such as depression and anxiety (Hughto et al., 2016). This intervention approach can include repetition of occupations to promote habituation of a previously established morning ADL routine or role-playing of the individual's work environment in which they will need to employ self-advocacy skills.

# Modify.

OT practitioners have a role in recovery after gender affirming surgeries. These surgeries can include, but are not limited to mastectomies, vaginoplasties, metoidioplasties, and phalloplasties. Each of these surgeries are accompanied with their own set of post-surgical precautions resulting in the need to modify occupations such as dressing and toileting. Therefore, OT practitioners may use their in-depth understanding of ADLs to promote independence during recovery from surgery as well as promoting engagement in occupations throughout the entire transition process by *modifying* the occupation, the context or environment, and/or the person.

# Prevent.

OT practitioners may implement *preventative* interventions, which is designed to address the needs of clients who are at risk for issues regarding occupational performance and reduce the occurrence of barriers to performance. (AOTA, 2014). Using this approach, OT practitioners may educate transmasculine individuals to engage in binding safely as to prevent the risk for skin breakdown and migration of the spinal column (Peitzmeier et al., 2017). Moreover, they may educate transfeminine individuals in tucking safely to prevent the onset of urinary tract infections or skin adhesions due to improper use of tape (Dornheim, 2017). In addition, this approach can work to preemptively address barriers that may serve as an obstacle to transgender individuals barring them from engaging in meaningful occupations.

# **OT Theory: Kawa Model**

OT practitioners use theory to guide the OT process. Within the profession of OT "a theory is defined as a set of interrelated assumptions, concepts, and definitions that presents a

systematic view of phenomena by specifying relationships among variables, with the purpose of explaining and predicting the phenomena" (Reed, 1984, p. 1). When examining gender as an occupation, the most appropriate guiding theory is the *Kawa Model* (Teoh & Iwama, 2015).

The Kawa Model was developed in 2006 by a group of OT practitioners in order to "...just ask the client how they want to live their lives so that it is more meaningful to them and look together at what they can do to achieve that" (Teoh & Iwama, 2015, p. 1). This specific theory allows the OT practitioner and client to examine the participant's life and the way in which their life journey varies due to the context in which experiences take place.

In order to metaphorically examine the client's journey through life, the Kawa Model uses five constructs: river flow, river banks, rocks, driftwood, and the spaces between the objects (Teoh & Iwama, 2015). When working with transgender clients, these elements can take on a universal meaning. The River Flow is defined as one's life flow and priorities. For these clients, the priority of intervention will be to facilitate engagement in the occupations that will affirm one's gender. The River Banks refers to environments and contexts, which for transgender clients are the societal expectations and rules that either inhibit or promote the client's gender expression such as gender roles. The Rocks represent the client's obstacles and challenges. This is especially important with transgender clients as these can be societal barriers such as access to medical care, social exclusion, and the threat of violence. The Driftwood stands for influencing factors such as gender expectations, societal values of gender roles, and social capital. Finally, the spaces are opportunities to improve the flow of one's life. This model is useful for understanding the life experiences of transgender people in order to shape the OT process.

Therefore, this study seeks to contribute to the cultural understanding of the OT process. In order to continue to best serve clients, OT practitioners must build their understanding of the impacts of transition on occupational engagement, whilst not omitting the cultural significance of gender identity and expression for clients.

### **Chapter 3: Methods and Procedures**

## **Research Questions**

1. What occupations do transgender people identify as being impacted during their transition process?

- 2. What occupations do transgender people identify as important?
- 3. How satisfied are transgender people with their current performance of occupations?

### **Participants**

### Inclusion and exclusion criteria.

Participants were required to meet the following inclusion criteria to be eligible for the study: (a) self-identify as transgender; and (b) be over 18 years old. Participants could not participate in the study if they identified as cisgender or under the age of 18. To differentiate between transgender and cisgender participants, the first question of the survey asked the respondent's gender identity. Those who chose cisgender were automatically excluded and redirected to the end of the survey. OT practitioners were not specifically recruited for the study, however transgender identified practitioners were not excluded. This was not an exclusion criterion as the questions did not address the OT process specifically, rather one's personal experiences with transness in relation to occupation.

## **Recruitment.**

Participants were recruited through a snowball recruitment design. A convenience sample of local LGBTQ+ and transgender groups were contacted and encouraged to distribute the survey. Participants were asked to share the survey with their transgender peers. The recruitment statement is included in Appendix C. Additionally, the researcher used personal connections to post on transgender inclusive social media groups and accounts.

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The researcher provided business cards to the Ithaca Planned Parenthood of the Southern Finger Lakes to be given to transgender clients. These cards, which can be found in Appendix D, contained a QR Code as a link to the survey and a brief description of the study.

# **Research Design and Measurement Tool**

The study was approved by the Ithaca College Institutional Review Board (IRB) on October 4, 2018. The IRB proposal is included in Appendix A and the thesis proposal presented to the OT faculty is included in Appendix B. The study was conducted via an anonymous online survey built using a Qualtrics survey online software platform (Qualtrics, 2018). The survey invited participants to complete a 10-15-minute survey that included multiple choice questions, Likert scales, and open comment boxes. The participants were informed that they could skip questions or withdraw from the study at any time. Additionally, if they felt psychological distress at any point, it was recommended to contact the Trevor Project through the link provided in the survey. This is an LGBTQ+ Organization focused on the mental health of LGBTQ+ youth and adults and participants could access a 24/7 toll free support number as well as online chat rooms. The survey was reviewed by 2 members of the transgender community for face validity and was adjusted according to their comments.

The survey consisted of three demographic questions including age, gender identity, and neighborhood categories (rural, suburban, and city). Participants were asked to rate where they saw themselves in their transition process on the researcherdeveloped Self Report Transition Progress Scale: from 1 (before realizing gender) to 15 (goal), which allowed respondents to define their own transitional goals as opposed to standards placed upon one's transition by external sources. Participants were then asked to

indicate which of the listed occupations they feel have been impacted by their transition. Next, they were asked to rate the importance of the occupations as very important, somewhat important, somewhat unimportant, or very unimportant. Additionally, participants rated their level of satisfaction with performance of the aforementioned occupation as very satisfied, somewhat satisfied, somewhat unsatisfied, or very unsatisfied. Following these questions, respondents were given the opportunity to share any information they felt was important for the researcher to know.

The occupations included in the survey items were identified using Table 1 of the OT Practice Framework to ensure that all occupations within the domain of OT were addressed (AOTA, 2014). The occupations were converted into easily accessible language so that no OT background was required to understand the information presented. For example, "activities of daily living" was listed on the survey as "activities oriented toward taking care of yourself." The researchers used the general constructs of asking about importance and satisfaction with performance that are seen in many common OT assessment tools such as the Canadian Occupational Performance Measure (Polatajko, Townsend, & Craik, 2007) and the Occupational Self-Assessment (Kielhofner, Forsyth, Kramer, & Iyenger, 2009). The survey can be found in Appendix E.

# **Recruitment Procedures**

The researcher utilized a snowball recruitment design in which respondents were encouraged to share the survey with their peers. The survey was posted on social media groups for transgender individuals including Facebook and Instagram in October of 2018. A business card was provided to the Planned Parenthood of Ithaca, which briefly outlined the study and provided a link to the survey. The recruitment materials are included in Appendices C and D.

At the close of the survey, each participant was invited to enter their email on a separate survey to enter to win one of five- \$20 Amazon gift cards. This design ensured the participants' identities remained anonymous to the researcher as the gift card survey results (i.e. email addresses) were not linked to the study survey results in any way. The survey closed on December 3, 2018 and the gift card winners were randomly selected by a research assistant and notified via email on January 9, 2019.

## **Analysis of Data**

The data was analyzed using IBM Statistical Package for Social Sciences (SPSS) Version 25 for Windows (IBM Corporation, 2017).

### **Study Limitations, Delimitations, and Assumptions**

### Limitations

The limitations of this study were due to the age and gender identity of the participants. The distribution of surveys was primarily done through social media and other electronic means, therefore most respondents were from the age of 18-25 and reported "Earlier" transition progress. Furthermore, different generations tend to have varying view on gender and presentation. Additionally, most respondents identified as transgender men, thus limiting the representation of varying genders. The limitations of this study mean that the results cannot be generalized the transgender population as a whole.

# Delimitations

The inclusion criteria to participate in the study included being over the age of 18 in order to narrow the focus of the study to the experiences of adult transgender individuals.

Moreover, the researcher chose not to include race or ethnicity into the demographic information as this would require a discussion of intersectionality and racial disparity that was beyond the scope of the current study.

# Assumptions

The researcher assumed that participants met all inclusion criteria and provided honest responses to survey questions.

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# **Chapter 4: Manuscript**

The following manuscript is formatted for submission to the peer-reviewed journal titled *American Journal of OT (AJOT)*. See Appendix F for author guidelines. Note: AJOT only permits submission of a total of 4 tables and/or figures. However, all tables and figures are presented here in compliance with thesis requirements. The ones to be included in the manuscript are indicated as such.

# Abstract

Importance: Throughout a transgender individual's transition process, their meaningful occupations will be impacted in various ways. OT practitioners must better understand the occupations of transgender individuals to fully meet their occupational needs.

Objective: To explore the occupations of transgender individuals and investigate the relationship between transition and occupation.

Design: Quantitative study utilizing an anonymous online survey design.

Participants: Participants were recruited through a snowball technique. To be included in the study, participants must self-identify as transgender and be over the age of 18.

Outcomes and Measures: The online survey collected demographic information, and selfreport of: occupations impacted by transition, importance of impacted occupations, and satisfaction with performance of impacted occupations.

Results: The study included 142 survey respondents, of which 80.1% were between the ages of 18-24. Gender identities represented include: transgender men (55.45%), non-binary individuals (21.2%), transgender women (14.6%), agender (2.9%), gender fluid (3.6%), and gender not listed here (1.4%).

Conclusions and Relevance: The results indicate that each individual reported at least one ADL or IADL to be impacted by their transition. Additionally, individuals who reported increased satisfaction with performance in their occupations also reported later stages of self-reported transition progress Additional studies are needed to explore exactly how occupations have been impacted.

What This Article Adds (not included in abstract word count): This article is the first of its kind to explore the occupational needs of transgender individuals. Here, the researcher lays out gender-specific occupations called "Transgender Modalities," with which OT practitioners should become familiar. The study also establishes a gender performance scale, Self-Reported Transition Progress, which allows transgender individuals to identity their own transition goals and allows for client-centered responses in the research process.

#### Background

#### **Transgender Health**

# Health impacts of stigma.

As with all marginalized groups, the transgender population faces significant stigma and oppression (Hughto, Reisnet, & Pachankis, 2015). The negative impacts of chronic stress on many aspects of health, including physical, mental, and emotional are well documented (Hughto et al., 2015). This understanding of the body's response to chronic stress is used in describing the relationship between oppression and health outcomes of transgender individuals. Social isolation, including rejection from family and friend groups, can have a profound impact on the mental and physical well-being of transgender individuals. Interpersonal stigma, defined by Hughto et. al. (2015) as enacted stigma such as physical violence or loss of social support is faced by the transgender population in substantially higher rates than their cisgender peers. A review of the violence experienced by transgender people in the United States found that 33-55% of gender minority individuals faced physical assault due to their gender identity (Safer et al., 2016). This high incidence of violence in the transgender community contributes to a high rate of mental health needs in the population. (Stotzer, 2009). According to the Epidemiologic Studies Depression Scale, 62% of trans women and 55% of trans men were diagnosed with depression, whilst 32% of transgender individuals, both transmasculine and transfeminine, have attempted suicide in their lifetime (Clements-Noelle, Marx, Guzman, & Katz, 2001).

### Access to healthcare.

Transgender individuals encounter a multitude of barriers when accessing necessary healthcare (Safer, et al., 2016). Downing & Pzerdworski (2018) found that 17.3% of trans women are uninsured compared to 9.6% of cisgender women and 23.1% of trans men are uninsured compared to 12.4% cisgender men. Similarly, over 50% of non-binary respondents reported having multiple chronic conditions including chronic heart disease, asthma, arthritis, diabetes, and depression whilst 13.2% of non-binary individuals are uninsured (Downing & Pzerdworski, 2018).

An often-overlooked facet of transgender healthcare is the ability for transgender clients to access general practitioners who are supportive of and understand the process of transition as well as the health impacts of this medical intervention (Safer et al., 2016). In fact, one third of respondents to the National Transgender Discrimination Survey (NTDS) reported having "at least one negative experience related to being transgender, such as verbal harassment, refusal of treatment, or having to teach the health care provider about transgender people to receive appropriate care" (James, et al., 2016, p. 5). The fear of this incompetent health care and inability to receive coverage leads transgender patients to avoid seeking medical intervention for illness and injury related care. (James et al., 2016).

# **Occupational justice.**

Transgender people face occupational injustice when they are not able to engage in meaningful daily occupations for various reasons such as oppression and decreased access. Due to the nature of oppression surrounding transness, these individuals will often opt out of engaging in occupations secondary to fear regarding their physical and emotional safety. For

example, if a transgender person feels unsafe when walking on the sidewalk out of fear of assault, they may stay at home, resulting in loss of occupational engagement. Furthermore, transgender individuals are often victim to verbal assault, which may impact one's mental health and consequently, their physical health (Stotzer, 2009).

Additionally, transgender individuals have decreased access to financial stability. According to the NTDS, 15% of transgender respondents were living in severe poverty, making less than \$10,000 (USD) per year, as compared to 4% of the country as a whole (James et al., 2016). This may be attributed to the significant challenges transgender employees face when applying for work, as transgender workers report unemployment at twice the rate of the American population [at 14% versus 7%] (James et al., 2016). According to Schilt and Wiswall, transgender women reported their wages fell by one third after transitioning, regardless of sexual orientation (2008). This lack of financial stability creates a lack of opportunities for transgender individuals to engage in meaningful occupations that require financial resources such as shopping, leisure activities, and travel.

# **Transgender Modalities**

The transgender community has needed to operate without external supports for the majority of its existence, resulting in self-developed adaptive strategies, equipment, and techniques to engage in the occupation of gender since transition is without a concrete start nor end and requires constant manipulation to individual's context and personal expression. These will be referred to as "trans modalities" in this research. There are many safety precautions related to these trans modalities that must be considered by healthcare

practitioners working with the trans population. Additionally, trans modalities are part of the occupation of gender and therefore there is a need for OT practitioners to understand these strategies in order to enable their trans clients to fully engage in their occupations.

### Binding.

Binding is the act of using external wraps, or binders, to flatten and spread breast tissue, creating a masculine chest. According to a recent survey, 51.5% of trans masculine individuals reported binding 7 days a week (Peitzmeier, Gardner, Weinand, Corbet, & Acevedo, 2017). Of this population, 87.2% reported using a commercial binder and 16.5% reported using elastic or other bandages (Peitzmeier, et al., 2017). This is an important statistic because of the negative health impacts that can be caused by using anti-inflammatory wraps. The most often reported issues were back pain (53.8%), overheating (53.5%), chest pain (48%), shortness of breath (46.6%), itching (44.9%), bad posture (40.3%), and shoulder pain (38.9%) (Peitzmeier et al., 2017). This study suggests that the best way to prevent negative health outcomes is to reduce the frequency of binding (Peitzmeier et al., 2017). It is important to note, however, that the psychosocial outcomes of binding may outweigh negative physical outcomes for the client.

## Packing.

To create the appearance of a phallus, transmasculine individuals may participate in what is called packing (Conard, 2017). This is defined as the act of using handmade or storebought prosthetics to create the appearance and feeling of a penis. Examples of homemade options to create this prosthetic can include a rolled-up sock or filling a condom with hair gel. Store bought prosthetics for transmasculine individuals include soft and hard packers,

adhesive prosthetics, and stand to pee devices (STPs). Ultimately, the choice depends on the individual's financial means and access to resources. STPs aid transmasculine people in standing while urinating by covering the vulva with a cup and voiding urine through a shaft which usually resembles a penis.

Due to the nature of these products, practitioners should recommend regular washing using an antimicrobial soap or cleanser designated for sex toys (Bad Vibes, 2018). This minimizes the risk for yeast infections and other bacteria that can grow from sweat and skin contact. Additionally, silicone can be uncomfortable when in direct contact with the skin, especially after washing. To combat this, the act of dusting is performed, which is brushing cornstarch onto the device. Cornstarch is used rather than talc powder due to correlational studies linking perineal exposure to talc and incidence of epithelial ovarian cancer (Harlow, Cramer, Bell, & Welch, 1992).

# Tucking.

To create the appearance of a vulva, transfeminine individuals may engage in tucking, which is the act of concealing the testes in the inguinal canals. Tucking for long periods of time can cut off blood circulation, therefore breaks should be taken (Hastings, 2017). Keeping the testes in the inguinal canals can overheat the sperm, however, this effect should reverse within 3 months (Hastings, 2017). The best way to avoid fertility issues is reducing the frequency of tucking, if possible. Practitioners should also address genital hygiene with people who tuck to avoid infection and skin breakdown.

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## Summary.

Trans modalities are essential for trans individuals in order to affirm their gender and fully participate in society. While many of the modalities have been self-developed over time, there is a clear role for healthcare providers to support the safe and effective use of trans modalities in daily life routines. More research is needed to fully understand the use of trans modalities as part of the occupation of gender. Transition is a process with no clear-cut start nor end, and it is likely to have an impact on daily occupations. The occupations of transgender individuals must be fully understood in order for OT practitioners to provide competent and affirmative client-centered care.

# **Purpose of Study**

The health impacts of stigma are significant and can lead to occupational injustice, however, there is limited research investigating the occupations of transgender individuals. The purpose of this study is to explore the occupations of transgender people during transition to better understand how transgender people carry out the occupation of gender. Understanding the occupations of transgender individuals is an important step to enable OT practitioners to meet the needs of this population.

The research questions are as follows:

What occupations do transgender people identify as being impacted during their transition process?

Which occupations do transgender people identify as important?

How satisfied are transgender people with their current performance of occupations?

#### Methodology

#### **Inclusion and Exclusion Criteria**

Participants were required to meet the following inclusion criteria to be eligible for the study: (a) self-identify as transgender; and (b) be over 18 years old. Participants could not participate in the study if they identify as cisgender or are under the age of 18.

### **Survey Design and Measurement Tool**

The survey consisted of demographic questions including age, gender identity, and neighborhood categories (rural, suburban, and city). Participants were asked to rate where they saw themselves in their transition process on the researcher-developed Self-Report Transition Progress Scale: ranging from 1 (before realizing gender) to 15 (self-identified transition goal). Participants were asked to indicate which of the listed occupations they feel have been impacted by their transition. They were then asked to rate the importance of the impacted occupations as "very important", "somewhat important", "somewhat unimportant", or "very unimportant". Additionally, participants rated their level of satisfaction with performance of the aforementioned occupations as "very satisfied", "somewhat satisfied", "somewhat unsatisfied", or "very unsatisfied". Following these questions, respondents were given the opportunity to share any information they felt was important for the researcher to know in a comment box.

The occupations included in the survey items were identified using Table 1 of the OT Practice Framework 3<sup>rd</sup> edition to ensure that all occupations within the domain of OT were addressed (AOTA, 2014). The occupations were converted into easily accessible language so that no OT background was required to understand the information presented. The

researchers used the general constructs of asking about importance and satisfaction with performance that are seen in many common OT assessment tools such as the Canadian Occupational Performance Measure (Polatajko, Townsend, & Craik, 2007) and the Occupational Self-Assessment (Kielhofner, Forsyth, Kramer, & Iyenger, 2009).

### **Recruitment Procedures**

The researcher utilized a snowball recruitment design in which respondents were encouraged to share the survey with their peers. The survey was posted on social media groups for transgender individuals including Facebook and Instagram in October of 2018. Cards were provided to the local Planned Parenthood to briefly outline the study and provide a QR link to the survey. At the close of the survey, each participant was invited to enter their email on a separate survey to enter to win on of 5- \$20 Amazon gift cards.

### **Analysis of Data**

The data was analyzed using IBM Statistical Package for Social Sciences (SPSS) Version 25 for Windows (IBM Corporation, 2017).

#### Results

The survey initially yielded 241 responses, however 99 surveys were removed as they had responded to less than 67% of the questions which meant that they did not answer questions regarding ADL and/or IADLs. Therefore, 142 surveys were used for data analysis.

# **Participant Demographics**

Most participants identified as a transgender man (n=76, 55.45%), followed by nonbinary (n=29, 21.2%) and transgender women (n=20, 14.6%). Some participants identified as

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Agender (n=4, 2.9%), gender fluid (n=5, 3.6%), and gender not listed here (n=2, 1.4%). Most respondents reported living in a suburb (n=58, 41.1%), followed by city (n=54, 38.3%) and rural areas (n=23, 16.3%). Most respondents were between the ages of 18-24 (n=113, 80.1%). Full demographic information is available in Tables 1 and 2.

### **Progress of Transition**

Most participants reported not yet having received gender confirming surgeries but were planning to do so. This information can be found in Table 3. Participants were asked to rank themselves regarding the progress of their transition using the Self-Reported Transition Progress Scale with a score of 1 indicating "before realizing your gender identity" and a score of 15 indicating "the goal of your transition process." Participants who scored themselves between 1 and 5 (n=44, 32.1%) were categorized as "Early" in their transition, participants who scored themselves between 6 and 10 (n=56, 40.9%) were categorized as in the "Middle" stages of their transition, and participants who scored themselves between 11 and 15 (n=32, 23.4%) were categorized as in the "Late" stages of their transition. Responses were collapsed into these three categories for the purposes of data analysis. For full information, see table 4.

# **Activities of Daily Living**

Participants were asked to report which Activities of Daily Living (ADLs) were impacted during their transition, and the results are presented in Table 5. Respondents were then asked to rank the importance of each impacted occupation (1=Very Unimportant, 2 = Somewhat Important, 3 = Important, 4=Very Important), followed by ranking their level of satisfaction with current performance in said occupation (1=Very Unsatisfied, 2= Somewhat

Satisfied, 3= Satisfied, and 4=Very Satisfied. Table 6 presents the results of importance and satisfaction ratings, and the differences between mean scores of importance and satisfaction (i.e. subtracting the satisfaction mean from the importance mean). The ADLs with the largest differences between importance and satisfaction are: Sleep and Rest (1.32), Bathing and Showering (1.12), Health Management (1.19), Dressing (1.15), Safety with Transgender Modalities (0.93), , and Swallowing (-1.17)

Spearman's Rank Order Correlation Analysis tests were run to assess the relationship between one's self-reported transition progress and their satisfaction with their performance in activities of daily living. ADLs were identified for this analysis if they met the following criteria: 0.5 or greater difference in means of reported level of importance and level of satisfaction with performance, and was reported to have been impacted by transition by at least 50% of respondents. The following five ADLs met the criteria: sleep and rest, health management, dressing, safety with trans modalities, and hygiene and grooming.

There was a medium, positive correlation between the two variables, r=.355, n=83, p=.001, with reported higher scores on the transition scale (i.e. later stages of transition progress) and higher levels of satisfaction with performance of sleep and rest. Findings for other ADLs were as follows: a medium, positive correlation between transition progress and satisfaction with health management r=.402, n=72, p=.000; a small, positive correlation between transition progress and satisfaction with performance of dressing , r=.215, n=94, p=.038; a medium, positive correlation between transition progress and satisfaction with performance of safe use of trans modalities, r=.392, n=80, p=.000; and a small, positive correlation with performance of hygiene and

grooming, r=.254, n=96, p=.012. Detailed information regarding the Spearman Rho Test is available in Table 7.

#### **Instrumental Activities of Daily Living**

Participants were asked to report which Instrumental Activities of Daily Living (IADLs) were impacted or changed during their transition and the results are listed in Table 8. Respondents were then asked to rank the importance of participating in this occupation followed by their level of satisfaction with their performance in said occupation. These results are presented in Table 9. The IADLs with the largest difference are: Financial Management (1.74), Gender Markers (1.70), Pronoun Use (1.62), Employment and Education Performance (1.49), Opportunities for Employment and Education (1.31), Familial or Peer Support (1.16).

Spearman Rho tests were run to assess the relationship between one's self-reported transition progress and their satisfaction with their performance in instrumental activities of daily living. IADLs were identified for this analysis if they met the following criteria: 0.5 or greater difference in means of reported level of importance and level of satisfaction with performance, and was reported to have been impacted by transition by at least 50% of respondents. The following IADLs met the criteria: shopping, pronoun use, familial and peer support, participation in employment and education, and safety in public spaces.

There was a small, positive correlation between the two variables of later stages of transition progress and higher levels of satisfaction with performance of shopping (r=.158, n=69, p=.196). Similar findings for other IADLs were as follows: a small, positive correlation between the two variables, r=.206, n=65, p=.099, with reported later stages of transition progress and higher levels of satisfaction with familial & peer support; small, positive

correlation between the two variables, r=.111, n=67, p=.370, with reported later stages of transition progress and satisfaction with participation in employment and education; and a small, positive correlation between the two variables, r=.142, n=65, p=.258, with reported later stages of transition progress and with higher levels of satisfaction with performance of safety in public spaces. Full results are listed in Table 10.

## Discussion

# **Exploring the Occupations of the Transgender Population**

Each participant reported at least one ADL and IADL to be impacted during their transition, which reinforces the occupational basis of gender construction. Gender is presented through participation in a multitude of occupations such as dressing, grooming, and mobility patterns. When a person begins to transition, they need to adapt their occupations accordingly. For example, 25.5% of respondents reported that "functional mobility" was impacted by their transition. This change may be due to the societal expectations of the postural positions of males and females. For instance, Vrugt and Luyeink (2000) found that often times women adopted a "closed sitting pattern" while men exhibited an "open sitting pattern" when seated on public transit.

Furthermore, 65.7% of participants reported that "shopping" was impacted, which may be related to the dressing tasks of gender presentation as masculine and feminine individuals are expected to don certain clothing such as ties and bras to represent a certain gender. Dressing can also include certain transgender modalities such as binding and tucking. Additionally, "hygiene and grooming" was reported to be impacted by more than 50% of respondents. The morning ADL routine may need to be adapted to include more gender specific tasks including hair styling, make-up, and shaving. Likewise, participants noted "familial and peer support" to be frequently impacted (n=79, 57.7%), possibly due to the need for adaptation in social situations. For example, the transgender individual's family and peers will need to adapt the ways to which they refer their loved one, whether it be through a new name or pronouns. Conversely, the transgender individual may have to manage rejection from their family and friends, secondary to the stigma faced by transgender people, which may lead the individual to change their peer groups (James, et al., 2016).

#### **Relationship between Importance and Satisfaction with Performance**

Many of the ADLs and IADLs in the survey were reported to have a high mean of importance and a lower mean of satisfaction with performance. This gap between importance and satisfaction indicates an area in which OT practitioners can work with clients using a client-centered care approach. (see Figures 1 and 2).

### ADLs.

The following ADLs had the highest gap between importance and performance: sleep and rest, health management, dressing, safety with transgender modalities, bathing and showering, hygiene and grooming, sex and masturbation, and personal device care.

The issue of sleep and rest in the transgender community has been discussed in the literature as likely due to the high levels of anxiety and depression in the transgender community (Stotzer, 2009). With an increase in access to medical care and satisfaction with their gender presentation, transgender people's quality of sleep may improve (Stotzer, 2009). OT practitioners routinely address sleep and rest, a role which can be utilized when working with the transgender population. The findings for health management in this study are

consistent with a needs assessment by the Washington, D.C. Transgender Coalition and the Human Rights Campaign (2015), in which transgender people reported that their highest concern is accessing medical care as many transgender people postpone necessary medical care due to the fear of discrimination by medical providers (James et al., 2016).

Bathing and showering, as well as sex and masturbation, require the individual to engage with their genitals, which can be highly triggering to a person who often feels disconnected from the body part. This phenomenon has not yet been explored in scientific literature; however, it is well documented and discussed within the transgender community and on social media platforms. For example, Reddit user MisfortunateFox states they shower without lights to reduce the visibility of their genitalia stating, "I shower in the dark. I've known other trans folk who do or did the same" (2017, p. 2). OT practitioners can collaborate with the client to identify adaptive techniques to minimize dysphoria that may come about during these moments such as education on self-soothing tactics to manage anxiety or a longhandled brush to minimize direct contact (AOTA, 2014). Dressing, transgender modalities, and hygiene and grooming are all necessary occupations for the presentation of gender, which may explain the high level of importance reported. Occupations must be newly habituated as transgender individuals engage in transition and OT practitioners hold the distinct value of facilitating performance of occupations. Furthermore, OT practitioners are trained in understanding the psychosocial impacts of independence and satisfaction with performance of occupations (Ostir, Markides, Black & Goodwin, 2000) and the overall connection to health and well-being.

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# IADLs.

The following IADLs were reported to have the largest difference between importance and satisfaction and will be discussed further: financial management, gender markers, pronoun use, participation in employment and education, opportunities for employment and education, and familial and peer support.

The low satisfaction of financial management may be related to the systemic stigma against transgender people in the workplace that has been documented in the literature. Systemic stigma results in higher levels of unemployment, homelessness, and an overall lower income than cisgender people of the same age (Harrison & Hemingway, 2012). The results related to lack of satisfaction in pronoun use is likely linked to the low satisfaction with familial and peer support. When considering the above mentioned IADLs, it is important to note that occupational performance is heavily dependent on the behaviors and opinions of those around the individual. Therefore, OT practitioners can support engagement in IADLs through the facilitation of self-advocacy skills of transgender individuals.

# **Transition Progress and Relationship to Occupation**

The relationship between level of satisfaction with performance of ADLs and IADL's and transition progress was explored through correlation analyses. These analyses showed that higher level of satisfaction with certain ADLs and IADLs correlated with later stages of self-reported transition progress, meaning that those who reported high satisfaction with their ADLs and IADLs also reported being closer to their transition goal (i.e. towards later stages of transition). One possible interpretation is that satisfaction with performance in the occupational basis of gender may positively contribute to self-perceived transition progress.

An additional interpretation is that transgender individuals in later stages of transition are experiencing higher levels of satisfaction with certain occupations due to increase of overall life-satisfaction through affirmation of their gender.

The strongest positive correlation was evident with health management. This finding is consistent with Hughto, Reisner & Panchankis' (2015) study which found that initiating hormone replacement therapy led to a significant improvement in psychological functioning and general quality of life in transgender individuals. Similar to this result, a medium correlation was reported with sleep and rest when compared to self-reported transition progress. This finding may be linked to the improved psychological functioning associated with improved gender performance as sleep is heavily dependent on mental health status (National Alliance on Mental Illness, 2019).

Safety with transgender modalities was shown to have a significant, medium positive correlation with self-reported transition process, indicating that increased satisfaction with safe use of transgender modalities lends to increased satisfaction with gender performance (i.e. later stages of transition). It is imperative that transgender individuals have access to trans modalities and are supported in their safe use. Access to OT practitioners who are educated in modalities that support the occupation of gender can be highly beneficial to transgender individuals.

Many IADLs are dependent on social interaction and the perceptions of those who surround the transgender individuals. A small positive correlation was found regarding familial and peer support compared to self-reported transition progress. This may be explained by the transgender individual's increased self-advocacy skills, emergence of new friendships, and personal growth of the individual's peers. Additionally, familial acceptance of transgender individuals may be a predictor for higher quality of life, thus a higher self-reported transition progress (Bockting et al., 2016).

## Conclusion

As a transgender individual continues along their transition progress, they will engage in a wide gamut of occupations, which will vary in importance and level of satisfaction with performance. OT practitioners can work with clients throughout this entire transition process as transgender individuals engage in occupations to better present their gender identity. The progress of transition is without a defined beginning and end, which requires constant adaptation to the individual's context and environment. Transgender individuals may have to "come out" across time, settings, and relationships including: the workplace, with their families and friends, and organization memberships. Each of these settings will require a different approach to social interaction and communication skills. Thus, the skilled intervention of OT practitioners can aid transgender clients in understanding the many variables one must consider. In summation, transgender people are required to consider an extremely wide range of variables regarding their transition and occupational therapy must be amongst the services available to support transgender individuals in facilitating the occupation of gender.

### **Implications for Occupational Therapy Practice**

- The transition process affects meaningful occupations of transgender individuals and OT practitioners must better understand this impact to provide client-centered and affirmative care.
- OT practitioners can promote overall life satisfaction and performance in occupations of gender by collaborating with transgender clients during their transition process
- OT practitioners can have a distinct role in addressing the occupational needs of the transgender population.

### Limitations

The distribution of surveys was primarily done through social media groups consisting of younger users, therefore most participants were between the ages of 18-25. Most participants identified as transgender men, thus limiting the representation of varying genders. Additionally, the study relied on self-report by participants. The limitations of this study mean that the results cannot be generalized the transgender population as a whole.

### **Recommendations for Future Research**

Qualitative research is needed to further examine how the occupations of transgender individuals are impacted and the consequential impact on health and well-being. Exploring whether transitioning has a positive or negative impact on health and well-being and to what extent occupations are impacted should also be investigated. Additionally, research is needed to investigate the role of OT intervention during the recovery phase after transgender individuals receive gender affirming surgeries. Finally, a community advisory board should be used to reach a wider age demographic that more accurately reflects the community, in

addition to preventing the perpetuation of systemic biases, that may come as a result of not centering transgender voices in academic research.

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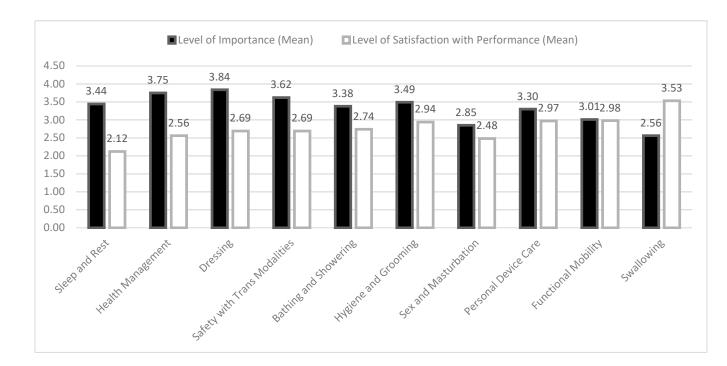
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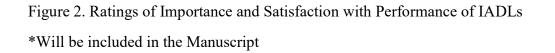
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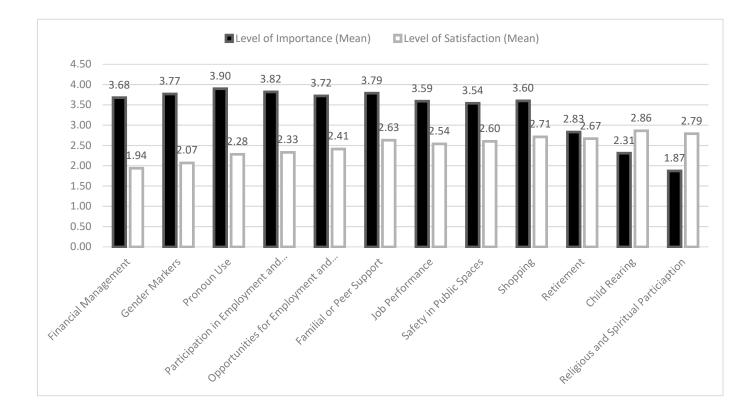
# **Complete Figures and Tables**

Figure 1. Ratings of Importance and Satisfaction of Performance in ADLs

\*Will be included in the Manuscript







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Demographics: Gender Identity and Age

Factor	Total Sample (%)	n
Gender Identity		
Transgender Man	55.5	76
Non-binary	21.2	29
Transgender Woman	14.6	20
Agender	2.9	4
Gender Fluid	3.6	5
Gender not Listed Here	1.4	2
Age		
18-24	80.1	113
25-34	5.7	8
35-44	2.8	4
45-54	2.1	3
55-64	0.7	1
65 years and above	0.7	1

Demographics: Residency

Factor	Total Sample (%)	n
Neighborhood Type		
Suburban	41.1	58
City	38.3	54
Rural	16.3	23

Demographics: Gender Confirming Surgeries

Factor	Total Sample (%)	n
Received Gender Confirming Surgeries		
Yes	6.4	9
No	89.4	126
Plan to Receive Gender Confirming		
Surgeries		
Yes	73.8	104
No	14.2	20

	-	-			
	Total				
	Sample				
Response	(%)	n			
Early	45.9	62			
1	0.7	1			
2	6.6	9			
3	13.9	19			
4	10.9	15			
5	13.1	18			
Middle	35.7	56			
6	10.2	14			
7	10.2	14			
8	7.3	10			
9	0.7	1			
10	7.3	10			
Late	17.5	32			
11	7.3	10			
12	0.7	1			
13	4.4	6			
14	2.9	4			
15	2.2	3			

Demographics: Self-Reported Transition Progress

ADLs Impacted by Transition

Factor	Yes (n)	Total Sample Yes (%)		
Dressing	115	51.1		
Hygiene and Grooming	108	56.9		
Safety with Trans Modalities	90	2.9		
Functional Mobility	78	35.0		
Sex and Masturbation	74	54.0		
Sleep and Rest	70	47.4		
Personal Device Care	69	50.4		
Health Management	65	78.8		
Bathing and Showering	48	83.9		
Swallowing	4	65.7		

Factor	Level of Importance (Mean)	Level of Satisfaction with Performance (Mean)	Difference
Sleep and Rest	3.44	2.12	1.32
Health Management	3.75	2.56	1.19
Dressing	3.84	2.69	1.1:
Safety with Trans Modalities	3.62	2.69	0.93
Bathing and Showering	3.38	2.74	0.64
Hygiene and Grooming	3.49	2.94	0.53
Sex and Masturbation	2.85	2.48	0.3
Personal Device Care	3.30	2.97	0.33
Functional Mobility	3.01	2.98	0.0
Swallowing	2.56	3.53	-0.9

Ratings of Importance and Satisfaction with Performance of ADLs

\*will be included in the Manuscript

Correlation of Self-Reported Transition Progress and ADLs

	<i>r</i> value
1. Transition Progress	
2. Health Management	.402**
3. Transgender Modalities	.392**
4. Sleep and Rest	.355**
5. Hygiene and Grooming	.255*
6. Dressing	.215*

*Note* p < .05, p < .01, two-tailed.

# IADLs Impacted by Transition

Factor	Yes (n)	Total Sample Yes (%)
Shopping	90	65.7
Pronoun Use	87	63.5
Familial or Peer Support	79	57.7
Participation in Employment and Education	75	54.7
Safety in Public Spaces	71	51.8
Gender Markers	62	45.3
Financial Management	54	39.4
Job Performance	48	35.0
Opportunities for Employment and Education	43	31.4
Religious and Spiritual Participation	24	17.5
Child Rearing	19	13.9
Retirement	7	5.

Ratings of Importance and Satisfaction with Performance of IADLs

Factor	Level of Importance (Mean)	Level of Satisfaction (Mean)	Difference
Financial Management	3.68	1.94	1.74
Gender Markers	3.77	2.07	1.70
Pronoun Use	3.90	2.28	1.62
Participation in Employment and Education	3.82	2.33	1.49
Opportunities for Employment and Education	3.72	2.41	1.31
Familial or Peer Support	3.79	2.63	1.16
Job Performance	3.59	2.54	1.05
Safety in Public Spaces	3.54	2.60	0.94
Shopping	3.60	2.71	0.89
Retirement	2.83	2.67	0.16
Child Rearing	2.31	2.86	-0.55
Religious and Spiritual Participation	1.87	2.79	-0.92

\*will be included in the Manuscript

Correlation of Self-Reported Transition Progress and Level of Satisfaction with Performance of IADLs

	<i>r</i> value
1. Transition Progress	
2. Shopping	0.206
3. Pronoun Use	0.130
4. Familial and Peer Support	0.206
5. Participation in Employment and Education	0.111
6. Safety in Public Spaces	0.142

*Note* \**p*<.05, \*\**p*<.01, two-tailed.

# Appendix A



October 4, 2018

Jamie Kimelstein, Graduate Student Department of OT School of Health Sciences and Human Performance

## **Re:** <u>IRB 0918-04 - Gender as an Occupation: Exploring the Role of OT in the Transgender</u> <u>Community</u>

Thank you for responding to the stipulations made by the Institutional Review Board for Human Subjects Research (IRB). You are authorized to begin your project. This approval is issued under the Ithaca College's OHRP Federal-wide Assurance #00004870 and will remain in effect for a period of one year from the date of authorization.

Please add the IRB approval number (IRB 0918-04) to ALL recruitment and consent materials.

After you have finished the project (when data collection is complete and there is no further risk to human subjects), please complete the *Notice-of-Completion Form* found on the Sponsored Research website. Please note that review/approval of future proposals is contingent upon submission of this form.

Should you wish to continue the approved project beyond the expiration date you may request an extension by sending an email to <u>irb@ithaca.edu</u> before October 3, 2019. The project can be extended up to three years. *If the project expires, you must complete a new application for expedited review.* 

Please note that if there are any adverse events resulting from this research, they must be reported to the IRB at <u>irb@ithaca.edu</u>.

Sincerely,

Warren J. Caldwone

Warren Calderone Director of Corporate, Foundation Relations, and Sponsored Research Institutional Review Board for Human Subjects Research

Cc: Julie Dorsey

953 Danby Road, Ithaca, NY 14850, (607) 274-3734, (607) 274-1732

www.ithaca.edu/sponsored-research

## **Appendix B: Thesis Proposal**

Gender as an Occupation: The Role of OT in the Transgender Community Jamie Kimelstein, OTS

Advisor: Julie Dorsey, OTD, OTR/L, CEAS

Committee: Luca Maurer

## **Research Problem**

Gender is a performative action which requires functional skills and abilities. Because of this, OT can play an important role in suggesting modifications to aspects of gender such as presentation, behavior, dressing, and exercise regimes. However, there are limited resources for OT practitioners for meeting the specific needs of the transgender community.

## **Rationale for study**

OT practitioners assist clients with establishing habits and routines and developing modifications to facilitate occupational performance and engagement. OT practitioners can play an important role in assisting transgender individuals with performing necessary occupations for existing in their own bodies.

## **Purpose of study**

The purpose of this study is to explore the role of OT in the transgender community. It is an attempt to create a new understanding of the ways in which OT practitioners will be able to assist transgender individuals to carry out the occupation of gender.

## **Research questions**

Which occupations do transgender people identify as being impacted during their transition process?

What role can OT practitioners have in addressing the occupational needs of transgender people?

# **OT** Theory

This research will be guided through the use of the Kawa Model, (Iwama, 2006). This theory was selected because of its focus on social and temporal contexts. The Kawa model describes one's life as a river in which, there are multiple constructs. These objects may positively or negatively impact the participant's life journey. They are as follows:

- 1. River Flow- Life flow and priorities
  - a. For this research, a priority of the client is to manage gender dysphoria and to effectively "pass" as their desired gender.
- 2. River Banks- Environments/contexts

- a. This research will focus on the societal expectations that come along with gender as well as the physical environments that may promote or inhibit the client's ability to perform their gender.
- 3. Rocks- Obstacles & challenges
  - a. For this study, the obstacles on which we will focus will be those related to gender performance. This can include access to medical care, passing in public spaces, social ostracization, etc.
- 4. Driftwood- Influencing factors
  - a. This study will focus on gender expectations, values, attitudes, and social capital as all of these can heavily influence one's ability to perform their gender.

# Methodology

This study will be an anonymous exploratory survey design using Qualtrics. The participants will be invited to complete an 10-15-minute survey in which they identify occupations that they feel have changed during their transition as well as providing information into the psychological effects of social acceptance. These survey questions were created using Table 1. of the OTPF as a guide to address occupations in the domain of OT. The relevant occupations have been translated into easily accessible language so that no OT background is required to understand the information presented. The use of the Occupations Table will also allow for easy analysis of the results as it is the basis for almost all OT intervention. The survey was reviewed by 2 members of the trans community for face validity and was adjusted according to their comments.

# Recruitment

The survey will be distributed using a snowball design. Personal connections will allow the researcher to distribute the survey to local LGBT groups and organizations. The respondents will be encouraged to share the survey with their trans-identified peers. Similarly, my committee member, Luca Maurer, has agreed to distribute the survey to trans groups and individuals with whom he is familiar. Distribution methods include email and posting to social media groups.

Inclusion Criteria: Participants must be self-identified as trans and over the age of 18.

**Exclusion Criteria:** Participants can not complete the survey if they identify as cisgender or are under the age of 18. Additionally, we are not looking for responses from OT practitioners.

## **Financial Assistance**

Financial assistance will be required for this study in order to provide incentive for the participants. After completing the survey, the participants will be given the option to click on a link for a new survey to be entered to win one of ten available \$10 Amazon Gift Cards. The raffle survey will not be linked to the main survey responses, so there will be no way to connect names and data.

# **IRB** Proposal

The proposal is currently being written and will be submitted for expedited review in the Fall 2018 Semester

## Appendix C

### **Recruitment Statement**

Hello,

I am an OT Graduate Student at Ithaca College and as part of my master's thesis, I am exploring the role of OT in the transition process of transgender individuals. I have chosen to do this research because, as a member of the transgender community, I have a personal understanding of the nuances of identity and its relationship with health and well-being. This survey will ask you to reflect on the daily activities in which you engage and how they may have changed throughout your transition. Results of this survey will help to create a new path for occupational therapists to follow when working with transgender clients.

You can skip questions or withdraw from the survey at any time. All responses will be kept anonymous and no identifying information will be asked. Once the survey is submitted, you will be redirected to a separate survey to enter to win a \$20 Amazon gift card as a thank you for participating in this study. Entry in the raffle is optional and your email address will not be attached to your survey responses maintaining anonymity.

This study is using a snowball sample recruitment strategy; therefore it is appreciated if you would consider passing this invitation along to people you know in the transgender community. The survey should take between 10-15 minutes to complete.

If you have any questions, please feel free to contact me at: Jamie Kimelstein OT Graduate Student Ithaca College Department of OT (607) 274-1975, jkimelstein@ithaca.edu

Or my faculty advisor at: Dr. Julie Dorsey, OTD, OTR/L, CEAS Associate Professor, Curriculum Director Ithaca College Department of OT (607) 274-1078, jdorsey@ithaca.edu

IRB: 0918-04

### Appendix D

#### Recruitment Quarter Card

# Help grow the services available to Trans People!

Hello, my name is Jamie Kimelstein and I am an Occupational Therapy graduate student at Ithaca College. As part of my master's thesis, I am conducting a survey to explore the activities that Trans people have identified as important and/or difficult. This study will help to increase the knowledge of occupational therapy practitioners so they can assist Trans and Gender Non-Conforming individuals specifically.

To take the survey: scan the QR-Code on the reverse side of this card or enter the link in your browser. You can skip questions or withdraw from the survey at any time. After completing the survey, you will be given the option to complete a separate survey to enter your e-mail address in order to enter to win a \$20 Amazon Gift card.

Jamie Kimelstein Occupational Therapy Graduate Student Ithaca College Department of Occupational Therapy (607) 274-1975, jkimelstein@ithaca.edu Dr. Julie Dorsey, OTD, OTR/L, CEAS Associate Professor, Curriculum Director Ithaca College Department of Occupational Therapy (607) 274-1078, jdorsey@ithaca.edu

#### HTTPS://ITHACA.QUALTRICS.COM/JFE/ FORM/SV\_BOYXLVESI7XNSR3

Scan the QR-Code below or type the above link into your browser



IF AT ANY POINT IN THIS SURVEY YOU FEEL TRIGGERED OR IN DISTRESS, PLEASE CONTACT THE TREVOR PROJECT BY PHONE AT 1-866-488-7386 OR ONLINE AT WWW.THETREVORPROJECT.ORG/GET-HELP-NOW

IRB 0918-04

### **Appendix E**

### **Qualtrics Survey Tool**

#### Hello,

I am an OT Graduate Student at Ithaca College and as part of my master's thesis, I am exploring the role of OT in the transition process of transgender individuals. I have chosen to do this research because, as a member of the transgender community, I have a personal understanding of the nuances of identity and its relationship with health and well-being. This survey will ask you to reflect on the daily activities in which you engage and how they may have changed throughout your transition. Results of this survey will help to create a new path for occupational therapists to follow when working with transgender clients.

You can skip questions or withdraw from the survey at any time. All responses will be kept anonymous and no identifying information will be asked. Once the survey is submitted, you will be redirected to a separate survey to enter to win a \$20 Amazon gift card as a thank you for participating in this study. Entry in the raffle is optional and your email address will not be attached to your survey responses maintaining anonymity.

This study is using a snowball sample recruitment strategy; therefore it is appreciated if you would consider passing this invitation along to people you know in the transgender community. The survey should take between 10-15 minutes to complete.

If you have any questions, please feel free to contact me at:

Jamie Kimelstein

**OT Graduate Student** 

Ithaca College Department of OT (607) 274-1975, jkimelstein@ithaca.edu

Or my faculty advisor at:

Dr. Julie Dorsey, OTD, OTR/L, CEAS Associate Professor, Curriculum Director Ithaca College Department of OT

(607) 274-1078, jdorsey@ithaca.edu

IRB: 0918-04

Which term best describes your gender identity?

- Trans Man
- Trans Woman
- Non-binary
- Agender
- Gender Fluid
- Cisgender (non-transgender)
- Gender not listed here

If you selected "Gender not listed here," please enter your identity below:

### Please indicate your age.

- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- 75 years old and above

How would you best describe the area in which you live?

- City
- Suburb
- Rural

Understanding that transitioning is a continuous experience, please indicate on the scale below where you feel you are in your transition process.

1=Before realizing your gender

15=Goal of your transition process

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15

	$\bigcirc$														
Have you received any gender confirming surgeries?															
Yes															
O No															
Do you plan on receiving gender confirming surgeries?															
O Yes															

O No

# Activities oriented toward taking care of yourself:

	Has this activity been impacted during your transition?			How important is this activity to you?	How satisfied are you with your current performance of this
	Yes	No	N/A		activity?
Bathing and showering (Examples: cleaning genitals, after gender confirming surgery, etc.)	0	0	$\bigcirc$	<b>•</b>	<b></b>
Swallowing (after gender confirming surgery)		$\bigcirc$	$\bigcirc$	▼	▼
Personal device care (Examples: cleaning and management of packers, binders, hip pads, etc.)	0	$\bigcirc$	$\bigcirc$	▼	•
Hygiene and grooming (Examples: hair styling, makeup, etc.)	0	$\bigcirc$	$\bigcirc$	<b></b>	<b></b>
Sexual activity and masturbation	$\bigcirc$	$\bigcirc$	$\bigcirc$	<b></b>	<b></b>
		tivity bee your tran	n impacted sition?	How important is this activity to you?	How satisfied are you with your current performance of this activity?
	Yes	No	N/A		

Health management (Examples: managing hormones, access to healthcare, etc.)	$\bigcirc$	$\bigcirc$	$\bigcirc$	•
Functional mobility (Examples: walking pattern to be more representative of your gender)	$\bigcirc$	$\bigcirc$	0	<b></b>
Sleep and rest (Examples: frequent waking, inability to fall asleep, etc.)	$\bigcirc$	$\bigcirc$	$\bigcirc$	▼
Dressing (Examples: wearing gender affirming clothing, binders, hip pads, etc.)	$\bigcirc$	$\bigcirc$	$\bigcirc$	<b></b>
Safety (Examples: tucking, binding, purchasing hormones, etc.)	$\bigcirc$	$\bigcirc$	$\bigcirc$	▼
Please share any comments about	Yes	No	N/A	

# Activities to support daily life within the home and community

Has this ac during	tivity been your trans	•	How important is this activity to you?	How satisfied are you with your performance in this
Yes	No	N/A		activity?

Please share any comments a			-	 	
	Yes	No	N/A		
Pronoun use (Examples: coming out, advocating for correct use)	0	$\bigcirc$	$\bigcirc$	<b></b>	▼
Gender markers (Examples: legal name, legal gender, etc.)	0	$\bigcirc$	$\bigcirc$	▼	<b></b>
	Yes	No	N/A		
	Has this activity been impacted during your transition?			How important is this activity to you?	How satisfied are you with your performance in this activity?
Familial or peer support	0	$\bigcirc$	$\bigcirc$	<b></b>	▼
Retirement	$\bigcirc$	$\bigcirc$	$\bigcirc$	▼	▼
Job performance (focusing, interacting with others, etc)	0	$\bigcirc$	$\bigcirc$	<b></b>	•
Shopping (gender affirming clothing, gendered products, etc.)	$\bigcirc$	$\bigcirc$	$\bigcirc$	<b></b>	<b></b>
Opportunities for employment and education (Examples: finding new job opportunities, interviewing, etc.)	0	$\bigcirc$	0	<b></b>	▼
Financial management (Examples: funding surgeries/hormones, etc.)	0	$\bigcirc$	$\bigcirc$	<b></b>	▼
Child rearing (Examples: fertility and parenting)		$\bigcirc$	$\bigcirc$	<b>T</b>	▼
Participation in employment and education (Examples: confidence at school and work, performance of work tasks, etc)	0	$\bigcirc$	0	▼	<b></b>
Safe participation in activities in public spaces	0	$\bigcirc$	$\bigcirc$	<b></b>	▼
Religious or spiritual participation (Examples: accessing an affirming congregation)	0	$\bigcirc$	$\bigcirc$	<b></b>	▼

Is there any additional information that you believe to be important for the researcher to know?

If at any point during this survey you felt triggered or in distress, please contact the Trevor Project via phone at 1866-488-7386 or online at https://www.thetrevorproject.org/get-help-now

Thank you for taking the time to complete this survey! Your responses have been recorded.

Please cope and paste the following link into your browser if you want to be entered to win one of four \$20.00 Amazon Gift Cards.

https://ithaca.qualtrics.com/jfe/form/SV\_bJFkyaoWPzh53dX

We truly value the information you have provided. Your responses will contribute to our research on the role of OT in the transition process of trans individuals.

### **Appendix F**

### **Guidelines for Contributors to AJOT**

The American Journal of OT (AJOT) is the official journal of the American OT Association (AOTA). Manuscripts for all categories are peer reviewed. We welcome the submission of manuscripts that are relevant to the study of occupation and the practice of OT.

### These include articles on the following topics as they relate to OT and participation in occupation:

• Incidence and prevalence of client factors and how they relate to occupational engagement, activity and participation, and roles

• Patterns of occupational engagement, activity, and participation in various populations (e.g., how people spend their time)

Relationship of engagement in occupations to health and development across the lifespan
 Physiological and psychological mechanisms of health and of conditions commonly encountered in OT practice that present barriers to occupational engagement, activity and participation, and roles

• Studies of the effectiveness, efficacy, and effects of interventions and programs that fall within the scope of OT (i.e., clinical trials) as well as cost–benefit studies of such interventions and programs • Health services research

• Health policy research relating to the facilitation of participation and healthy engagement • Studies establishing the psychometric properties of instruments

• Pedagogy relating to the entry-level, postprofessional, or continuing education of OT practitioners; interprofessional education of health professionals in general may be considered as it relates to the education of OT practitioners

• Manuscripts exploring timely topical or professional issues (The Issue Is articles). (Note that space for these articles is limited, and manuscripts may not be accepted for review if they cannot be published

within a reasonable time frame; see "Information for Authors" at https://otjournal.net for updated information.) AJOT aims to publish a variety of articles to reflect the broad range of OT. However, the goal is for the majority of articles to be effectiveness and instrument development studies.

### AJOT will not consider manuscripts on the following topics:

- Manualization of interventions
- Descriptions of clinical trial protocols that do not include outcome data
- Descriptions of clinical programs (i.e., articles that do not answer a research question)
- Case studies.

To be considered for publication, manuscripts on the following topics must meet certain requirements:

• Single-subject design studies and case series studies must have a sample size of at least 3 participants.

• Articles describing research related to psychometric properties of translated assessment instruments must have evidence that the researchers used best practice in translating the instrument (i.e., language and transcultural translation and back-translation).

• Manuscripts on psychometric properties of instruments that examine only one psychometric factor will be considered for publication only as a Brief Report and must meet the page limits for this type of article. If the manuscript describes the phases of the instrument's development and at least one of the psychometric properties, it may be considered as a featurelength manuscript.

Clinical Trial Registration Manuscripts describing clinical trials must be registered in a clinical trial registration system (e.g., Clinicaltrials.gov); for trials in which participant recruitment started Jan 1, 2016, or later, registration must occur prior to participant recruitment to be considered for publication. AJOT uses the National Institutes of Health definition of clinical trial

(http://grants.nih.gov/grants/guide/notice-files/NOTOD-15-015.html): The American Journal of OT 7212430010p1 Downloaded from http://ajot.aota.org on 07/30/2019 Terms of use:

http://AOTA.org/terms A research study in which one or more human subjects are prospectively assigned to one or more interventions (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes. Trials whose participant enrollment began before January 1, 2016, must be registered retrospectively. Manuscripts that are accepted must provide the trial registration website address and trial registration number in the final, unmasked manuscript in the "Acknowledgments" section.

#### The following types of trials do not need to be registered:

• Trials that evaluate the effects, efficacy, or effectiveness of educational methodologies and techniques for OT practitioners or for continuing education

• Trials that do not have client health-related biomedical or behavioral outcomes. Submission Process To submit a manuscript, go to https://ajot.submit2aota.org/ and follow the online instructions. Authors are encouraged to use an ORCID iD with the AJOT manuscript submission system (see

### https://orcid.org/register).

Manuscripts must be submitted with the authors' explicit assurance that the manuscript is not simultaneously under consideration by any other publication. The journal cannot assume responsibility for the loss of manuscripts. AJOT uses a continuous publishing workflow, whereby an article is published online as soon as it has been edited and prepared for publication.

### Authors' Responsibilities

It is the authors' responsibility to follow all the instructions in these guidelines. Manuscripts and resubmissions not following the guidelines will be returned. Copyright, Authorship, and Financial Form As part of the submission process, all authors must provide original signatures for copyright release, authorship responsibility, and financial disclosure. The statement of authorship responsibility is certification that each author has made substantial contributions to (1) the study conception and design,

acquisition of data, or analysis and interpretation of data; (2) the drafting and revision of the article; and (3) the approval of the final version. Moreover, each author takes public responsibility for the work. AJOT publishes only original content; manuscripts that have been published in whole or in substantial part, whether in print or online, will be rejected. The only exceptions to this policy are (1) research presented at conferences and (2) dissertations and theses that have been archived in university library systems. The combined Copyright Transfer/Author Certification/Financial Disclosure Form may be downloaded from the AJOT submission website at https://ajot.

submit2aota.org/journals/ajot/forms/ajot\_certification.pdf. A completed, signed form must be uploaded before submitting a manuscript. Manuscript Preparation AJOT uses the sixth edition of the Publication Manual of the American Psychological Association (APA6; 2010) as the style guide. Consult this manual for style questions not addressed in these guidelines (see also APA Publications and Communications Board Working Group on Journal Article Reporting Standards, 2008). AJOT is participating with several other major rehabilitation and disability journals in a collaborative initiative to enhance clinical research reporting standards through adoption of the EQUATOR Network reporting guidelines (Chan, Heinemann, & Roberts, 2014). Authors are required to use established guidelines appropriate to their research design in the preparation of manuscripts submitted to AJOT, and reviewers refer to the guidelines in evaluating all AJOT submissions. Author Order The order of authors in the byline follows APA6 guidelines. The principal contributor appears first, and subsequent names are in order of decreasing contribution. Authors are encouraged to limit the number of coauthors to seven or fewer.

### Types of Articles Research Articles—

Nonreview, Feature Length.

Feature length research articles are original research reports that focus on philosophical, theoretical, educational, occupational science, or practice topics. Unless the manuscript is unique to OT practice or education, manuscripts should be written to the topic rather than OT's importance in the area (e.g., the importance of sleep hygiene to function throughout the day, rather than OT's unique role in sleep hygiene). (22 pages maximum, or 4,000 words, including title page, abstract, acknowledgments, references, tables, figures, and illustrations) Feature-length research articles must include an "Implications for OT Practice" section summarizing the implications of the research for OT practice or general interprofessional clinical practice; this section must include a bulleted list of the key points. Authors must be careful in this section to not go beyond their data and level of evidence of their study. If the research is still at a feasibility or low level of evidence, 7212430010p2 November/December 2018, Volume 72(Supplement 2) Downloaded from http://ajot.aota.org on 07/30/2019 Terms of use: http://AOTA.org/terms the data can be only promising (or not promising) for potential use, and further testing is required. Thus, practitioners would need to make practice decisions about the data with extreme caution and acknowledgment of the limited evidence that the study provides. The intent of the "Implications for OT Practice" section is to specify what this research adds to our knowledge for practice. Studies on intervention effectiveness at any level of evidence and design may be submitted. For feasibility studies, however, only feasibility questions, rather than outcome data, are addressed. Manuscripts must include the following information, as appropriate:

• The standard error of measurement (SEM) of the quantitative outcome measures (Page, 2014). The article must either discuss how the changes on the outcome measures after intervention compare with the outcome assessments' SEMs or provide the number of participants who exceeded and did not exceed the SEM for each group. Only changes exceeding the SEM can be considered true change and not just

measurement error. If SEMs have not been determined for a particular outcome measure, authors should discuss what the field commonly considers the minimally detectible change for that measure . • For randomized controlled trials (RCTs), a primary outcome and a primary testing time for that outcome (if there is more than one postintervention testing time) so that ratings of trial quality that include retention can be completed. It is common for study retention to be high at immediate postintervention testing but for participant attrition to occur over time. When a primary endpoint has not been identified, it is not clear how to score the study's quality related to the retention time. Testing differences at other testing times is acceptable but will be considered secondary outcomes . • Effect size and Fragility Index. P values do not indicate the size or robustness of the effect. It is possible for results that have little clinical or real-world significance to achieve statistical significance. Therefore, when appropriate, authors need to include the following information in efficacy trials (i.e., Phase 2, small RCTs; two-group nonrandomized trials; and one-group pretest-posttest trials) and effectiveness trials (i.e., Phase 3, medium and large RCTs): - Effect size related to the comparisons. -Fragility Index (Feinstein, 1990; Walsh et al., 2014) for the authors' primary outcome and any other outcomes used to indicate the effectiveness or efficacy of the intervention. The Fragility Index is a measure of the robustness of the effect by examining the number of participants who would need to not successfully respond to the intervention before the effect would become nonsignificant. The higher the Fragility Index is, the more robust the outcomes of a trial are. It is calculated by creating a binary outcome for each outcome of interest (i.e., the amount of change that would be classified as successful is determined, and participants in each group are classified as successful or not). Then, a 2 · 2 contingency table is constructed (Intervention Group · Success Status). Cells consist of the number of participants in each group. Participants are added iteratively to the cell with the smallest number, and Fisher's exact test is computed until p > .05. The number of added participants is the Fragility Index. In the "Discussion"

section, authors must discuss the real-world impact of their results. They should consider the effect size, the robustness of the effect, and the meaning of the amount of change for increasing real-life function, engagement, or satisfaction with occupations. Authors should not simply rely on expert definition of clinically significant change for an outcome measure; instead, they should comprehensively evaluate the meaning of the magnitude of changes. Multiple methods exist for determining clinical significance. The most common approaches use either distribution methods or anchor measures to determine the minimally important difference (Jaeschke, Singer, & Guyatt, 1989). Distribution methods use the distribution of the data and compute several statistics to arrive at clinical significance. Anchor measures use data indicating participants' perception of the importance of the intervention-related changes (e.g., what they can do now that they could not do before; activities being easier, less time consuming, more satisfying). When the Fragility Index is low, the discussion should reflect the lack of robustness in the data. Thus, when effect sizes have small clinical significance or robustness is low, results may be promising, but more exploration of the intervention is warranted, either to refine the intervention protocol to make it more effective or to determine whether the intervention is more effective for subgroups in the population. Ultimately, of course, such research might result in a conclusion that the intervention is not very effective. The discussion needs to reflect this uncertainty. To increase the transparency of clinical research and improve the ability to evaluate published articles for methodological and analytical rigor, AJOT has adopted reporting standards based on the CONsolidated Standards Of Reporting Trials (CONSORT) Statement (Moher, Schulz, & Altman, 2001; see http://www.consort-statement.org) for randomized trials and SCRIBE (Tate et al., 2016) for N-of-1 The American Journal of OT 7212430010p3 Downloaded from http://ajot.aota.org on 07/30/2019 Terms of use: http://AOTA.org/terms trials. Also see "Reporting Standards for Intervention Effectiveness Studies" (Gutman, 2010) at https://ajot.aota.org/article.aspx?articleid51854539 and "Information Commonly

Unreported in Intervention Effectiveness Studies" (Gutman & Murphy, 2012) at

https://ajot.aota.org/article. aspx?articleid51851543 Research Articles—Critical Reviews, Feature Length. Authors of critical reviews of all types (e.g., systematic reviews, scoping reviews, mapping reviews) are encouraged to adhere to the page and word count limits for other featurelength articles; the accompanying tables will be published online only and are not included in those limits. Review articles covering an exceptionally extensive body of research may be as long as 26 pages, or 5,000 words (title, abstract, body, and references; tables and figures do not count in this limit because they will be placed online). Tables and figures for review articles are limited to no more than five total. AJOT does not accept narrative reviews. Systematic reviews are conducted when sufficient studies exist to be able to assess the strength of the evidence related to a topic. Systematic review articles should attempt to answer a narrowly focused question; questions that are unfocused in terms of intervention, outcome targets, or populations create difficulty in interpreting findings in a useful manner. Authors should follow AJOT's guidelines for systematic reviews, available at https://ajot.submit2aota.org/

journals/ajot/forms/systematic\_reviews.pdf. Authors conducting systematic reviews who find sufficient homogeneity in the discovered literature should conduct a meta-analysis. When homogeneity exists in only part of the literature, the authors should conduct a meta-analysis of the homogeneous domain, followed by narrative results of the part of the literature that is not homogeneous. Generally, previous systematic reviews should not be used as primary data, but they may be included in introductory material and the discussion. If the authors choose to use previous systematic reviews as primary data, they must include a separate risk-of-bias table for included systematic reviews. Systematic reviews must include clear statements about the status of the answer to the research question and strength of the evidence related to that status. They should also provide an "Implications for OT Practice" section that is consistent with the answer to the research question and the level of evidence. When it is clear that

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more research is needed or that additional questions that may potentially modify the answer to the research question must be answered, authors should include statements related to this research need. Authors of systematic reviews should follow the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) for systematic reviews and metaanalyses (http://www.prisma-statement.org/PRISMAStatement/Default. aspx). Authors are encouraged, but not required, to register their systematic review protocols prospectively at https://www.crd.york. ac.uk/PROSPERO/. Scoping reviews and mapping reviews attempt to answer questions about a broad field or a topic for which limited data are available. These review types typically describe what is known about a topic rather than review the strength of the intervention evidence. These reviews should include a clear statement of what the research gaps are and recommendations for future research. An evidence table should be included in the manuscript. The table format may vary, but all evidence tables should include the important characteristics of each study included in the review. A diagram (map) of the findings may be included, but it cannot substitute for the table. Because guidelines for scoping reviews have not yet been developed, authors should follow the procedures of the Joanna Briggs Institute (Peters et al., 2015) and the PRISMA-P guidelines (http://prisma-statement.org/Extensions/Protocols. aspx). Research Articles—Other Types, Feature Length.

Other types of feature-length research should follow published guidelines:

• Qualitative studies should follow the COnsolidated criteria for REporting Qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007; http://www.equator-network.org/reporting-guidelines/coreq/).

• N-of-1 studies (single subject or case series) should follow the Single-Case Reporting guideline In BEhavioural interventions (SCRIBE; Tate et al., 2016) guidelines for single-case research in the behavioral sciences.

• Observational studies should follow the STrengthening the Reporting of OBservational studies in Epidemiology guidelines (STROBE; von Elm et al., 2007; <u>https://strobestatement.org/</u>).

• Diagnostic (identification of specific impairments or occupational problems) studies should follow the STAndards for the Reporting of Diagnostic accuracy studies (STARD; Bossuyt et al., 2015; http://www.equator-network.org/wp-content/uploads/2015/03/ STARD-2015-paper.pdf).

For all studies, authors should consider the size of the effect and its clinical relevance in forming their discussion to keep the discussion within the bounds of their data and to not overstate the impact on OT. *Brief Report.* 

A Brief Report is a short report of original research that is of a pilot or exploratory nature or that addresses a discrete research question and lacks broad implications. The research can be of any design. Authors should follow the reporting guidelines stated above to the 7212430010p4 November/December 2018, Volume 72(Supplement 2) Downloaded from http://ajot.aota.org on 07/30/2019 Terms of use: http://AOTA.org/terms extent possible, given the size constraints. (15 pages maximum, or 3,000 words, including title page, abstract, acknowledgments, references, tables, figures, and illustrations) *The Issue Is.* 

The Issue Is articles address timely issues, policies, or professional trends or express opinions supported by cogent argument from the literature. They provide a forum for scholars to debate professional issues that have an impact on the evolution of the profession. The Issue Is articles have three primary sections: (1) background information about the problem in question as it relates to the profession and to the larger society, (2) logically presented arguments supporting the author's position, and (3) the steps the profession must take to promote positive change. Limited space is allocated to The Issue Is articles, and otherwise acceptable manuscripts may be rejected if they cannot be published within a reasonable time frame. Authors should check the AJOT website at http://ajot.aota.org/ss/ authors.aspx to see whether

AJOT is accepting manuscripts for this type of article. (15 pages maximum, or 3,000 words, including title page, abstract, acknowledgments, references, tables, figures, and illustrations) Letters to the Editor. Beginning in 2019, letters to the editor discussing a recent AJOT article or other broad issue relative to the journal will be considered for publication. Letters must be scholarly, contribute to the professional discussion of a topic, include references as appropriate, and be no more than 750 words in length, including references. Letters may be edited for length and to conform with AJOT editorial style and will published at the sole discretion of the Editor-in-Chief. Letters should be submitted by email to ajotproduction@aota.org. Editorial Style and Manuscript Format Refer to APA6, along with recent issues of AJOT, for guidance on manuscript format. Careful attention to style details will expedite the peer review process. Manuscripts will be returned to authors if there are extensive issues with APA style. Authors are responsible for ensuring that a blind review process can take place by submitting a masked version of the manuscript, which contains no identifying information, including names and affiliations of all authors and acknowledgments. Unmasked articles will be returned for masking before they are reviewed. Authors of manuscripts that are accepted will be asked to provide an unmasked version. Double-space the entire manuscript, including abstract, text, quotations, acknowledgments, tables, figure captions, and references. Leave 1-inch margins on all sides, and keep the right side unjustified. Number all pages, starting with the title page, and use line numbering in the text, starting with the page containing the abstract and key words. Use only Times New Roman 12-point font. Manuscripts are compiled and converted to PDF format during the online submission process. Specific instructions are provided at https://ajot.submit2aota.org/. During the submission process, manuscripts are converted from Word to PDF. However, if the manuscript is written on a system whose default language is written right to left (e.g., Arabic, Hebrew), the conversion process will not work properly. In such cases, please send the Word version with line numbers to Lorie Richards, AJOT Editorin-Chief, at

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conclusion. This section should consist of a short paragraph followed by a bulleted list of the practice implications, and it should be included in the manuscript's word count. Although Brief Reports do not require a separate section, they should clearly indicate the implications for clinical practice in their discussion. This section is meant to be a brief section highlighting the study's implications for clinical practice. It should be written in lay language and should not include implications for research or restate the results or discussion. Rather, it should look ahead to how the findings might be extended to routine clinical practice. The points discussed in this section should stay within the limits of the study findings: • If the study tests the effects of a particular intervention, then mention what those effects might mean for clinical practice. Do not include statements about general OT practice unless tested in the study. • Do not include statements related to a particular assessment approach if the study did not test assessment practices. • If the study provides confirmatory evidence, then use wording such as "this study confirms previous work that. . . . " or "the results offer further evidence that. . . . " • If the study suggests a promising type or amount of service that is not feasible as a result of current health care or reimbursement policies, it may be more appropriate to suggest that practitioners advocate for changes in policies rather than provide that service. • For pilot or feasibility studies, the only statements that can be made are as to whether the intervention may have potential to facilitate benefits if larger studies show similar results. In addition, the following statement may be made: "If practitioners choose to implement this approach clinically, they need to carefully document treatment content, client responses to the treatment, and changes in client functioning (or occupational engagement) from start to termination of treatment." If the findings have relevance for OT education, authors may include a section on implications for OT education (this would be the only "implications" section if the study is educational research). It is not sufficient to argue that new content must be included in entry-level curricula. OT education programs typically are overloaded with content; therefore, authors making recommendations

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The following are examples of commonly used reference citations:

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• Journal Article (hard copy or not available online): Dunton, W. R., Jr. (1926). An historical note. OT and Rehabilitation, 5, 427–439.

• Journal Article (online version, with DOI): Arbesman, M., & Lieberman, D. (2011). Methodology for the systematic reviews on OT for adults with Alzheimer's disease and related dementias. American Journal of OT, 65, 490–496. <u>https://doi.org/10.5014/ajot.2011.002576</u>

Journal Article (online version, no DOI): Gram, M., & Smed, K. (2011). We can drink our coffee more slowly: Discursive uses of age in relation to holiday consumption—Examples among Danish and German mature travellers. E-Journal of Applied Psychology, 7(1), 2–7. Retrieved from http://vbn.aau.dk/en/publications/ we-can-drink-our-coffee-more-slowly-discursive-usesof-age-in-relation-to-holiday-consumption--examplesamong-danish-and-german-mature-travellers(7a54a952-b230-44b7-8ebd-0c0b1aee13f4).html
Book With Corporate Author and Author as Publisher: American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing. World Health Organization. (2001). International classification of functioning, disability and health. Geneva: Author.

Book With Author(s): Frank, G. (2000). Venus on wheels: Two decades of dialogue on disability, biography, and being female in America. Los Angeles: University of California Press.
Edited Book: Law, M. (Ed.). (1998). Client-centered OT. Thorofare, NJ: Slack.
Chapter in Edited Book: Case-Smith,

J. (2010). Evidence-based practice in OT for children with an autism spectrum disorder. In H. M. Kuhaneck & R. Watling (Eds.), Autism: A comprehensive OT approach (3rd ed., pp. 701–742). Bethesda, MD: AOTA Press. Tables. Provide descriptive titles, and begin each table on a new page after the references.

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