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Evan Altman Date

A Systematic Review of the Most Frequently Mentioned Barriers and Facilitators to Cancer Screening and Care in Transgender and Gender-nonconforming Individuals

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A Systematic Review of the Most Frequently Mentioned Barriers and Facilitators to Cancer Screening and Care in Transgender and Gender-nonconforming Individuals

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Thesis Committee Chair: Dr. Michael Goodman MD, MPH and Dr. Roger Rochat MD

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2017

Abstract

A Systematic Review of the Most Frequently Mentioned Barriers and Facilitators to Cancer Screening and Care in Transgender and Gender-nonconforming Individuals

By Evan Altman

There are approximately 1.4 million transgender people in the United States. This is a very hard to study, medically-underserved community. In this communication we examine the literature on barriers to and facilitators of cancer screening and care in transgender people. We identified and systematically reviewed 16 studies that used qualitative and quantitative methods to collect information on cancer screening and care among transgender persons, healthcare providers, and advocates for transgender healthcare. The main barriers to cancer screening and care in transgender people include avoidance of healthcare, discrimination, and lack of nationally published guidelines. The main facilitators include access to providers who are educated about transgender health and welcoming clinical environments. While there is much to learn about providing adequate cancer screening and care for transgender individuals, it is likely that issues discussed in this review are commonly experienced by the transgender community. Cancer screening and care for transgender individuals may improve through increasing exposure to transgender healthcare issues in medical schools and training programs, and by expanding healthcare services so that transgender people can be recognized as an important, relevant population with unique healthcare needs.

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[1] Brief description of guidelines for the general population are provided for review and comparison

Glossary of Terms

Sex (*biological sex*): biologically and anatomically defined status at birth; determined solely by internal and external sex organs, sex hormones, and chromosomes; typically defined as male, female, or intersex

Intersex (Intersexuality): person who is born with anatomy that does not fit the typical definitions of the male or female sexes; may have combined anatomy and may or may not influence gender

Gender: attitudes and expression of a person (traditionally based on the male/masculine and female/feminine sex distinctions and social constructs); based on inherent feelings and experiences; can be the same or different from biological sex (see above)

Gender Identity: the personal experience of being male or female, or identifying as masculine, feminine, neither, or a gender that is beyond the confines of the male-female gender binary

Transgender: a person whose gender identity or expression does not align with their biological sex (see above)

Cisgender: a person whose gender identity matches their biological sex

Gender-queer, gender non-conforming, gender-fluid: non-binary gender expression where a person may or may not identify with one specific gender, no socially defined gender, or multiple genders; identity may shift or changed based on certain situations, or circumstances (may be fluid)

Gender Dysphoria: distress tied to ones own personal conflict with their gender experience and expression; person may experience a spectrum of distress with their anatomy

Gender-Affirming Care: the set of healthcare practices that are specifically related to (and often result from) the gender dysphoria that causes a person to undergo gender transformation; interventions include sex hormone use and gender reassignment surgery; care that enhances the outward and psychological appearance of the preferred gender identity

FtM; Transman; Transgender male/man: female to male, a transgender male, a female (biological sex) at birth who identifies as male

MtF; Transwoman; Transgender female/woman: male to female, a transgender female, a male (biological sex) at birth who identifies as female

Neovagina: vagina generally constructed in transwoman who desire sexual reassignment; removal of the penis and restructuring of nerve tissue is commonplace; a vaginal orifice is created using inverted penile skin, skin grafts, colonic tissue, or scrotal flaps depending on surgeon preference. The vagina is often a close pouch and can function sexually, but not reproductively

Barrier: a circumstance, person, or obstacle that prevents communication, actions, or progress

Facilitator- a circumstance, person, or obstacle that makes communication, progress, or actions easier or more likely to occur

Chapter 1: Introduction

Over the last few years there has been excellent progress in understanding the healthcare needs of the Lesbian, Gay, Bisexual, and Transgender (LGBT) community;

however, important knowledge gaps persist (Institute of Medicine 2011, Bowen 2006, Mayer 2008, Coulter 2014). The barriers to improving our knowledge of the healthcare needs of this population include lack of high quality demographic data, paucity of well-designed, systematic studies, and important methodological issues specific to transgender health research (Reisner 2016, Lancet 2011, MacCarthy 2015).

The transgender population in the United States, is currently estimated to include 1.4 million people (Williams Institute 2016). This number however is likely an underestimate due to the reluctance of transgender persons to publically identify themselves for personal, cultural, professional, or other reasons **(Zucker and Lawrence, 2009; Institute of Medicine 2011).**

While transgender people experience the same common health problems as the general population, they also have unique health concerns. The health conditions thought to affect this population at higher rates include depression, substance abuse, sexual health problems, as well as specific surgical and hormone-related problems associated with gender-affirmation therapy (de Haan 2015, Bourgeois 2015, Weinand 2015).

An important area of priority in transgender research is cancer prevention and control. Cancer-related risk factors that may disproportionally affect transgender people include Human Papilloma Virus (HPV), Human Immunodeficiency virus (HIV), and Hepatitis B and C infections (WHO 2017), as well as lifestyle-related modifiable risk factors such as smoking, obesity, and lack of physical activity (Fredriksen-Goldsen et al. 2014). Additional factors that are hypothesized to influence cancer risk in transgender people include exposure to high doses of cross-sex hormones and long term consequences of surgical gender affirmation, however many studies have not found any increased risks here (Dahl et al. 2008, WPATH 2001). Thus, more data is needed to make any conclusions about cancer risk associated with hormone use. Furthermore, many transgender individuals are using non-prescribed hormones, often due to an inability to access to quality providers or lack of adequate insurance coverage (Sanchez 2009).

A separate concern is a glaring lack of provider education that precludes health care professionals from properly counseling and screening transgender patients. Health care providers may be hesitant to bring up the patient's natal sex for fear of embarrassing the patient, or because they do not know how to discuss these issues (Shetty et al. 2016). For example, one study showed that many providers were not aware that some transwomen, who have had gender-affirmation surgeries, still had prostates and were still at risk for prostate cancer (Loughlin 2015). Transgender patients may sometimes choose to ignore their natal sex and are reluctant to undergo screening that may exacerbate their own gender dysphoria (White 2015, Unger 2014). For example, a recent WHO report acknowledged the need for transgender men to have cervical cancer screening (Lancet Oncology 2015), however, few studies have evaluated how often patients and providers actually follow these guidelines.

With these considerations in mind, the overall goal of this communication is to systematically evaluate the available published data on cancer screening and care in the transgender population. Our primary objective is to identify potential barriers and facilitators that may affect cancer screening and care of transgender people. To achieve this goal, we first review the literature on cancer screening and care, and then provide an overview of the available data pertaining to barriers and facilitators of cancer screening and cancer care in this population. A summary of the available evidence may then be used in the future to design systematic quantitative studies and to monitor access to and utilization of cancer screening services among transgender people.

Chapter 2: Review of the Literature

A Brief Medical History of Transgenderism

Although mention of the transgender population in the literature seems to be a relatively recent phenomenon, transgender people have undoubtedly existed throughout history. The first-known gender reassignment surgeries were performed in the early 1900s in Germany, Denmark, and later in the United States (Meyerowitz 2004). The concept of transsexualism was first categorized and described by Henry Benjamin in *The Transsexual Phenomenon" (*Benjamin 1969*).* In the early 1970's, however, the concept of transsexualism became stigmatized when it was increasingly classified as a disease (Kubie and Mackie 1968). In the field of Psychiatry, criticisms of transsexualism, as well as a push to classify it as a mental disorder began right around the time the phenomenon was being described in the literature (Meerloo 1967). One article, entitled *The Transsexual Experiment*, and published in the American Journal of Psychiatry characterized the male sexual reassignment movement as a "carnival atmosphere that prevails in the management of male transsexualism" (Stoller 1975). A 1966 study of medical practitioners reported that fewer than 50%, and in some specialties less than 40%, would have approved sexual-reassignment surgery for their patients (Green, Stoller, McAndrew 1966). Transgender persons were traditionally thought to have mental illness and were diagnosed with "Gender Identity Disorder", a stigma that was finally changed in 2013, when the Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-V) changed the term to "gender dysphoria," and acknowledged that transgenderism is not a disorder (APA 2013).

Transgender Population Healthcare Gaps

A 2015 position paper on LGBT healthcare by the American College of Physicians published in the Annals of Internal Medicine acknowledged that "transgender individuals face additional challenges in gaining care" when compared with the LGBT population as a whole and experience greater difficulty with healthcare access and insurance coverage, especially with regard to trans-specific interventions such as surgery and hormones (Daniel and Butkus 2015). Further, it is important to remember that not all transgender individuals may want or receive gender-affirming care. There is also a concern about routine medical care for transgender individuals with regard to chronic illnesses and diseases of aging, such as cancer. A report called the National Transgender Discrimination Survey highlights some of the main reasons why transgender people do not receive adequate medical care; some of these include delaying medical care due to discrimination and lack of affordability (Grant et al. 2016). Almost 20% of the patients have outright been refused care and almost 50% of patients in the report have had to teach their medical providers about transgender health issues (Grant 2016).

Cancer in the Transgender Population

As the percentage of geriatric Americans increases, our society is simultaneously experiencing shortages of healthcare providers, particularly in primary care fields, which are indispensable for screening patients for cancer and providing preventive care to patients from all walks of life (AAMC 2016). Because many transgender people may be approaching advanced age, and because cancer is a rapidly growing health concern globally, especially among those over age 50, cancer prevention and control are important issues to address in the transgender community (Berger et al. 2006). Currently, there is much debate over whether or not hormone therapy increases cancer risk in transgender people who are on hormones long-term and much more data is needed. Dhejne et al. 2011; Bernstein and Potter 2014). At present, medical colleges and societies, which produce clinical practice guidelines, provide no universal recommendations for cancer screening in transgender patients (Deutsch 2016). While "official" consensus information is lacking, certain organizations have put out recommendations for healthcare providers who want to use peer-reviewed, evidence-based medicine to treat their transgender patients (WPATH 2016; Deutsch 2016; USPSTF 2014).

Cancer Screening Guidelines and Information in Transgender[2] Patients

Although no universal clinical guidelines exist for the screening of transgender patients, clinicians who care for transgender patients must use and sometimes adapt current cancer screening guidelines meant for use in the general population. It is standard to use "organ-based routine cancer screening" (Deutsch 2016). If a patient has the organ in question, cancer screening should be provided specifically for that organ, regardless of gender, if the patient meets screening criteria. Two sets of guidelines for cancer screening in transgender patients are the most inclusive and accessible in the literature and the information by cancer subtype below has been adapted by combining best practice guidelines from the University of California, San Francisco Department of Family and Community Medicine (UCSF) and The World Professional Association for Transgender

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[2] Brief description of guidelines for the general population are provided for review and comparison

Health (WPATH)[3]. Often providers will modify screening exams for the comfort and respect of a transgender patient and their anatomy.

Breast Cancer

-No consensus for screening in general population as guidelines vary by professional organization (ACOG 2017, ACS 2017)

-Duration of Estrogen use influences level of risk (WPATH 2016)

- Transgender female patients may have a lower risk due to lower lifetime exposure to feminizing hormones, however denser breast tissue leads to higher rates of false negative mammogram results (Deutsch 2016)

-Screening by mammogram every 2 years starting at age 40, and every year starting at age 40 for transgender male patients who have not undergone mastectomy

-No consensus for transgender men who have undergone mastectomy

-Obtain surgical history in transgender men, because some have had breast reductions and not complete mastectomies, thus retaining breast tissue (Deutsch 2016)

- Screening every 2 years starting at age 50 (with 5-10 years of feminizing hormone use) in transgender female patients

Colon Cancer

-General Population: men and women undergo colonoscopy every 10 years, or flexible sigmoidoscopy every 5 years

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[3] These guidelines are adapted from cancer screening guidelines for the general population put out by The United States Preventive Services Task Force and the American Cancer Society.

-Transgender women with colonic neo-vagina should have vaginoscopy at the time of colon screening

-Transgender men should be screening according to general guidelines, every 10 years by colonoscopy, or every 5 years by flexible sigmoidoscopy

Prostate Cancer

-For general population, providers should discuss risks and benefits of using Prostate Specific Antigen(PSA) level to screen for prostate cancer (USPSTF 2014)

-Rectal exam may be performed in primary care settings on natal males and transgender females with prostates; for transgender women digital "neovaginal" examination of the prostate may be more appropriate and useful (Deutsch 2016)

-Anti-androgenic medication and removal of the testicles in transgender females may reduce risk of prostate cancer (Deutsch 2016)

-PSA collection in transgender females is not well studied and normal lab value ranges have yet to be widely established (Marks et al. 2006)

Cervical Cancer

-There is some consensus for guidelines for Pap testing in women in the general population; multiple sets of Guidelines exist and depend on age and risk factors (USPSTF 2014; ACOG 2017)

-Women aged 21-65 receive a Pap test every 3 years; every 5 years if combined with HPV test for women aged 30-65 (USPSTF 2014)

- No one under 21 should receive Pap testing (USPSTF 2014, ACOG 2017)

-Multiple sources point to the fact that Transgender males may receive non-adequate Pap tests, and testosterone therapy may alter cytology results (Peitzmeier et al. 2014)

-Transgender men with negative hysterectomy history should receive a Pap test every 3 years for ages 21-65; every 5 years with HPV test for ages 30-65

-Transgender women should not receive Pap testing of the neovagina (more research is regarding neovaginal cancer)

Ovarian/Endometrial Cancer

- Routine Screening in the general population is through the use of the Bimanual vaginal exam, usually at the time of Pap testing, however no true guidelines exist to regularly screen for ovarian and endometrial cancers

-Symptomatic women in the general population may receive Transvaginal Ultrasound and/or CA-125 antigen blood testing (ACS 2017)

-Transgender men with negative hysterectomy history with no symptoms should receive bimanual pelvic examination in conjunction with Pap testing every 3 or 5 years depending on age and risk factors (routine exam)

- Transgender men who are symptomatic should receive a pelvic ultrasound after being examined by a Gynecologist or Primary Care Physician.

Chapter 3: Manuscript

Abstract

There are approximately 1.4 million transgender people in the United States. This is a very hard to study, medically-underserved community. In this communication we examine the literature on barriers to and facilitators of cancer screening and care in transgender people. We identified and systematically reviewed 16 studies that used qualitative and quantitative methods to collect information on cancer screening and care among transgender persons, healthcare providers, and advocates for transgender healthcare. Some of the main barriers to cancer screening and care in transgender people include avoidance of healthcare, discrimination, and lack of nationally published cancer screening guidelines, while some of the main facilitators included providers who were educated about transgender health and welcoming clinical environments. While there is much to learn about providing adequate cancer screening and care for transgender individuals, it is likely that issues discussed in this review are common in herein uncovered may have been widely experienced by the transgender community. We can improve cancer screening and care for transgender individuals by increasing exposure to transgender healthcare issues in medical schools and training programs, and by improving healthcare systems so that transgender people can access services and be recognized as an important, relevant population with unique healthcare needs.

Introduction

Despite recent increases in the field of LGBT healthcare, important knowledge gaps persist (Institute of Medicine 2011, Bowen 2006, Mayer 2008, Coulter 2014). The barriers to improving our knowledge of the healthcare needs of this population include lack of high quality demographic data, paucity of well-designed, systematic studies, and important methodological issues specific to transgender health research (Reisner 2016, Lancet 2011, MacCarthy 2015).

While transgender people experience the same common health problems as the general population, they also have unique health concerns. The health conditions thought to affect this population, at higher rates, include depression, substance abuse, sexual health problems, as well as specific surgical and hormone-related problems associated with gender-affirmation therapy (de Haan 2015, Bourgeois 2015, Weinand 2015).

An important area of priority in transgender research is cancer prevention and control. Cancer-related risk factors that may disproportionally affect transgender people include Human Papilloma Virus (HPV), Human Immunodeficiency virus (HIV), and Hepatitis B and C infections (WHO 2017), as well as lifestyle-related modifiable risk factors such as smoking, obesity, and lack of physical activity (Fredriksen-Goldsen KI et al. 2014).

A separate concern is a glaring lack of provider education that precludes health care professionals from properly counseling and screening transgender patients. For example, a recent WHO report acknowledged the need for transgender men to have cervical cancer screening (Lancet Oncology 2015), however, few studies have evaluated how often patients and providers actually follow these guidelines.

The goal of this communication is to systematically evaluate the available published data on cancer screening and care in the transgender population and to identify potential barriers and facilitators that may affect cancer screening and care of transgender people. We review the literature on cancer screening and care, and then provide an overview of the available data pertaining to barriers and facilitators of cancer screening and cancer care in this population.

Methods

Relevant studies were identified by searching EMBASE and PUBMED databases with no limits on date of publication, type of study, study design, or of the minimum number of subjects involved in each study. Review articles were also used to identify relevant papers. The following search terms were used.

- - "Transgender" OR Transsexual OR Gender-Nonconforming OR "trans" OR "gender queer" OR gender-fluid OR MtF OR FtM AND
- "Cancer screening" OR "Cancer care" AND

Studies that did not mention transgender or LGBT cancer screening and care in the abstract and title were excluded in the primary phase of review. The remaining studies went through a full-text review to select for inclusion in the study (Fig.1).

Eligibility/inclusion criteria were as follows:

- Only original, full-length articles
- Published in peer-reviewed journals.
- Direct involvement of transgender individuals and/or healthcare providers/advocates who work or have worked with transgender patients.

- Barriers to and/or facilitators of cancer screening and care are reported in the paper

Included studies were reviewed for “barriers” and “facilitators” that were directly mentioned at least once by transgender subjects, healthcare-providers, and trans-healthcare advocates. Some of the factors were documented in health records, such as patient charts; these factors may have also been mentioned in interviews, focus group discussions, or surveys of subjects, providers, or advocates. The number of times a barrier or a facilitator was mentioned in the literature was documented for each category of interest: cancer screening and cancer care. The most common (i.e., mentioned at least twice) barriers and facilitators in each category were tabulated and reviewed in a qualitative fashion.

Results

A total of 159 papers were initially identified (Fig.1). After a review of article titles and abstracts, 50 studies (31%) were qualified to undergo further evaluation. Further evaluation included more detailed consideration of the full study text, and 34 papers (68%) did not meet the inclusion criteria. In the final stage of study review, 16 studies (10%) met inclusion criteria and were selected for this systematic review. Further review qualified 9 studies as “cancer screening” studies, and 7 studies as “cancer care” studies.

Study Characteristics

Studies that met inclusion criteria and their individual characteristics, including location of study, and the population involved, are listed in Tables 1 and 2. For both groups (cancer care and cancer screening) of data, study subjects are defined as FtMs, MtFs, gender queer and gender non-confirming individuals, healthcare providers, and transgender health advocates. Fifteen studies were done in the United States (most, but not all, were conducted in large, urban cities) and one study was done in Canada.

The 9 studies on cancer screening in transgender individuals are summarized in Table 1. Seven of these studies used qualitative methods. Of those, three used focus groups; one with transgender health advocates, and another two with medical providers. Four qualitative studies used in-person and phone interviews of transgender patients. Other studies used quantitative methods; three studies used online surveys that targeted transgender individuals and three used retrospective chart review of patient data (one of these studies also looked retrospectively at the subjective data directly taken from patient charts completed by providers). The majority, 6 out of 9, studies focused on cervical cancer screening. One looked at breast cancer screening, one looked at both breast and cervical cancer screening, and one remaining study looked at anal cancer screening.

Seven studies published from 2008 through 2016 examined barriers to and facilitators of cancer care in transgender people (Table 2). Two of those studies used qualitative methods; both based on in-person interviews (one study was an interview with a single transgender patient). Five studies used quantitative methods; one study used interview data of transgender cancer patients from the Cancer's Margins project, which studies the experiences of transgender people with cancer, in Canada, three studies used internet questionnaires, administered one to OB/GYN providers, oncology practitioners and cancer patients, and one study used retrospective review of survey data from the LIVESTRONG dataset (a national survey of cancer survivors in the United States, which included a subset of transgender patients).

Barriers and Facilitators

The most frequently mentioned barriers and facilitators are listed in Tables 3 and 4. Factors that were only mentioned once were not included in the tables, but are presented and discussed below.

Cancer Screening

Cancer screening: Subject-based Barriers

The most frequently mentioned barrier to cancer screening was healthcare avoidance. For example, 74% of participants in the Porsch et al. study, which looked at transgender individuals (both men and women) who used Planned Parenthood for Gynecologic care in New York City, had avoided or delayed healthcare in the past (Porsch et al. 2016). In another study which compared transgender patient chart data with cisgender patient chart data for use of mammogram services at a community health center in Boston transgender patients were less likely than cisgender patients to get Breast Cancer Screening (mammograms) as often as recommended [AOR=0.53, 95%CI=0.31-0.91] (Bazzi et al. 2015). Transgender patients, qualified for this study if they were either transwomen on 5 years of estrogen or postoperative transman. Another study conducted at Fenway Health in Boston, used patient chart data to show that transmale patients were also less likely to undergo Cervical Cancer Screening (Pap Testing) [AOR=0.63, 95%CI=0.47-0.85] than cisgender female patients (Peitzmeier et al. 2014).

Newman and colleagues interviewed 19 transgender healthcare advocates in Los Angeles about barriers and facilitators to anal cancer screening. Transmen who have sex with men are less likely to undergo screening for anal cancer for a variety of reasons, however avoidance of healthcare because of masculine stigmas was stressed. As one study participant in a focus group put it, "When a man gets sick…The doctor is the last resort…we have grown accustomed to ignoring our body when it says something to us" (Newman et al. 2008).

Another online study participant, in the Potter et al. study which interviewed transmale patients and providers who work with transmale patients about Pap testing, stated that, 'It's uncomfortable for me as someone who does not identify as female to schedule an appointment for something that's typically seen to be a women's health issue (Potter et al. 2015). Other frequently mentioned barriers across the different studies were discrimination and anatomical and/or gender dysphoria.

Cancer screening: Subject-based Facilitators

The most frequently mentioned subject-based facilitators in the literature included patients being educated about what screening and preventive healthcare tests they needed and having private insurance. A majority of patients in the Agenor et al. study, which interviewed transmale patients and providers who work with transmale patients about Pap testing, knew that if they had a cervix, it still needed to be screened for cervical cancer regardless of their gender identity (Agenor et al. 2016). Having private insurance was also shown to increase the likelihood of cancer screening in transgender individuals (Johnson et al. 2016).

Cancer Screening: Provider-based and Healthcare-based Barriers

The most frequently mentioned provider-based barriers were a lack of national screening guidelines for medical providers and societal and/or medical stigma. In one study, providers reported that trans-men were at a lower risk for HPV (anal or vaginal) due to the assumption that men do not participate in insertive sex (Agenor et al. 2016). In another study, providers believed that trans- men had fewer sex partners and that trans-men could not be started on hormone therapy unless they had received Pap testing (Potter et al. 2015).

Cancer Screening: Provider-based and Healthcare-based Facilitators

The most frequently mentioned provider-based facilitators included a welcoming clinic environment, including gender-neutral facilities, and knowledgeable and accommodating medical staff. In one study multiple providers explained that they are likely to adjust their screening recommendations based on an individual patient's gender affirmation status; these providers also mentioned being "creative" in the process of performing Pap tests and altering the test to address distress, fear, or anxiety such testing creates for transgender men (Agenor et al. 2016). Potter et al. provided an abundance of strategies to improve cancer screening visits for transgender patients, including having non-gendered brochures and literature available to patients as well as being very open and detailed when explaining the physical examination process before it is done (Potter et al. 2015).

Cancer Care

Cancer Care: Subject-based Barriers

The most frequently mentioned subject-based factors by patients were discrimination and impact of intersectional factors, such as race, religion, sexual orientation, marital status, etc. on care. One gender queer person describes leaving *their*[4] queer partner, who was a person of color, at home in order to not further complicate *their* care, or influence how healthcare staff looked at them; another “gender queer, trans, 2-spirit[5], butch” individual who was Native American and Filipino was not sure if their[6] substandard care was being poorly impacted by their race or by their gender expression (Taylor and Bryson 2016).

Cancer Care: Subject-based Facilitators

Frequently mentioned subject-based factors focused on having social support as a facilitator, but no two studies consistently agreed on whether this social support came in the form of friends and family or a romantic partner. Some studies referenced marriage or

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[4] This person preferred the pronoun “their” for themself.

[5] A historical term used by Native American communities to reference LGBT members of their own community.

[6] This person did not identify with a particular pronoun but this pronoun is used in this text to honor this person’s non-binary, complex identity.

being in a relationship (Kamen et al. 2016), other studies mentioned peer networks or support groups (Kamen et al 2015).

Cancer Care: Provider-based and Healthcare-based Barriers

The most frequently mentioned provider-based factors were the gendering of cancer, such as breast cancer being thought of as a “woman’s cancer” (Taylor and Bryson 2016) and providers lacking knowledge of LGBT healthcare issues. Other commonly mentioned barriers were gendered clinics, providers defaulting to heteronormative assumptions about all patients, and uncoordinated care for transgender and gender-nonconforming patients, such that gender affirming care is not coordinated with cancer care (Elk and Kallio 2016).

Cancer Care: Provider-based and Healthcare-based Facilitators

The most frequently mentioned provider-based factors that served as facilitators were providers actively educating their transgender and gender non-conforming patients about specific healthcare needs and using medical paperwork that does not request gender-binary classifications, but rather by using questions that emphasize open-ended disclosure (if warranted) of gender. As one study participant put it, “More options on the forms means there is more room in people’s minds.” (Dutton et al. 2008).

Other Factors

Some other factors that were only mentioned once as barriers to cancer care include limited oncology care due to geographic restriction, lack of resources for transgender cancer patients, and social worker involvement. Social worker involvement was mentioned as a barrier with the disclaimer that although social workers can sometimes improve care, patients having a social workers involved in their case are likely worse off financially or having no support from family or friends. Additional factors that were only mentioned once as facilitators to cancer care were self-education online, providers involving people accompanying patients to visits or in the hospital, being a provider who is listed as LGBT-friendly, LGBT staff and providers being involved in care, and national healthcare guidelines specific to transgender patients. Providers treating all patients the same was mentioned both as a barrier and a facilitator to cancer care in transgender patients[7].

Some other factors that were only mentioned once as barriers to cancer screening include providers using inappropriate resources, inconsistent pronoun use by providers and healthcare facilities, patients being misinformed about post-surgical risks, reluctance of transgender patients to disclose identity to providers, possession of old, gender-inappropriate identification cards or papers by patients, and the physical gender expression of the patients (“butch” vs “feminine”). Some factors that were only mentioned once as facilitators to cancer screening include advertising campaigns at LGBT venues and events, patients being “out” to providers, treating each patient as an individual, having a higher percentage of female patients, and patients having higher education levels.

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[7] Treating all patients in the same way was noted as a barrier if providers have heteronormative assumptions and don’t consider trans-specific needs, but can also be a facilitator in making trans gender patients feel comfortable and like any other patient who walks into a practice.

Chapter 4: Discussion, Conclusions, Public Health and Research Implications

Overall, 16 original studies that included barriers and facilitators for the screening and care of transgender cancer patients could be found with studies using both qualitative methods, such as interviews, and quantitative methods, such as surveys, to explore the good and bad of cancer screening and care for the transgender population. The most commonly mentioned barriers to cancer screening were healthcare avoidance, medical and social stigmas associated with being transgender, and the lack of national cancer screening guidelines for transgender patients; the most commonly mentioned cancer screening facilitators were knowledgeable providers, education of patients by providers, welcoming clinic environments, and being insured. The most commonly mentioned barriers to cancer care were discrimination, providers lacking knowledge to care for transgender persons, gendering of cancers, and intersectional factors, such as race, age, sexual orientation, and socioeconomic status; the most commonly mentioned facilitators were social support, providers educating transgender patients, and open-ended gender questions on medical paperwork. A common theme in this review is that patients across multiple studies were much less likely to seek healthcare if they did not know they still had certain organs, or if they did not feel like they identified with the body part that needed to be screened.

Limitations

While informative, this systematic review has its limitations. All of the studies examined self-reported factors. Because there is a general lack of accurate epidemiological studies on transgender patients (IOM 2011, Reisner 2016) and it is often hard to recruit these patients to structured prospective cohort studies, it is appropriate to use self-reported and retrospective healthcare data (such as charts or electronic medical records) to increase our knowledge pool when it comes to this significantly underrepresented population.

Although self-reported data may vary from individual to individual, it is currently the best way to study healthcare barriers and facilitators in a specific population. The factors themselves are sometimes defined differently throughout the fifteen studies, and although we group them for the purposes of our study, the fact remains that factors may have different meanings depending on individual study context from which the factor was pulled.

Of note, all of the studies represent the transgender population in the traditional male and female binary categories. The classification of persons as transgender, transsexual, gender non-conforming, differed from study to study and may impact the applicability and consistency of the data across studies and again, when attempting to extrapolate this data to the entire transgender population.

Transgender patients are known to avoid healthcare, so these studies may only be reaching the more available and willing portion of the transgender population. The portion of the population that is unwilling to come forward may or may not be experiencing the worst outcomes. Cancer is more prevalent in older age groups and this population grew up in a time where being transgender was less socially acceptable. We did consider if this factor affected the results of this study.

This study is qualitative in nature and any quantitative analysis of the data is limited to percentages of studies that report a specific factor. Further quantitative statistical analyses are not possible at this time.

Research Challenges

An important challenge facing researchers is the lack of systematically- collected data and inconsistently or ill-defined research terminology across the literature. The inherently heterogeneous nature of the transgender population makes this study and other studies of transgender persons difficult because in an attempt to group and categorize data, we risk stratifying a population which in and of itself rejects classification and prides itself on fluidity of identity and thought. When it comes to feelings and opinions associated with cancer screening and care in transgender patients, viewpoints may differ greatly depending on how the person interviewed identifies and presents publically, as well as how this person has been perceived in healthcare and public settings in the past. In other studies, it was evident that the same situation can affect people differently based on their own perceptions of their gender identity and their relationship to society at large. In the Cancer’s Margins study, described above and in Table 2, one trans-male patient was happy to receive a mastectomy that was covered by his insurance for breast cancer as he saw this as a treatment for his gender dysphoria and not necessarily for breast cancer alone; however, another gender-nonconforming, "butch” patient was upset at the prospect of mastectomy because she felt it would “intensify her felt sense of masculinity and impose a more normatively coherent gendered body” (Taylor and Bryson 2016).

Proposals for Future Research

Large scale epidemiological studies are needed to better characterize the transgender population, with careful attention to the fluid nature of the identities of transgender persons (MacCarthy et al. 2015). This is a difficult task given the diversity within the transgender community. Most current studies focus on the easiest classification of transgender persons; those who present with gender dysphoria for transition related care (Zucker and Lawrence 2009). Very few transgender cancer-specific epidemiological studies exist and this is going to become especially important as the baby-boomer population ages. A few longitudinal studies have been established to understand the long-term effects of surgeries, hormone use, and other quantifiable health outcomes, including cancer (Weinand and Safer 2015), in the transgender population. These types of studies are needed in an effort to develop better empirical evidence-based guidelines (Reisner et al. 2016). Advancement of recruitment methods of subjects will be of great benefit to the development of cancer care guidelines. It is likely that this will require active participation of the transgender community. Many of the studies here are single-center and may represent biased views subject geographic and political influence. Examples of this that may influence study design and results include, taking place in the North versus the South or Conservative areas versus Liberal areas where transgender people may have had entirely different experiences. Multi-center studies could increase the size of study populations and ensure that regional or other intersectional biases are avoided. Larger study populations could also allow us to confirm that the factors we have described above are ubiquitously experienced.

Conclusions and Public Health Implications: Proposals for Changes Clinical Practice

This study brings to light many problems, most notably discrimination and avoidance, which affect cancer prevention and control in among transgender people. . The study also offers ideas on how to improve cancer control practices in this population e trans population, such as how medical providers can become more informed and create clinical environments that are conducive to treating a diverse patient population. When looking to specific factors that helped and hindered providers some clear patterns were evident; there is a need to provide clinical guidance to practitioners on how to best treat and care for transgender cancer patients and transgender patients undergoing routine screening for cancer. The following are proposals for changes to the current state of clinical medicine and training to increase the ability of practitioners to create and foster environments of compassion and knowledge for transgender patients. There will be a substantial benefit for the public health needs of the transgender community.

There is a need for the creation of national guidelines for screening transgender patients for cancer as well as guidelines for care of transgender patients with cancer. Because cancer screening and care involves a variety of medical specialties, including but not limited to Surgeons, Obstetrician/Gynecologists, Urologists, Endocrinologists, and Primary Care physicians, there is a need for the governing bodies of medicine, such as the American Medical Association to call for the creation of national guidelines by specialty specific colleges. This will require a multidisciplinary approach that considers the unique world of gender-affirming care and utilization of healthcare facilities by transgender persons (Esteva de Antonio and Gomez-Gil 2013). Creation of national guidelines will provide a backbone for providers who are not well-versed in working with and caring for transgender patients and establish standard of care for the transgender population. The idea is to normalize care and eventually have published guidelines that reflect the medico legal standard of care.

There is a need to establish and/or increase training in nursing programs, medical schools and residency training programs in working with transgender patients. A 2012 study at Tulane University Medical School involved starting a pilot program to train students to work with LGBT patients and it shed light on the fact that there is little training in existence for medical students, and even currently established curriculums are limited, some calling for just three hours, and in some cases optional lectures (Sequeira et al. 2012). Just recently, in 2014, the Association of American Medical Colleges recognized this lack of training and established guidelines for medical school curriculums to include training on LGBT patient populations (Bergen 2014). Hopefully medical schools will recognize this huge opportunity and influence other training programs to follow suit. If practitioners are not trained in certain aspects of medicine, they cannot be expected to be knowledgeable and provide adequate care in these areas. This is a systemic issue that is currently in a state of flux, however uptake should be 100% in the future.

Other changes in the Healthcare system are necessary and will only begin to occur if there is an increase in transgender visibility and the barriers transgender patients experience daily when attempting to get medical care. This includes better insurance coverage which will likely come with the creation of guidelines and recognition of procedures by insurance companies. Current changes to the system of documentation in medicine will also allow for more welcoming clinical environments. If patients walk into a hospital or doctor's office and are expected to identify as either and only male or female, much is already lost, but if the future inclusion of non-binary gender questions with ever increasing implementation of electronic medical systems is successful, we can give patients more options to identify as they choose and document patient information for future use in healthcare settings to avoid alienating people. Increases in research funding and encouragement of researchers and research trainees at influential public health organizations such as the Center for Disease Control and the American Cancer Society to study cancer prevention and control in the transgender population would be exponentially beneficial to the future of transgender medical care.

A variety of other factors were mentioned throughout the study, however some common themes emerged: an alarming number. One issue of importance is that many providers lack the knowledge to care for transgender patients. In one large multi-center study of OB/GYNS providers, Unger uncovers that comfort levels with treating transgender patients lingers at 35.3% and 29% for MtF and FtM patients respectively and that 80% of the providers were not trained in medical school or residency to work with transgender patients. We were also able to uncover that there is general lack of research and data to accurately support care for transgender patients, the current healthcare system is not always equipped to care for transgender patients, and that transgender patients have an abundance of negative experiences associated with healthcare. Clearly transgender people are not always getting the proper cancer screening and care they deserve. The transgender population has special needs when it comes to screening and treating for cancer due in part to anatomical differences and changes from gender-affirming care. Organs that undergo changes as part of gender-affirming therapy may be affected by malignant transformation and are also commonly screened for cancer. For all of the above reasons, establishment of evidence-based clinical practices for screening, diagnosis and care of cancer in transgender people will require high-quality data, which are not available at this time.

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APPENDIX

- "Barriers" AND "Facilitators"

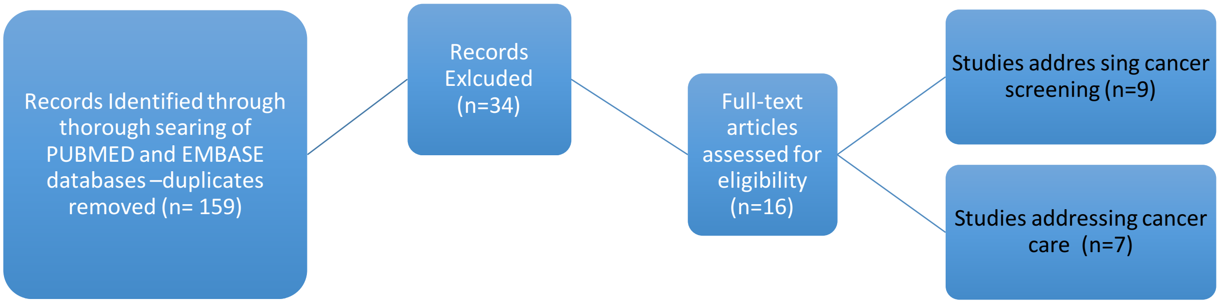

Figure 1. PRISMA diagram demonstrating search and retrieval of studies (Moher et al. 2009)

Table 1. Studies of Cancer Screening among transgender individuals, USA, 2008-2016

Study	**Study Methods**	**Issued and Population Approached**
Porsch, Dayanada, and Dean 2016	Internet Survey, Snowball Sampling	Use of Preventive Sexual Health Services at Planned Parenthood by 113 Transgender individuals in New York City
Bazzi, Whorms, King, and Potter 2015	Retrospective chart review	Breast Cancer screening in 1263 transgender persons and Sexual Minority Women at an Urban community Health Center in Massachusetts
Agenor et al. 2016	Interviews and Focus Groups	32 Transmasculine patients and 17 healthcare providers (variety of settings, advanced nurses and doctors, must have done at least one Pap test on a transmasculine individual, cervical cancer screening at Fenway Health in Boston
Johnson et al. 2016 a	Telephone interviews and Internet questionnaires- *Qualitative and Quantitative, and Mixed Analysis*	Transgender men, Lesbian and Bisexual Women ages 21-65, Cervical Cancer Screening (226 internet surveys, 20 phone interviews); participants from all over the United States
Johnson et al. 2016 b	Telephone interviews and Internet questionnaires- *Qualitative*	Transgender men, Lesbian and Bisexual Women, Cervical Cancer Screening ages 21-65 (20 phone interviews, 226 internet surveys; participants were from all over the United States recruited online and from 300 LGBT centers
Potter et al. 2015	Literature Review, Qualitative Interviews (one on one) and	3 Focus groups with 17 healthcare providers(PCPs,

	Quantitative Internet Survey of FtM individuals, focus groups of providers	OB/GYNS, PAs and NPs[8]) and online and in person interviews with 118 FtM individuals
Peitzmeier, Khullar, Reisner, and Potter 2014	Retrospective chart review	4,882 Women and 350 FtM persons aged 21-64, with a cervix using an urban, community health center for Pap Testing at least once in 2012 in Boston
Peitzmeier, Reisner, Harigopal, and Potter 2014	Retrospective Chart Review	Pap test results of Women and 233 FtM persons, aged 21-64 using an urban, community health center between 2006-2012 (compared to 3625 natal women) in Boston
Newman, Roberts, Masongsong, and Wiley 2008	Focus Groups	19 (16 Male, 3 Female) Transgender health advocates in four focus groups in Los Angeles; Anal Cancer Screening of Gay, Bisexual, Transgender, and Men who have sex with men

Table 2. Studies of Cancer Care among transgender individuals, USA, 2014-2016

Study	Study Methods	Study Subjects
Kamen, et al. 2015	Internet Survey	291 LGBT Cancer Patients in the United States (9 transgender patients with mixed cancers)
Shetty et al. 2016	Email Survey	108 Oncology Providers at Moffitt Cancer Center at the University of South Florida
Kamen, Mustian, Dozier, Bowen, and Li 2016	Retrospective Review	Data from 207 LGBT cancer survivors in LIVESTRONG study in the United States

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[8] Physician assistants and Nurse Practitioners

		(all cancer types, 63.5% women, mean age=49)
Elk and Kallio 2015	Patient Interview	Interview with 1FtM Transgender Cancer Survivor in New York City
Taylor and Bryson 2016	Patient Interviews	Trans and Gender-nonconforming cancer patient interviews from the Cancer’s Margins project in Canada (68 patients with breast and/or gynecologic cancer) and the United States (15 patients) aged 33-64
Unger 2014	Cross-sectional Email Survey	141 OB/GYN providers at 9 academic centers in the United States (Boston, Cleveland, Raleigh-Durham, Albuquerque, Denver, San-Francisco, and Richmond)
Dutton, Koenig, and Fennie 2008	In-person Interviews about Gynecologic Care	6 Transgender men aged 19-45

Table 3				
Barriers to, and Facilitators of, CANCER SCREENING in Transgender Individuals (Total number of included studies =9)				
	FACTORS	**# Studies which evaluated the corresponding factor**	**# Studies reporting factor as a barrier**	**# Studies reporting factor as a facilitator**
PATIENT RELATED	**Anatomical /Gender Dysphoria**	**6**	**6**	
	Discrimination	4	4	
	Education about screening	5		5
	Family history	2		2
	See regular provider	3		3
	Healthcare Avoidance	**7**	**7**	
	Higher Income	2		2
	Increased Sexual Behavior	2		2
	Lack Insurance	3	3	
	Negative Past Interactions	3	3	
	Older Age	3		3
	Patient Educates Provider	2		2
	Peer support/role models	3		3
	Past Abnormal Pap	2		2
	Private Insurance	4		4
	Provider Recommends Screening	2		2
	Screening History	2		2
HEALTHCARE/PROVIDER RELATED	Access to gender-affirmative care	2		2
	Flexibility	2		2
	Billing/coding issues	2	2	
	Can’t afford Healthcare	2	2	
	Gendered Facilities	2	2	
	Updates communications patient (change in gender, etc.)	2		2
	Cultural-sensitivity	2		2

	Training			
	Inadequate testing-Histopathology and/or provider discomfort	3	3	
	Lack of Experience with LGBT Patients	2	2	
	Lack of Screening Guidelines	**4**	**4**	
	Modify Interventions for transgender patient	2		2
	No education on LGBT health	3	3	
	Non-gendered exam terminology	2		2
	Original-gender Screening	3		3
	Provider knowledgeable about LGBT issues	**5**		**5**
	Putting Non-binary Gender Questions on forms	2		2
	Stigma	**4**	**4**	
	Vaginal Swab over Pap Test for FTM (Cervical screening) for patients who refuse	2		2
	Welcoming Clinic Environment	**5**		**5**

Table 4[9]				
Barriers to, and Facilitators of, CANCER CARE in Transgender Individuals (Total number of included studies = 7)				
	FACTORS	**# Studies which evaluated the corresponding factor**	**# Studies reporting factor as a barrier**	**# Studies reporting factor as a facilitator**
PATIENT RELATED	Being in a relationship	2		2
	Discrimination	**3**	**3**	
	Gender Dysphoria as a result of surgery or treatment	**3**	**3**	
	Intersectional Factors	**3**	**3**	
	Lack of Insurance	2	2	
	Multiple people involved in care and support	2		2
	Peer Networking/ Support	2	1	2
HEALTHCARE/PROVIDER-RELATED	Cancer Surgery as Gender Affirming Care	2		2
	CME training for providers	3		3
	Provider educates LGBT Patients	**4**		**4**
	Gendered Cancers	**4**	**4**	
	Gendered Clinics	**3**	**3**	
	Heteronormative assumptions about all patients	**3**	**3**	
	Lack of Cancer Care Guidelines	**3**	**3**	

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[9] **BOLD**ed factors are MOST consistently mentioned factors, in at least 4 out of 9 studies evaluated.

	for Transgender Patients			
	Lack of Inquiry regarding patients preferences for care	2	2	
	Lack of knowledge of LGBT health issues	**4**	**4**	
	Little or No LGBT education in Medical School and Residency	2	2	
	Paperwork to ask non-binary gender questions	**3**	**0**	**3**
	Uncoordinated care- gender affirming + cancer care	**3**	**3**	