

Assessing the Quality of Care Delivered to Transgender and Gender Diverse Patients with Cancer in Ireland: A Case Series

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Transgender cancer care • Disparity • Quality of care • Case series • Gender diverse

ABSTRACT

Introduction. “Transgender” and “gender diverse” are umbrella terms encompassing those whose gender identities or expressions differ from those typically associated with the sex they were assigned at birth. There is scant global information on cancer incidence, outcome, and mortality for this cohort. This group may present with advanced cancer, have mistrust in health care services and report anxiety and depression at higher frequencies, a finding often seen in marginalized groups because of minority stress.

Materials and Methods. Medical oncologists were contacted by secure email to identify patients who self-identify as transgender and gender diverse in three Irish hospitals. Five patients were identified. A retrospective chart review was conducted and a pseudonymized patient survey was distributed.

Results. All patients included in our chart review ($n = 5$) were diagnosed with advanced disease on initial diagnosis. Two

patients identified as men, two as women, and one as a transwoman. Two of five patients' health record charts reflected a name or gender change. Three patients had gender transitioning treatment postponed. Assessing comorbidities, it was seen that four patients required psychiatry input. Predominant issues noted in our patient survey by the two respondents ($n = 2$) were “misgendering,” lack of a gender-neutral hospital environment, lack of inclusion in cancer groups, and barriers in changing name and/or sex on hospital records.

Conclusion. Components of care requiring revision include patient accessible pathways to change names and gender on health records, earlier access to psychological support and targeted screening and support groups. Resources for hospital staff to improve awareness of correct terminology and to provide gender neutral facilities are worthwhile. *The Oncologist* 2021;26:e603–e607

Implications for Practice: The implications for practice on an international level include patient-friendly pathways for changing hospital name and gender so that patients may feel comfortable using wristbands. The need for international screening guidelines for transgender patients and national transgender cancer support groups is highlighted. On a day-to-day level for providers, the correct use of pronouns makes a big difference to patients. Asking about preferred pronoun on first visit and noting on patient's file is worthwhile. It is important for providers to know that increased psychological support should be offered early on first clinic visit and engaged with as necessary when patient has a history of anxiety or depression. Providers should discuss openly that some gender transitioning treatment will be postponed because of cancer care and refer to both the physical and psychological sequelae of this. Asking transgender patients which room or bathroom they would prefer when rooms are gendered is essential.

INTRODUCTION

It is estimated almost 1% of individuals in a population identify with gender identities or expressions that differ from those typically associated with the sex they were assigned at birth [1]. These gender identities can include

both binary identities such as man, woman, transman, and transwoman or nonbinary identities such as gender diverse, gender fluid, or genderqueer, among others [2]. The incidence of people with cancer among this cohort is currently

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unknown. There is a scarcity of data worldwide on transgender and gender diverse people with cancer because of a lack of collaborative international databases and national registries. A search for transgender individuals among 385,820 patients within the Mayo Clinic Tumor Registry from 1972 to 2017 yielded only one case [3]. Researchers have attempted to quantify the number of transgender and gender diverse individuals with cancer. Nash et al. (2018) used North American Association of Central Cancer Registries tumor registry data to describe the frequencies of cancers among 805 transgender and gender diverse patients [4]. They found the patterns of cancer diagnoses among transgender and gender diverse people are different from those in male and female patients with cancer, with elevated proportional incidence ratios for viral infection induced cancers. There is also evidence that these patients can present with more advanced disease. An article published in the *Lancet* (2015) highlighted the lack of guidelines for prostate-specific antigen and digital rectal examination in monitoring transgender or gender diverse women for prostate cancer [5]. Brown and Jones (2015) reported on late-stage diagnosis and mortality seen in transgender or gender diverse persons with breast cancer and highlighted the importance of mammography and breast examination in this cohort [6]. It has been found that patients also may not be aware of their risk for cancer or appropriate screening recommendations in altered body parts [7].

A survey finding published in the *Journal of Clinical Oncology* last year underlined the need to improve the quality of care delivered to transgender and gender diverse patients; 63% of oncologist respondents to the survey did not feel they knew enough to adequately care for this patient cohort with cancer [8]. Results from the 2011 National Transgender Discrimination Survey also reflected this finding. It was seen that more than 50% of respondents found they had to educate their own providers about their care [9]. The issuing of recommendations to address the needs of transgender and gender diverse populations has been named as a key clinical care advance by the American Society of Clinical Oncology in 2018. This highlights the move to improve provider knowledge [10]. McDowell et al. (2017) found that transgender and gender diverse patients who reported positive relationships with providers found cervical smear testing more acceptable than those who did not [11]. There are data to support the assertion that transgender and gender diverse people may avoid screening programs for cancers that are gendered, for example, breast screening, leading to a late diagnosis [12]. Transgender and gender diverse patients can have a lack of trust in health care services due to previous negative experiences [9]. The 2011 National Transgender Discrimination survey highlighted this finding: 19% of their sample reported being refused care altogether because of their gender identity, and 28% of respondents reported being subjected to harassment in a medical setting [9]. It is important that a fear of discrimination or emotional distress on revealing birth gender does not result in suboptimal care. Transgender and gender diverse individuals as a stigmatized minority group often are the target of discrimination and violence, which are linked to adverse health, particularly

psychological distress. The minority stress model has been well described. Bockting et al. (2013) found social stigma to be positively associated with psychological distress in the 1,093 persons surveyed in their sample, a finding supporting this model [13]. If oncologists are aware of the issues surrounding the care of these patients, they will be able to provide better care. We aimed to identify the areas of care that could be improved for cancer care in this increasing patient group.

MATERIALS AND METHODS

Irish oncology consultants in three hospitals were contacted by secure e-mail and asked to identify patients who self-identify under the umbrella terms “transgender” and “gender diverse” (including all binary and nonbinary terms such as man, woman, transman, transwoman, gender fluid, gender diverse, genderqueer, and all other identities) under current or recent care. Patients were identified in three hospitals in Ireland: Cork University Hospital, Cork; Mercy University Hospital, Cork; and St James’s University Hospital, Dublin. A total of five patients were identified by individual treating consultants from a total pool of approximately 600 patients. The five charts were then reviewed by a member of the research group. Data recorded, by retrospective chart review, included demographic and clinical factors including age, patient self-described gender identity term, diagnosis, stage at diagnosis, medical and psychiatric comorbidities, and social history. We examined whether cancer treatment affected gender transitioning treatment. We checked whether patients’ health record charts reflected a change of name or gender.

To answer the research questions in this case series, we developed a patient survey based on themes in the validated “U.S. National Transgender Discrimination” survey [9], including past experiences of discrimination or of being treated equally, experiences with health care professionals, smoking, alcohol use, legal name change, and documentation [9]. We added focused questions exploring patients’ opinion on cancer screening services, support groups, hospital room and bathroom assignment, and medical gender transition care. The paper survey include 18 open-ended questions (survey available upon request from corresponding author). Surveys were posted to identified patients after they were contacted by phone and the purpose of the case series was explained. The first question was an open-ended question asking patients how they self-identified, for example, male, female, transman, transwoman, gender fluid, gender diverse, genderqueer, and all other terms. Approval for our project was obtained from the Clinical Research Ethics Committee of the Cork teaching hospitals and St. James’s University Hospital.

RESULTS

Five patients were identified, all of whom had advanced disease at diagnosis (Table 1). These included (a) stage IIIc high grade ovarian cancer, (b) stage IV gastrointestinal stromal tumor, (c) stage IVb diffuse large B cell lymphoma,

Table 1. Results

Results of retrospective chart review	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
Sex assigned at time of birth	Female	Male	Male	Female	Man
Current gender identity as described by patient	Man	Woman	Transwoman	Man	Woman
Advanced stage of cancer on diagnosis?	Yes	Yes	Yes	Yes	Yes
On active transitioning treatment on diagnosis	No	Yes	Yes	No	Yes
Transitioning treatment postponed because of cancer	Yes	No	Yes	No	Yes
Name/gender change reflected on HRC or OLC	HRC: no, OLC: yes	HRC: yes, OLC: yes	HRC: no, OLC: yes	HRC: no, OLC: yes	HRC: yes, OLC: yes
Psychological illness for which attending psychiatric services	Yes	No	Yes	Yes	Yes

Abbreviations: HRC, health record chart; OLC, outpatient letter correspondence.

(d) locally advanced desmoid tumor, and (e) metastatic castrate-resistant prostate cancer. Two patients identified as men, two as women, and one as a transwoman. Two patients had recently died. The patients ranged in age from 19 to 69 (median 44) years. Three had been smokers. There was minimal alcohol use reported among all patients.

Recent outpatient letters dictated by oncologists on all five patients reflected the patient's chosen name and gender pronoun, but only two health records and two patient identification wristbands reflected this. All patients were without other medical comorbidities; however, four patients had documented psychological illness for which they were attending psychiatry services and taking regular antidepressant or antianxiety medication(s). Three patients had gender transitioning treatment hormones postponed because of cancer care. Reasons documented for discontinuing gender transitioning hormones included concerns of increased tumor growth secondary to sex hormones and poor bone health. One patient was able to remain on luteinizing hormone-releasing hormone agonists as part of gender transitioning treatment but had to postpone full gender reassignment surgery because of a decline in performance status.

The patient survey was completed and returned by two of the three living patients. Results of the survey are outlined in table 2. One of the issues identified by those patients included "misgendering," defined as referring to someone using a word, especially a pronoun or form of address, that does not correctly reflect the gender with which they identify. One patient noted "There were (sic) a lot of mis-gendering but I'm used to that. My generally poor mental health and lack of progress on transitioning made it hard to confront". In relation to misgendering, the same patient said "It's all about communication. Let individual patients be your guide on how to interact with them. If you don't have all the information, gender neutral terminology is best."

Admission to hospital accommodation based on original sex was identified as an issue by the two patients; "In the [birth gender] rooms, I felt more comfortable even if my dysphoria made it hard to feel I deserved to be there". The same patient stated, "I feel the hospital isn't set up to consider trans patients." When asked if one patient has felt

included in cancer educational or screening campaigns throughout their life, the patient said they felt "the constant gender segregation of cancer." The psychological distress caused by delay of gender transitioning treatment was reflected in patients' responses: "Because of my treatment, my bones have weakened, and this may mean I can't start hormone replacement therapy," "my lack of fitness and tiredness has slowed transition." Regarding medical documentation, one patient expressed frustration at their inability to change their name during treatment, "I must use my deadname until I can legally show it's changed," as this meant that their original birth name had to be used by nursing staff for patient identification each time blood products or chemotherapy was administered. One male patient felt that the support group for their cancer that they were directed to was gendered toward female individuals when they attended.

Positive responses about the quality of care delivered included "once the staff were aware of my name change, they all started using it," and "all my interactions with the health service, for the most part, improved my mental well-being and self-worth." Neither patient reported an episode of harassment or refusal of treatment due to gender identity while using medical services.

DISCUSSION

This case series in combination with the patient survey identified a number of issues affecting the quality of care delivered to transgender and gender diverse patients with cancer. One of the main barriers in patient care noted was difficulty in changing health record name and gender. This was noted on our chart review and by the two respondents of our survey. Protocols for safe blood transfusion and chemotherapy administration require a verbal name-band check with birth name and gender from health record chart. For a transgender or gender diverse patient in Ireland to change their hospital health record chart they require (a) a gender recognition certificate, (b) a new birth certificate, (c) a name change by deed poll, and (d) an affidavit of confirmation. For patients with advanced cancer and limited prognosis, it is difficult, in terms of time and energy, to obtain these documents. There should be a patient-

Table 2. Issues as identified by two patients

Misgendering by hospital staff
Lack of gender neutral ward or bathroom selection
Gender transitioning treatment delay
Inability to change name/sex on medical correspondence
Lack of inclusion in cancer screening campaigns
Lack of inclusion in gendered cancer support groups
Identity checking for chemotherapy or blood product administration
Lack of gender neutral approach in hospital

accessible online pathway in hospitals for transgender and gender diverse patients with cancer to change name and gender on their medical documentation. Oncologists should be aware that health records may not reflect the patient's chosen name, gender identity term, and pronouns. It is essential that on first review, the patient's medical oncologist identifies what the patient's preferred name and self-described gender identity term are and what pronouns are to be used. This should be documented clearly in the health care record for other health care workers to note. All health care workers, if unsure of this when meeting the patient, should ask the patient. Respecting the use of a chosen name, gender identity term, and preferred pronouns and using inclusive language are essential to build a respectful and trustful relationship between the patient and the clinician.

Additional support during a transgender or gender diverse patient's cancer journey is essential, and increased psychiatric support should be offered early on and engaged with as necessary. Inclusion in gender-specific cancer support groups and educational groups could be improved by more gender-neutral groups as well as having targeted screening and support networks. Although the cancers of the patients included in this case series were not screen detected, this finding was apparent in our survey by both respondents and in the findings from our literature review as outlined previously. A national webpage with information about screening recommendations for transgender and gender diverse patients is necessary. The creation of international screening guidelines specific for transgender and gender diverse people would be required for this. A national support group targeted at transgender and gender diverse patients with cancer is necessary to discuss issues such as delayed hormone treatments and hospital name and gender change pathways and for individuals to meet with others in the same scenario. Cancer treatments can delay gender transitioning therapies. This needs to be acknowledged and taken into account when planning and discussing patient's treatments at first visit. In the case of our patients, exogenous hormones were discontinued because of poor bone health, concerns of exogenous hormones aiding tumor growth, and postponed surgery due to poor performance status. International guidelines to aid in the decision making of continuing or discontinuing exogenous hormones for patients with cancer are currently lacking. This decision was made in a discussion with each

patient and their oncologist about the hypothesized effects of the gender-affirming treatment, favoring discontinuation in their own unique cases. Guidelines to aid in this decision making are required. In addition, it would be pertinent if transgender and gender diverse patients could be asked which gender room they would prefer to be in on checking in to hospital when rooms are gendered. All patients in this project presented with advanced disease on initial diagnosis. It is unclear if this is due to disparity of care or chance because of the small sample size. It is necessary to build up more databases like this to investigate further, preferably an international data-sharing consortium. Furthermore, education campaigns for providers are necessary to provide awareness to staff of transgender cancer related care issues.

Despite the added cancer care needs of the transgender and gender diverse population, we feel that all oncologists should continue to care for current and future patients in this cohort without the need for a specialized centralized center. Specific expertise can be sought as needed on a case-by-case basis. Patients would be at a distinct disadvantage in terms of cost, time, and safety if they had to travel far distances to get required cancer care. It is important that all practicing oncologists are up to date on how to care for transgender and gender diverse patients with cancer.

The limitations of the case series were its small size and retrospective nature. The results of the patient survey is based upon the opinions of two patients, leading to subjective bias. Our case series also lacks the inclusion of gender diverse patients and screening preventable cancer types to comment further on our patients' uptake of screening campaigns. Our results did, however, interplay with those of other studies. The LGBT Health 2015 study by Taylor et al. interviewed transgender and gender diverse patients about gaps in their care [14]. Participants interviewed in their study agreed that breast and gynecology cancer services are designed as "women's" clinics, and participants also reported feeling unwelcome while attending cancer services. Participants in their study also reported seeking information specific to transgender and gender diverse cancer care and support networks online without success. Our findings differ with the findings of the 2011 U.S. National Transgender Discrimination Survey, in which a high number of respondents (28%) reported postponing care because of a fear of discrimination, and perhaps this is something that has improved over the last 10 years [9]. Because we relied on identification of participants by the treating consultant, it is possible that individuals who have not openly revealed that they identify as transgender or gender diverse are under-represented in our sample. Only two patients completed this survey, as two of the patients had already died from advanced cancer before completion and other patient declined.

CONCLUSION

The quality of care delivered to transgender and gender diverse patients with cancer needs to be improved. Components of care requiring revision include easier pathways for patients to change names and gender on health records,

increased awareness and use of all binary and nonbinary gender identity terms, increased gender neutral facilities in hospitals, increased awareness by health care providers of transgender and gender diverse-related cancer care issues with increased education, earlier access to psychological support for patients, and more inclusive screening and support groups.

AUTHOR CONTRIBUTIONS

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DISCLOSURES

Dearbhaile C. Collins: Seattle Genetic, Merck Sharpe & Dohme (C/A) AZD, Pfizer, Genmab, Roche, Eli Lilly & Co, Merck Sharpe & Dohme (H), Genmab (SAB). The other authors indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board

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