Abstract

Introduction

Patients undergoing radiotherapy for pelvic cancers will often experience acute and late toxicity which can result in symptoms which have a significant impact on psychosocial functioning and quality of life. Having written information regarding these symptoms enables informed decision-making and ongoing support. Transgender and non-binary communities are a marginalised but steadily growing subsection of the radiotherapy patient population yet their needs differ from those of the general population. This study aimed to evaluate the relevance of the pelvic radiotherapy patient information booklets with regard to these communities.

Methods

An online survey was distributed via social media to evaluate the perceptions of these communities of four commonly distributed pelvic radiotherapy information booklets.

Results

There were 19 full responses and most participants expressed discomfort regarding being provided with (11 / 19) or picking up (10 / 19) the booklets. Although most (11/19) agreed that the material in the booklets was relevant, the same number felt that the wording was not. Some of the language and assumptions made regarding the transgender and non-binary communities were incorrect and had the potential to cause distress.

Conclusion

The importance of providing guidance and support to these communities was identified.

Implications for Practice

Further research is required to establish how best to provide inclusive patient information for transgender and non-binary individuals.

Keywords:

Transgender; Radiotherapy; Pelvis; Information booklets

Evaluating the perceptions of the transgender and non-binary communities of pelvic radiotherapy side effect information booklets

Background

"Transgender" is an adjective used to describe a person for whom their gender does not match that which they were assigned at birth, based on their physical characteristics. A transgender man, for example, would have be assigned a female gender at birth. Some individuals may feel as though their gender cannot be described as "man" or "woman". For some, this is because their gender fluctuates; these individuals may use terms such as "genderfluid". For others, they may identify with no gender at all, and prefer terms such as "agender" or "neutrois". Others may simply feel that their gender identity exists outside of the man/woman dichotomy, and may use terms including "genderqueer" and "non-binary". Non-binary is also often used as an umbrella term for all genders outside of man or woman. Some non-binary individuals also identify as transgender; some do not. The opposite of transgender is cisgender, which is used to describe those people who do feel comfortable identifying with the gender they were assigned at birth.[1] A person's gender identity is distinct from their gender role, which is a combination of attributes commonly associated with a particular gender in a societal context, including personal style, hobbies and personality traits, and their sexual orientation, which describes whom one is attracted to romantically or sexually. People whose gender differs from the one assigned to them at birth can present in ways typical or atypical to their gender, or a combination of the two.[1]

Estimates for the number of transgender people in the UK vary, and this number is difficult to assess. A 2011 report[2] estimated that between 300,000 and 500,000 adults in the UK experienced some degree of gender variance, with the number of people presenting for treatment at a gender identity clinic increasing by 11% per annum since 1998. Despite the UK government describing transphobia within the National Health Service as "completely unacceptable",[3] and the legal measures protecting transgender and non-binary people from transphobia, the community still face barriers in accessing healthcare services, gender-affirming or otherwise. Lesbian, gay, bisexual and transgender (LGBT) people are also less likely to feel like they had been treated with dignity and respect by staff in hospital.[4-6] The National Transgender Discrimination Survey[7] found that 50% of respondents had encountered ignorance from healthcare providers sufficient to make them feel that they were teaching their providers about basic aspects of transgender health in order to access appropriate care. Evidence[7,8] suggests that transgender or non-binary status has led to verbal harassment or treatment refusal. Furthermore, 28% of respondents claimed to have postponed medical appointments due to a fear of discrimination. This is particularly concerning for oncology patients where delays can impact on tumour progression and survival[9]

There are a number of health factors common to the transgender and non-binary communities which may increase their risk of cancer, especially in the pelvic region. These communities typically exhibit higher rates of smoking[10,11] and alcohol/drug dependency or abuse.[7,10] Studies from the United States have shown that transgender populations have a risk four times higher than the general population of being HIV positive,[10,12,13] increasing the risk of anus and prostate cancer.[14,15] There is also an increased incidence of human papilloma virus infection,[16] which is associated with cancers of the cervix and anus.

Pelvic radiotherapy provides numerous challenges to patients, and a strong support system is necessary for a good quality of life and standard of care. Recent work[17] has highlighted the importance of providing LGBT patients with information specific to sexual practices in a supportive environment. This is challenging due to the lack of training in LGBT issues and support strategies among radiographers[17,18] combined with the frequent reluctance of patients to identify their needs to staff.[6] In addition, this group is not as homogenous as the LGBT term suggests with very different needs arising in patients having undergone gender confirmation surgery. Unsurprisingly, many members of the broader LGBT community report high levels of isolation after a cancer diagnosis.[17] This can be compounded by estrangement from birth families[19] which is common in the transgender community. Cancer incidence increases with age[20] and transgender elders are over twice as likely to live alone than their cisgender counterparts[21] This lack of social support is likely to have a significant negative impact on a patient’s experience through the cancer care pathway. Additionally, anxiety and depression linked to a cancer diagnosis[15,22,23] compounds existing anxiety levels within the transgender and non-binary populations. The unique relationship between therapeutic radiographer and patient means that radiographers are conveniently placed to recognise signs of emotional or mental distress in patients and provide relevant written information or refer them to appropriate support services. Therefore it is important to ascertain whether the radiotherapy information booklets are inclusive of these patients, providing them with the information they need to manage their side effects and empowering them to make decisions regarding their treatment and ongoing care.

Methods

The study adopted survey method with a range of 5-point Likert style questions gathering quantitative data regarding the appropriateness of the information. Additional open questions sought clarification of these responses and a final open question sought qualitative data concerning participant experiences and perspectives. The survey utilised an online questionnaire via “SurveyMonkey” to seek opinions on four information booklets: “Pelvic Radiotherapy in Women - Managing Side Effects During Treatment” (Booklet One),[24] “Pelvic Radiotherapy in Men - Managing Side Effects During Treatment” (Booklet Two),[25] “Managing the Late Effects of Pelvic Radiotherapy in Women” (Booklet Three)[26] and “Managing the Late Effects of Pelvic Radiotherapy in Men” (Booklet Four).[27] These booklets are available to the public via the Macmillan Cancer Support website. Participants were invited to provide feedback on as many booklets as they wished. Demographic questions were designed according to guidance from the LGBT Foundation and from Stonewall.[28,29] Table 1 shows the questions used within the survey.

Recruitment and data collection

Information regarding the study and a link to the questionnaires were passed to representatives from the major UK transgender support and campaign groups for distribution via their social media and contact networks. This distribution strategy had the potential to reach a large number of individuals. Fully anonymous data collection was facilitated via the online survey tool.

Data analysis

Descriptive statistics were used to summarise the quantitative data. The responses to the free text questions underwent thematic analysis to identify codes using an approach adapted from Giorgi.[30] All responses to each questionnaire were grouped together as one data set. Three passes of the data were completed in order to fully identify all the possible codes. The full dataset was read initially in order to make sense of the participant responses. After this, the data was interrogated more closely to identify codes from common words, phrases or sentiments. Codes were then arranged into broader categories in order to better guide interpretation. In order to eliminate bias and aid in the objective interpretation of the responses, the author used a reflexive approach guided by the seven key questions proposed by Weis and Fine.[31]

Ethics

Respondents were warned at the start of each questionnaire and in the participant information sheets about the language used in the booklets and the inclusion of references to medical procedures and pelvic anatomy. Helplines were provided for any respondents who became distressed through reading the booklets. Consent was embedded within the survey and participation was impossible without this. The project gained University of Liverpool Ethics Committee approval.

Results

In total, 45 responses were submitted with 41 respondents consenting to the study as seen in Table 2. Of these, and excluding a respondent who had identified as cisgender, only 19 provided complete responses to questionnaires regarding one or more booklets. None of the participants chose to provide feedback concerning Booklet 4 “Managing the Late Effects of Pelvic Radiotherapy in Men”. The responses relating to each of the other three booklets did not differ significantly and thus were grouped together to provide an overall response as seen in Table 3. Most participants expressed discomfort regarding being provided with (11 / 19) or picking up (10 / 19) the booklets. Although most (11/19) agreed that the material in the booklets was relevant, the same number felt that the wording was not. Thematic analysis of the 57 open text suggestions led to the derivation of 16 codes. Five responses were not included either because they were duplicates, incomplete or because they added no new information (for example “see above”). Tables 4-6 summarise the key themes arising and form the basis for the following discussion section.

Discussion

Relevance of wording

There were not enough responses to the Likert scales to perform a quantitative analysis, however these responses triangulate with the free text questions to indicate that respondents would generally not feel comfortable being provided these booklets in a consultation with a healthcare professional or taking them from a public information centre. Most respondents felt that the information provided was relevant and in some cases this was felt to be more important than the language used. While this is a reassuring finding, there were plenty of comments indicating that the wording was not relevant and in some cases had the potential to compound anxiety and distress. The majority of feedback related to the exclusivity of the booklets to transgender and non-binary patients with many respondents stating firmly that they were not the gender addressed by the title of the booklet. Misgendering can result in psychological trauma, dissociation, self-doubt, depression and anxiety[32] and can cause distrust of either the person responsible for the misgendering or the environment it occurred in,[33] which is not conducive to a positive experience throughout treatment. The aim of the booklets[24-27] is to inform patients and empower them to make their own decisions regarding treatment and side effects. The negative comments included in this data is at odds to these negative responses. It is also important to acknowledge that side effects may be different for any patients who have undergone gender confirmation surgery and may now lack organs that are referred to.

Influence of staff members

Feedback suggested that the level of comfort in being given the booklet by a healthcare professional would depend on that member of staff's understanding and respect of gender. It is important that any staff involved in a patient's treatment have a sound knowledge of the issues faced by transgender and non-binary patients,[17] allowing them to put those patients at ease and facilitate inclusive, empowering discussions where the patient and their holistic needs are central. A number of studies[4,8,34] have indicated that many healthcare professionals feel that a patient's gender identity is irrelevant to their care. A national service evaluation of radiotherapy departments in the UK[34] found that 74.6% of radiographers would not alter their care if a patient was transgender, and 56.7% either agreed or strongly agreed that a patient's transgender status was irrelevant. Although many respondents in these studies mentioned the importance of patient centred care, ignoring someone's transgender status is a form of erasure. Given the generally negative experience of transgender people in the health service, this denial of one's identity can even be detrimental to their care and work to disempower the patient.[4] More training should be provided to radiographers regarding the importance of acknowledging gender[8] as well as using inclusive language[17] and appropriate pronouns. Therapeutic radiographers must be registered with the Health and Care Professions Council (HCPC) in order to practice in the UK. Practicing non-discriminatory care, working in partnership with patients and respecting their dignity are important aspects of the HCPC's standards of conduct, performance, ethics and proficiency for radiographers,[35] to which registrants must adhere in order to maintain registration. Training in order to better understand the needs of transgender and non-binary patients would not only be beneficial for the patients but also support radiographers in this provision of non-discriminatory care.

Limitations

The study was subject to a number of methodological limitations. Firstly, the study was conducted by a single researcher, with their own opinions shaped by their own lived experiences. While this is a valuable aspect of qualitative research, it can threaten the objectivity of the data interpretation and analysis. A reflexive approach to the data analysis[31] was thus adopted to minimise the effect of this as discussed in the Data Analysis section. Secondly, the majority of the respondents to this survey identified as non-binary, despite being only 10-35% of the transgender population.[2-4] Transgender women are estimated to outnumber transgender men at a rate of around 4 to 1,[7] but there were no respondents to this survey who identified themselves as transgender women. Gender variance in individuals assigned male at birth is more likely to be stigmatised,[36,37] thus transgender women and transfeminine non-binary people are more frequent victims of discrimination and violence[38,39] and may feel less safe disclosing their trans status and discussing their own uncomfortable experiences, which may account for this underrepresentation. Were this research to be repeated or expanded on, more links would be sought with organisations involving and advocating for transgender and non-binary people, making it possible to gather data from a more representative sample, and therefore increase the response rate. While the survey was designed to be as accessible to transgender and non-binary people as possible, it is likely that some respondents were prevented from responding to the survey as a result of it being online and advertised via social media websites Facebook and Twitter. Facebook has been found to be more popular with women[40] but it is unclear how this corresponds to transgender populations. Twitter also has an overwhelmingly young user base; it is possible that older users are discouraged by their perceptions of its use and the jargon related to it.[41] This may have biased the feedback within the study and future work should aim to harvest data from the patients themselves.

Conclusion

The results from the survey highlighted that the sampled members of the transgender and non-binary community found the information provided by Macmillan Cancer Support's pelvic radiotherapy information booklets to be of a high standard. They also identified that some of the wording and assumptions made the information feel irrelevant to them, and were alienating and distressing. Respondents suggested either splitting the books into genitourinary systems with more gender neutral language, or combining the booklets to apply to all patients, regardless of biological sex or gender. This may warrant further investigation in order to find the best solution for this group. The survey's sample size was small, and the majority of the respondents were non-binary. Future work should adopt more direct qualitative methods such as interviews or focus groups, and attempt to gather feedback from binary transgender people, especially transgender women.

This study has also highlighted some important considerations for healthcare professionals when involved in the care of transgender and non-binary individuals. It is essential for radiographers to be provided with appropriate training on the issues faced by the transgender and non-binary community in order to provide sensitive and affirming care. This will increase the likelihood of attendance to treatment appointments, pursuit of appropriate holistic care, and better long term outcomes for this population.

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Table 1: Survey questions

Question	Type
What is your gender?	Multiple choice & Open
Is your gender identity the same as the gender given to you at birth?	Yes / No
I would feel comfortable if this booklet was given to me by a doctor or healthcare professional in a private consultation	Likert & Open
I would feel comfortable picking up this booklet in a public information centre	Likert & Open
The material presented in this booklet is relevant to me.	Likert & Open
The wording used in this booklet is relevant to me.	Likert & Open
Please add your suggestions or feedback regarding this booklet	Open

Table 2: Survey responses

	Booklet One	**Booklet Two**	**Booklet Three**	**Booklet Four**
Full responses	11	4	4	0
Non-binary	9	3	4	0
Trans man	2	0	0	0
Same as birth	0	1	0	0

Table 3: Collated Likert responses

Likert stem	SD	D	N	A	SA
I would feel comfortable if this booklet was given to me by a doctor or healthcare professional in a private consultation.	7	4	4	1	3
I would feel comfortable picking up this booklet in a public information centre.	7	3	4	2	3
The material presented in this booklet is relevant to me.	2	3	3	9	2
The wording used in this booklet is relevant to me.	6	5	6	2	0

Key: SD = Strongly disagree; D = Disagree; N = Neither agree nor disagree; A = Agree; SA = Strongly agree.

Table 4: Negative aspects (Trans-exclusionary)

Subtheme	Indicative comments
Not a man/woman	"The booklets are for 'women' and 'men'. I'm not either." "I am not a woman, however I have the body type the leaflet intends to reference…"
Exclusionary language	"When talking in terms of biology yes it describes me, when talking about "women" it does not" "Explicitly recognise the existence of non-binary people in the text..." "It's not inclusive of trans, intersex or non-binary people"
Misgendering	"I would prefer not to be given a booklet marked as being for women" "...the relation of these as 'female' and a marker of my 'womanhood' make me infinitely uncomfortable."
Inaccurate sexual assumptions	"...it assumes I am having penetrative sex with a male partner" "This...implies certain ways of having sex…are the only ways."
Inaccurate social assumptions	"The unnecessary assumptions made about those who have vaginas, wombs etc are incredibly unhelpful" "There are unnecessary assumptions about what kind of clothes people who are men or women would wear"
Confusing language	"the wording (women/men/female/male) will make things difficult and confusing for non-binary people, trans people and intersex people."
Trans specific issues	"I'm quite interested to know how radiotherapy would affect a trans man or non-binary person who was taking testosterone for example"
Dysphoria/discomfort	"...would cause me intense dysphoria in itself and make me feel deceptive and complicit in my own discomfort..." "I would feel uncomfortable receiving this unnecessarily gendered booklet."

Table 5: Positive aspects (Informative content)

Subtheme	Indicative comments
Relevance	“I’d recognise that biologically the information was accurate” “I still have typical female genitalia and I feel it is relevant to anyone with a uterus undergoing radiotherapy around that area.”
Informative	“It contains all the relevant information, who cares how that information is presented? What matters most is that it's there.” “If you have a uterus/penis/ovaries etc. and you need radiotherapy, it’s important to have access to this information.“
Health is the priority	“I am more concerned about not being ill than what gender people might perceive me as being” “Because health is more important than whether or not i feel comfortable for a short moment“
People’s perceptions are irrelevant	“I guess I just don’t care about being misgendered.” “I can’t imagine members of the public would really care about a booklet I'm reading.”

Table 6: Suggestions for improvement

Subtheme	Indicative comments
Non-gendered language	“I noticed both the use of "reproductive system" and "female reproductive system." The first includes all gender identities that have a uterus and I prefer that.” “A more appropriate label could be "Pelvic Radiotherapy in Men and AMAB individuals". AMAB stands for "assigned male at birth", so this title would be much more inclusive.” “It does use the words "some women" a lot. I don’t suppose it'd hurt to change it to "some people"”
Organ specific language	“I personally would find "Pelvic radiotherapy for cervical, ovarian and endometrial cancer" less objectionable” “It’s pretty clear that in a medical or physiological context, the word woman means any person with a vagina” “… change the titles of the booklets to something physiologically specific and medically relevant. For example 'long term effects of radiotherapy on the health and function of penises/ovaries/testicles' etc.”
Combined booklet	“Offer a gender neutral version of the guide, which contained the contents of both the men's and women's guidance “It would be much simpler to make a universal guide, which includes diagrams for people with vaginas and penises.”
Staff attitude	“The healthcare professional would have the opportunity to acknowledge to me that the leaflet was misgendered in regards to me but that it was the best they had.” “It would depend on the doctor and how aware they were”