The Trans Primary Care Guide: A Community-Based Approach to Developing a Web-based, Illustrated Resource for Primary Health Care Providers

Abstract

**Background:**
There is a large gap in educational and training resources on trans-sensitive care in health professional curricula. In-person continuing medical education training sessions are often limited by time, place, and instructor availability. Web-based technologies offer the potential to easily reach primary care providers across the province. However, existing online training resources are lengthy in content, lack visual communication strategies, and do not encompass the multitude of different transition options sought by trans individuals.

**Objective:**
This article describes a community-based, participatory approach to the design and development of a web-based, illustrated resource guide with non-sequential access to medical and basic care protocols and guidelines to improve primary care providers' knowledge and confidence in caring for trans clients.

**Methods:**
The design and development of the *Trans Primary Care Guide* was informed by a participatory design research strategy focused on iterative improvement of the resource through iterative review by an advisory committee, formative evaluations with trans participants and primary care providers, and usability testing.
Results: A web-based, illustrated resource (*Trans Primary Care Guide*) was developed to educate primary care providers on the health care needs of trans and gender-diverse people.  

Conclusions: Successful implementation of the web-based resource was in part due to the utilization of design strategies to help primary care providers contextualize trans-competencies, the community-academic partnership and due to the early engagement of trans participants to ensure that information is gender affirming and culturally specific to regional community needs.

Trial Registration: Not applicable.

Keywords: Transgender, Trans, Gender-Variant, Genderqueer, Two-Spirit Persons, Primary Care, Continuing Medical Education, Community-based, Participatory, Medical Illustration, Multimedia, Professional Development

Introduction

Trans people, a heterogeneous group of individuals whose gender identity does not align with the gender they were assigned at birth, face major barriers in the access to both general and transition-related care.\textsuperscript{1–6} Despite the growing visibility of the trans community and increased appreciation of the importance of diversity in medical education, large gaps in health providers’ knowledge of trans issues and needs remain.\textsuperscript{1,2,7–15} The health care concerns of trans and gender-diverse people have largely been excluded from medical and nursing educational materials and curricula.\textsuperscript{2,14,16–18} As a result most health care professionals are not sufficiently knowledgeable and are uncomfortable caring for trans clients.\textsuperscript{5,19–21}

Given the practical constraints of many physicians and nurses, convenient access to pertinent information is extremely useful. Since web-based learning is easily accessible to anyone with an internet-capable device and a certain level of technical ability, its use in medical education, especially in continuing medical education, has increased due to the ability to disseminate teaching materials widely and enhance learning.\textsuperscript{22,23} Internet-based resources on trans care targeted at health care providers are scarce and are limited by the fact that trans care is usually only one component of modules focused on LGBT health or sexual and gender diversity,\textsuperscript{14–27} which can be problematic as the ‘T’ is often overlooked.\textsuperscript{15,17,28} While some existing online resources can truly be considered web-based learning interventions\textsuperscript{29}, such as the openly accessible e-learning tools provided by the Gender Identity Research and Education Society\textsuperscript{30} and the “Acknowledging Gender and Sex” e-learning module by the Center of Excellence for Transgender Health\textsuperscript{31}, others tend to be either archived video- and/or audio-recorded lectures, PowerPoint slides or educational materials that need to be facilitated in face-to-face training sessions.\textsuperscript{25,27,32–35}

Particularly striking is the lack of illustrated medical discourse through visual communication and narratives\textsuperscript{36}, especially since visual communication can greatly enhance textual information, and can help bridge cultural, societal and gender barriers in
a way that may decrease the stigmatization of marginalized populations.\textsuperscript{37,38} Existing trans health resources and published guidelines are largely text-based. While some include photos or embedded videos of trans or gender-diverse people, images are often limited or could be considered nonessential multimedia.\textsuperscript{29} Well documented biases in medical imagery, whether in relation to sex, gender or race, are troublesome as they shape our conceptions of the human body and may implicitly perpetuate stereotypes.\textsuperscript{37,39–41} Since medical students and professionals rely heavily on instructional materials to enhance their learning, particular attention must be paid to the use of imagery in medical education.\textsuperscript{41,40} When it comes to acknowledging gender identity, medical professionals often tend to adopt a neutral stance in order to avoid stereotyping, however this may ultimately render the person and their unique health care needs as invisible.\textsuperscript{42–45} With the goal of empowering gender diversity in medical education a neutral gaze may conceal important differences and reinforce the already prevalent gender biases in medicine.\textsuperscript{12,40,45,46} Educational designers must not only pay close attention to the use of language, as Sklar\textsuperscript{12} suggests, but also to the type of imagery used in educational initiatives that promote gender diversity.

**Goal of this study**

Current considerations for the delivery of health care to trans people have emphasized the importance of community partnerships that improve the delivery of training initiatives.\textsuperscript{16,47,48} With the goal of widespread acceptance and adoption, the researchers partnered with local leaders in LGBTQ health care, Sherbourne Health Centre (SHC), and advocacy program Rainbow Health Ontario (RHO) to develop a web-based, illustrated resource guide that met regional community needs to increase primary care providers’ (PCPs’) awareness, knowledge and comfort in caring for trans and gender-diverse clients. This article describes the design, development and formative evaluation of the resulting *Trans Primary Care Guide*.

**Methods**

**Study Design**

The design and development of the *Trans Primary Care Guide* resource was informed by a participatory design research strategy focused on iterative improvement of the resource which included a needs assessment, formative evaluations with trans participants and primary care providers, and usability testing.

**Advisory Committee**

While the clinical content for the website was based largely on the Guidelines and Protocols for the Primary Health Care and Hormone Therapy for Trans Clients\textsuperscript{49}, the medical guidelines were supplemented by competency-based training informed by a needs assessment, published protocols\textsuperscript{50,51}, standards of care\textsuperscript{52} and years of experience in caring for trans clients at Sherbourne Health Centre. In order to ensure accuracy of information an advisory committee was formed to review and verify relevant visual and textual content on a continual basis. The advisory committee consisted of (1) medical content experts, who were both part of the Primary Care Team at SHC as well as Faculty
Leads for LGBTQ Health Education at the University of Toronto, (2) key informants from RHO’s Trans Health Connection Team, and (3) Biomedical Communications (Medical Illustration) experts and researchers from the University of Toronto.

**Needs Assessment**

To learn more about trans health and incorporate years of experience in caring for trans clients at Sherbourne Health Centre, the primary investigator/designer (Speck) attended multiple Trans Health Connection training sessions which are in-person continuing medical education workshops that provide information on high-quality, comprehensive care of trans clients. At these sessions, Speck consulted with attending service and health care providers to better understand their attitudes towards caring for trans and gender-diverse clients. Critical observations and consultations with attending service and health care providers during these sessions reinforced research findings that many providers are uncomfortable with caring for trans clients because they perceive their own knowledge to be inadequate to meet their clients’ needs. Many providers were uncertain of the perceived risks of hormone therapy, and tended to falsely believe that trans clients always require specialized services that require particular expertise (endocrinologists and surgeons). To address these findings and help RHO decentralize trans expertise out of Sherbourne Health Centre and Toronto to reach care providers in remote locations across the province of Ontario, the objectives of the project were to develop a web-based, visual and interactive resource that:

1. increases PCP’s awareness of the health care inequalities experienced by trans individuals and persuades them of the urgency for care for this highly marginalized population
2. increases PCP’s knowledge of trans health care needs by offering timely access to essential guidelines and protocols on the management of care for new or newly transitioning trans clients
3. increases PCP’s comfort and confidence in welcoming trans clients into their day-to-day practice by enriching the medical and non-medical discourse with illustrations that exemplify trans-competent practice

**Building a non-linear, interactive framework**

Taking into account the individualized, non-linear assessment and treatment paths in trans care as well as the varying degrees of prior knowledge and experience of care providers, it was crucial to design an interface that provides non-sequential access to all information in the resource. Firstly, Speck created a sitemap (Figure 1) and wireframes (Figure 2) to visualize the adaptation of clinical content from the published protocols to an interactive framework. Incorporating best practices in interaction design, visual design, and information architecture, Graphical User Interface designs (Figure 3) were utilized in order to provide a user-friendly, navigation framework that simulated SHC’s individualized, client-centred approach to trans care. These initial visual guides to representing the framework and hierarchy of information on the website were extremely useful in communicating the non-linear, interactive approach to the advisory committee which allowed for feedback to be incorporated early through multiple iteration cycles before development of the website.
Figure 1 A sitemap was designed to visualize how the clinical content from published Guidelines and Protocols was to be organized in the website.

Figure 2 Example of an early interactive PDF wireframe adapting clinical content to non-linear desktop, tablet and mobile interfaces. Red numbers indicate how the interactivity or navigation is designed.
Figure 3 An early responsive Graphical User Interface (GUI) Design focused on simulating SHC’s individualized, client-centered approach to trans care with non-sequential access to information along a patient’s care journey.

Formative Evaluations of Draft Illustrations and Visualisations

With the goal of high-quality care provision, especially for a diverse LGBT population, competency-based medical education has been proposed to help break down barriers between LGBT clients and their health care providers.\textsuperscript{43,53,54} Taking this into consideration, the researchers aimed to develop contextual illustrations that would promote the understanding and application of trans-competent skills, while engaging information visualizations intended to help to clarify complex medical content.

Given the extensive informational and institutional erasure of trans people, it was imperative to include the voices and opinions of trans people in the development of the resource.\textsuperscript{48,2} Although the Trans Primary Care guide is directed at health care professionals, the resource was intended to be openly accessible and the visualisations to be used by providers at the point of care in consultation with their clients in order to foster a collaborative approach to care.

After receiving approval from the University of Toronto Research Ethics board (Protocol 00032181), trans participants were recruited through RHO’s social media communication platforms (Twitter and Facebook) to participate in an anonymous, online Google Forms survey which consisted of two sections. The first section asked participants to view and evaluate draft webpage designs with embedded illustrations of patient-provider interactions (Figure 4).
Client History

Rationale for assessment period

The assessment period is important for:
- Establishing rapport with the client
- Ensuring the client is ready
- Ensuring the client has all the information they need to start hormone therapy

Using respectful language

Facilitate a trusting, open relationship by using respectful language.
Always name your client by their chosen name and pronouns. Use references that describe someone’s present identity, not their assigned identity.
If you are unsure, ask the client how they would like to be called.

“May I ask your name?”
“May I use your pronouns?”

“How would you like to be addressed?”
“What name and pronoun would you like me to use?”

Figure 4 An example of a draft webpage design and illustration presented to participants in the online survey.
In the second section of the survey participants were shown the webpage on the expected effects of feminizing/masculinizing hormone therapy (Figure 5). For the placeholder image of a body illustration, the participants were presented with two different styles of illustration depicting the expected physical effects of feminizing and masculinizing hormone therapies. Since depictions of human bodies, and especially bodies undergoing significant changes under hormone therapy are highly sensitive subjects, Speck created depictions of the human body in varying degrees of detail and abstraction. In close collaboration with the advisory committee two styles were chosen to be formally evaluated by trans participants (Figure 6 and 7): style A which was a more diagrammatic, non-representational illustration of a body in anatomical position and style B, which included more detailed nuances of body form and an affirmative stance.

Critical insights from these evaluations suggested that most participants regarded the patient-provider illustrations to be acceptable and respectful, while the majority of participants favoured the more diagrammatic illustration style A because it was perceived to be more objective/gender-neutral/professional and more appropriate for a medical guide. Nuanced qualitative feedback was also given such as the importance of universal shapes for the groin regions across feminizing and masculinizing hormone effects diagrams as well as the importance of trans-sensitive language in the medical diagrams, for example warning physicians that terms such as ‘vagina’ or ‘erection’ may be
triggers to some clients. These valuable insights informed further revisions of the illustrations in order to reflect the views and preferences of the trans community.

**Illustration style A**

**Illustration style B**

*Figure 6 Participants were shown two styles of bodily representations in the visualization of the expected effects of feminizing hormone therapy regimens.*

**Illustration style A**

**Illustration style B**

*Figure 7 Participants were shown two styles of bodily representations in the visualization of the expected effects of masculinizing hormone therapy regimens.*

**Usability testing**

Once the written clinical content had been approved by the advisory committee, Speck developed a web-based prototype using HTML, CSS, JavaScript and a responsive front-end development framework called Bootstrap. Usability testing with graduate students in the Biomedical Communications program (as proxies for educated health care professionals) was conducted on this prototype to gather insights into the ease of finding information, navigation, and overall impressions of the website design. The full report
can be read in Appendix 1. These insights allowed Speck to make changes to the website prototype in order to accommodate a more intuitive site architecture and layout of information.

Formative evaluations with primary care providers
After redesign of the illustrations and prototype based on the feedback received, the full Trans Primary Care Guide website was developed. Sections of the website were incorporated into an online survey that aimed to collect initial feedback on the extent to which the visual communication methods employed helped primary care providers understand the clinical information. Although this portion of the study has not been formally evaluated due to small participant size, initial qualitative feedback demonstrated the value of visual narratives. Participants also gave preferences for more content including visual and interactive features. Based on this feedback, Speck added additional contextual illustrations and interactive components such as links to recommendations on how to provide trans-competent care (Figure 8).

The revised illustrations of the anticipated bodily effects of hormone therapy were also adapted to an interactive format to include visualisation of the time course of expected onset and maximum effect (Figure 9).
Results
After final review by the advisory committee, the *Trans Primary Care Guide* was officially launched on RHO’s Trans Health Connection page on July 14th, 2016.

Discussion
This study provides valuable insight into the importance of an iterative design research process that strategically uses qualitative feedback in order to improve upon the design of an educational resource before its implementation. It also provides an example of how trans individuals can be included early in the research and development of training materials in order to ensure the creation of educational initiatives that are accepted by the local community.

Conclusion
The community-academic partnership that had been developed for this project will be continued in order to further develop projects that apply visual communication strategies to the training of health care providers and students on LGBT health. Although this project is directly relevant to the continuing medical education (CME) of primary health care providers, the approach to the design and development of the web-based resource can be applied to other educational and e-learning initiatives.

As the community of competent doctors and nurses grow throughout Ontario, this will hopefully improve the delivery of care and stimulate further initiatives and research to increase the visibility of this marginalized and underserved population.
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Principal investigator and designer: Kelly Speck, MScBMC, Biomedical Communications Program, Department of Biology, University of Toronto Mississauga, Mississauga, ON, Canada
Project supervision: Shelley L. Wall, AOCAD, BA, MA, MScBMC, PhD Biomedical Communications Program, Department of Biology, University of Toronto Mississauga, Mississauga, ON, Canada

Advisory committee:
Donna Turner, Senior Health Promotion Specialist, Program Training and Consultation Centre, Cancer Care Ontario
Jordan Zaitzow, Trans Health Connection, Rainbow Health Ontario
Dr. Amy Elizabeth Bourns, Family Physician, Sherbourne Health Centre
Dr. Ed Kucharski, Physician, South East Toronto Family Health Team - Michael Garron Hospital

Conflicts of Interest
None to declare.

Abbreviations
SHC: Sherbourne Health Centre
RHO: Rainbow Health Ontario
References:


