

Original Publication

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Complete Androgen Insensitivity Syndrome: A Problem-Based Learning Case

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Abstract

Introduction: To address the lack of medical education on lesbian, gay, bisexual, transgender, queer (LGBTQ), and difference in sex development-affected (DSD-affected) individuals, the University of Louisville initiated the eQuality project. The mission of eQuality is to promote mastery of the skills, knowledge, and attitudes required for excellent care for patients within the LGBTQ, gender-nonconforming, and DSD community. This problem-based learning (PBL) case was implemented to address both medical and psychosocial factors that affect individuals born with DSD and their families.

Methods: Students complete a 10-question multiple-choice pretest prior to distribution of the PBL case and a 10-question multiple-choice posttest after completion of the PBL. They also evaluate the efficacy of the case by answering three open-ended questions regarding comprehension, competence, and attitudes, as well as any barriers to acquisition and implementation of knowledge. Along with a specific lecture and patient panel, this piece helps to incorporate more information specifically on DSD into the curriculum.

Results: The posttest average score was 20% higher than the pretest. The posttest ($n = 144$) had a range of 90% to 99% of students answering each question correctly, whereas the range for the pretest ($n = 155$) was from 29% to 94%. **Discussion:** Based on the objective assessment and student comments, learning increased through this PBL process. Despite this clear increase in knowledge, some students believed that either societal barriers or personal barriers would prevent them from implementing their newly gained knowledge in practice.

Keywords

Problem-Based Learning, LGBTQ, Sexual Minorities, Disorders of Sex Development, Differences of Sex Development, DSD, PCRS

Appendices

- DSD PBL Objectives & PCRS Map.docx
- DSD PBL Case - Student Copy.docx
- DSD PBL Discussion Guide .docx
- DSD PBL Evaluations.docx

All appendices are peer reviewed as integral parts of the Original Publication.

Educational Objectives

By the end of this session, learners will be able to:

- Describe three challenges that patients with differences in sex development (DSDs) face when accessing and receiving health care.
- Compare similarities and differences between the health care encounters of lesbian, gay, bisexual, transgender, queer, and DSD-affected communities.
- Identify three ways in which a physician can appropriately and sensitively work with a patient who is from a community that suffers from health disparities.
- Identify three ways in which discovering a patient's DSD affects the patient's psychosocial health.
- Describe what steps may be necessary to ensure the patient receives adequate, well-researched, and supported health care.
- Describe general health requirements/protocols for patients who are born with a DSD and for patients who may present with an undiagnosed DSD later in life.

Introduction

Members of the lesbian, gay, bisexual, transgender, queer (LGBTQ), and difference in sex development (DSD) communities have faced serious societal stigma for decades, and still, across the US, many continue to face struggles that are unimaginable to communities that belong to the societal norm. The unique set of issues that the DSD community faces apart from the LGBTQ community is often overlooked and results in a lack of DSD content in most medical school curricula.

Historically, not unlike the LGBTQ community, DSD-affected individuals have faced suboptimal medical care that was often physically and psychologically damaging. It was common practice to affirm a particular sex for DSD-affected individuals based on a variety of factors, such as physician and parental opinions. Sex-assignment procedures not only are unnecessary but are very invasive and sometimes damaging in the long run. They have been shown to have long-term effects on gender identity, sexual health, psychological health, and so forth. Common procedures range from genital cosmetic surgeries to gonadectomies to hormonal therapy, all in an attempt to match sex and gender norms. These ill-advised practices paved the way for increasingly stigmatizing the health care for DSD-affected individuals. Unfortunately, some of these practices still exist, and it is of utmost importance for the new generation of physicians to be educated on how to approach DSD-affected patients. To this day, there is a limited amount of mental health support specific to the DSD population, and in the majority of the US, expert care for adults born with a DSD remains scant and often difficult to find.¹

A cross-sectional survey conducted by Obedin-Maliver and colleagues in 2009 examined the hours of LGBTQ- and DSD-related curricula in medical schools in the US and Canada.² From the 132 medical schools surveyed, there was a median reported time of 5 hours dedicated to teaching LGBTQ- and DSD-related content in the entirety of the 4-year undergraduate medical curriculum. Not only did the survey discover this limited amount of time dedicated to LGBTQ- and DSD-related content, some schools reported 0 hours of LGBTQ- and DSD-related content. The data for DSD-specific content in medical schools are uncertain. The study did highlight that roughly 60% of medical schools were teaching about DSDs in their curricula, but topics related to transgender health and DSDs remained those that students felt least prepared to address.² Other than this particular statistic, there is a significant gap in understanding how medical students are trained to care for patients with a DSD. There is also no clear indication of what DSD-related topics are being taught at those schools claiming to teach about DSDs. The LGBTQ and DSD community, while a minority, is a group that is becoming much more visible as the norms of society are shifting towards acceptance of diversity across many characteristics.

To address the lack of medical education on LGBTQ- and DSD-affected individuals, the University of Louisville initiated the eQuality project. Building off a publication of the AAMC Advisory Committee on Sexual Orientation, Gender Identity, and Sex Development,¹ the mission of the eQuality project is to implement a comprehensive medical school curriculum that requires students to learn, practice, and demonstrate mastery of skills, knowledge, and attitudes required for excellent care for patients who are LGBTQ, gender nonconforming, and/or born with DSDs. The vision is to transform medical education by applying the AAMC competency specifiers to the care of patients, regardless of identity, development, or expression of gender/sex/sexuality, at the University of Louisville School of Medicine.

At the University of Louisville School of Medicine, problem-based learning (PBL) sessions are incorporated into each integrated course during the 2 preclinical years. PBLs are designed to help students begin thinking more critically as they start to see cases as they may present in a real-world clinical setting. Typically, the PBL case is related to the current body system being taught and addresses more complex patients than those presented in the classroom. An important aim of a PBL is to focus students' learning on complex psychosocial factors and other pieces of patient history that also play into a patient's diagnosis. The PBL facilitator, often an experienced physician, ensures students stay focused on major educational objectives and helps to provide insight when students have difficulty understanding the key points.

With the start of the eQuality project, team members deemed it necessary to resemble the current curricular model of using PBL cases to apply understanding, and so they developed a case on a patient

presenting with a DSD. After a series of discussions and research of current literature, the decision was made to create a case based on a teenager presenting with symptoms and history suggesting a diagnosis of complete androgen insensitivity syndrome (CAIS). Students had been introduced to the topic of DSDs with both a lecture and a panel of patients from this community during the previous semester. The lecture provided an embryological and biochemical foundation for DSDs, while the panel focused on personal medical experiences. However, this PBL was an opportunity for students to learn more about complete androgen insensitivity and use this knowledge in relating to others. This PBL case relates the topics of sex, gender identity, gender expression, and sexual orientation to six suggested educational objectives that provide students with direction and an example of the depth of knowledge students should gain from this case. The AAMC competency specifiers relevant to the case educational objectives are listed in Appendix A.

Methods

At our institution, students review this PBL case over two 2-hour sessions during the second half of their first preclinical year. During the first session, the students read through the case (Appendix B), identify words and themes they do not understand, and begin to formulate a series of individual educational objectives. Learners who are more experienced with PBL cases may be able to do this without prompting. Less experienced learners should be given the six educational objectives to serve as a starting point for them to refine. Facilitators should work with all learners to refine their educational objectives before learners begin their independent research. Between 2 and 5 days later, the students meet again for a second 2-hour session to share their answered educational objectives and findings with their peers.

Alternatively, the PBL case could be shortened to one session, which is customary at other medical institutions. In this format, students are given the case to review, are asked to create their own educational objectives, and conduct research on their own before the session. Students then come together for the session and discuss their findings with each other to establish their knowledge and fill in any gaps in their research.

In either session format, the facilitators should use the discussion guide (Appendix C) to address any points that students do not discuss and help clarify pieces of the case that students may still not fully understand. Under each major discussion point, the guide includes further questions to promote discussion.

Students' change in knowledge from this PBL case is assessed using a pre-/posttest format. At the start of the first session, students complete a 10-question multiple-choice pretest (Appendix D) before they have access to the case. After the second session, students complete a 10-question multiple-choice posttest along with three open-ended postsession evaluation questions regarding knowledge, competence, and any barriers to implementing gained knowledge (Appendix D). It is important to note that the pre-/posttest questions are not the same, which prevents the ability to perform statistical testing.

Results

This PBL case was successfully implemented in the spring of 2016 with first-year medical students. All students ($N = 155$) completed the pretest, with an average of 7.2 correct answers. The 144 students (93%) who completed the posttest averaged 9.1 correct answers. Along with this improvement in the number of correct answers between pre- and posttest, comparing Table 1 and Table 2 shows how the distribution of correct answers was more consistent for the posttest. In the pretest, the percentage of correct answers ranged from 29% to 94%, and two questions (numbers 1 and 7) were answered correctly by only 30% of students, whereas all posttest questions were answered correctly by at least 90% of students. Statistical testing was not performed for the pretest and posttest as the questions from these two tests were different and did not align well enough for meaningful results.

Table 1. Distribution of Answers to Pretest Questions (N = 155)

Question	A	B	C	D	TRUE	FALSE	Other ^a	Correct Answer
1	23	25	61	46			0	30%
2	6	144	2	2			1	93%
3	3	1	120	31			0	77%
4	4	7	7	137			0	88%
5	2	2	4	146			1	94%
6	21	102	22	9			1	66%
7	4	96	45	8			2	29%
8					144	11	0	93%
9					5	146	4	94%
10	81	2	1	71			0	52%

Questions 1-7 and 10 were multiple choice. Questions 8 and 9 were true/false.

^aIncludes no response and is considered an incorrect answer.

Table 2. Distribution of Answers to Posttest Questions (n = 144)

Question	A	B	C	D	TRUE	FALSE	Other ^a	Correct Answer
11	1	0	132	11			0	92%
12	0	133	4	7			0	92%
13	129	0	5	10			0	90%
14	8	133	0	0			3	92%
15	137	0	1	5			1	95%
16	142	0	1	0			1	99%
17	3	137	3	0			1	95%
18					129	15	0	90%
19					6	136	2	94%
20	2	1	132	7			2	92%

Questions 11-17 and 20 were multiple choice. Questions 18 and 19 were true/false.

^aIncludes no response and is considered an incorrect answer.

For open-ended postsession evaluation question 1, 79% of students responded yes when asked if the session changed their knowledge and competence regarding individuals born with a DSD. The following quotes demonstrate students' increased awareness:

- “This made me more aware of DSDs diagnosed later in childhood. We had a good discussion of how physicians should approach counseling the patient/family.”
- “I became more informed about many details involving protocols for decision making and the difficulties these patients [with DSDs] face. There are an incredible number of things that are made difficult for these individuals that I had never known before.”

The majority of students responded positively to the second open-ended postsession evaluation question, indicating that they would be more sensitive when dealing with the many facets of sex, gender, and sexuality with patients. A few students' comments on this question indicated they would use the information they learned to teach others about and remind others of these particular distinctions. Many of the responses mentioned increased sensitivity when working with patients, such as the following from two students:

- “[It is important] to be sensitive to the emotional needs of my patients and provide the necessary support/guidance.”
- “I will always be sensitive to people's feelings and have learned how to better communicate about these disorders.”

In response to the third open-ended postsession evaluation question, the majority of students (87%) stated that there were no barriers that would prevent them from implementing what they learned from the session. The other 13% identified several barriers to implementing their knowledge of DSD-affected individuals, including the following:

- Societal norms:
 - “Societal views on DSDs.”
 - “Society is unaccepting.”
 - “Society is built on black and white gender norms.”
 - “[The] law of public bathroom use and trying to explain that to my patients.”
 - “There's always the potential for patients to be difficult or non-responsive to my counsel due to deeply ingrained cultural biases”

- Religion:
 - “I think religion is a huge barrier as well as general cultural upbringing. It is difficult to explain the medical aspects while keeping in mind that some people’s beliefs will directly contradict sound medical advice.”
 - “Personal conflict with religious beliefs.”
 - “I personally could not help a patient with a DSD transition to the opposite sex because of religious conflicts.”
- Parents:
 - “I believe parents can be a barrier in the situation of pediatrics. Proper education may be a possible tool for overcoming this barrier.”
- Lack of interaction with DSD-affected individuals:
 - “General lack of interaction with individuals going through these difficulties—getting over what may be slightly uncomfortable to talk about.”

Discussion

This PBL was incorporated into the first preclinical year in spring 2016. One of the main objectives of this case was to have students understand the various definitions of and distinctions between gender expression, gender identity, sexual orientation, and sex. Earlier in the year, we had given the students a baseline level of knowledge on the LGBTQ and DSD communities. In addition to refreshing the topics taught earlier in the year, this session allowed students to build upon their knowledge and, furthermore, to have appropriate, respectful, and open conversations with patients from these communities. Many students also felt that the sessions increased their awareness and would help them in their future practices. With a 20% improvement in the number of correct answers on the posttest, it appears that many students were able to create effective case educational objectives and learned about DSDs from this particular case. The student responses to the postsession evaluation also show that students were able to take a focused case, learn more about both the nonspecifics and specifics relating to that case, and later apply this knowledge to other similar areas, particularly in understanding sex, gender, and sexuality.

Measuring the effectiveness of the current session is limited in two ways that we will address in future iterations. First, the pretest and posttest contain two separate and unique question sets, which prevented us from performing a statistical analysis. Instead, we were only able to compare the pretest and posttest by focusing on the change in the overall percentage of correct answers. The second limitation is that the questions in the pretest and posttest do not directly map to the educational objectives specified in the case. Future improvements of this case will include creating pretest and posttest question sets that correlate well with each other and that also map directly to the educational objectives for the case. With these changes and a revision of our current evaluation methods, we will be able to do a statistical analysis to measure knowledge acquisition as a result of this PBL case.

In the future, we may also expand on this learning experience by including an additional teaching method. To build upon the knowledge and attitudes gained from the patient panel, DSD-specific lecture, and DSD PBL, it would be ideal to allow students to practice skills and behaviors for caring for patients with a DSD. This activity could include counseling a parent whose child was born with ambiguous genitalia or counseling a patient who has just received a CAIS diagnosis.

This case was able to help students learn more about the intricacies of sex, gender, and sexuality and their application to the understanding of DSDs. Based on the data and comments, student knowledge was markedly increased through the PBL process. Despite this increase in knowledge, there were still some students who felt that some barriers remain. This information is vital to our incorporation of LGBTQ material into the curriculum in hopes that all providers can provide competent, sensitive, and skilled care to a patient with a DSD. Most importantly, this case, in addition to the lecture and patient panel from the fall of 2015, has helped many students become more aware of the DSD patient community, more aware of the way they discuss sex, gender, and sexuality, and more sensitive to the needs of patients from the LGBTQ community.

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Ethical Approval

This publication contains data obtained from human subjects and received ethical approval.

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