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Sexual Minority Health: A Bibliography and Preliminary Study of the Book Literature

Sharon A. Weiner

ABSTRACT. The literature on health in people who identify as sexual minorities is scattered in many types of resources and disciplines. To begin to address the need for relevant, well-organized information for LGBT people and health care providers, this study first identified books published in a ten-year period and then examined the topics, the number of books published per year, most prolific authors, and primary publishers. A wide range of publishers published a relatively small number of books (521). Most were about mental health or relationships and 24% were personal accounts. There were many subject deficiencies in the published book corpus.

KEYWORDS. Analysis of literature, books, information gaps, LGBT+, sexual minorities

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INTRODUCTION

Health information is important for all people. Accessing health information can provide a basis for self-care, illness prevention, and decision-making about treatments. For those who identify as a sexual minority, the societal issues with delivery of health care due to stigmatization and the increased risk for certain diseases and conditions have serious consequences.¹ For this article, the definition of sexual minorities includes non-heterosexuals, i.e., lesbians, women who have sex with women (WSW), gay men, men who have sex with men (MSM), bisexuals, transgender people, intersex people, and others listed in the Appendix (collectively identified in this paper as “LGBT”). Though there is diversity within sexual minority groups, they share a

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historically marginalized social status relative to society’s cultural norm of the exclusively heterosexual individual who conforms to traditional gender roles and expectations...Their “otherness” is the basis for stigma and its attendant prejudice, discrimination, and violence which underlie society’s general lack of attention to their health needs and many of the health disparities.²

</EX>

LITERATURE REVIEW

Interpersonal networks are a primary source of health information for health care providers and lay people.^{3,4} But the health care system has been slow to recognize the need for specialized training for health professionals and students about health and LGBT people. It has been slow to

develop LGBT-inclusive policies.² The American Association of Medical Colleges only developed a statement on curriculum and institutional climate changes in 2014.⁵ The Human Rights Campaign began producing an annual Healthcare Equality Index in 2007 to highlight health care facilities that have inclusive and nondiscriminatory policies for LGBT people.⁶ Nursing curricula have very limited content on LGBT health.⁷ As a result, self-care is a necessary alternative for many people. The ability to find and critically evaluate information is a pre-requisite for good self-care.

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Mistrustful of organized health care, misunderstood or not recognized by health care providers, and often treated without full disclosure of the truth, the L/G/B/T patient is very likely to be attracted to self-care and its promise of being able to avoid the health care establishment if you stay well. The self-care movement...has appeared as an important counterweight to all of the negative factors in the daily struggle of members of the L/G/B/T community to maintain good health.⁸

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Because of the sensitivity of the topic of LGBT health, lay people as well as health care providers may prefer the privacy of the Internet and print resources to find information.⁹

Information Resources on LGBT Health

Due to the small amount of government funding allocated for research about LGBT health, research on this topic is very limited.^{2,10,11} This has an influence on the volume and quality of publication in the scholarly literature on this topic and on the practice of evidence-based health

care. “In the self-care movement, information is vital, and collecting and disseminating information are activities of extremely high value.”⁸ PubMed <<http://pubmed.gov>> includes most citations that appear in the scholarly biomedical journal literature. It includes many highly specialized biomedical journals that result from the evolution of subdisciplines or from specialized interest in a topic. However, in comparison with the 26 journals found on the topic of women’s health in Ulrichsweb, there are few journals that focus **solely** on LGBT health, and most began publication in the last ten years. They include:

- *Journal of Gay and Lesbian Mental Health*. Taylor & Francis, 1988-
- *Journal of GLBT Family Studies*. Taylor & Francis, 2005-
- *Journal of LGBT Issues in Counseling*. Taylor & Francis, 2006-
- *LGBT Health*. Mary Ann Liebert, Inc., 2014-
- *Transgender Health*. Mary Ann Liebert, Inc. 2015-

Snyder’s analysis of topics and trends in the biomedical journal literature about LGBT health retrieved over 20,000 articles published in the past 50 years.¹¹ This implies that scholarly biomedical articles about this topic were distributed in journals that were on many other subjects.

There are many other types of sources in which relevant information on LGBT health might appear such as books, book chapters, government reports, popular magazines, blogs, audiovisual materials, and primary source materials. But there is no resource or database that collects citations to all of these information sources and organizes them in a single place. Such a resource would not only be convenient, but increase efficiency in finding information, result in the likelihood of finding more comprehensive information, and help to compensate for the tendency of people to search quickly and superficially. The LGBT Life database from EBSCO covers the topics “family” and “psychology” but not “health.” In fact, there are few compilations

of any information resources related to LGBT health. Links to a selection of consumer health resources are available through organizations such as the National Library of Medicine's MedlinePlus <<https://www.nlm.nih.gov/medlineplus/gaylesbianbisexualandtransgenderhealth.html>>, the Centers for Disease Control <<http://www.cdc.gov/lgbthealth/>>, the Fenway Institute <<http://fenwayhealth.org/the-fenway-institute/>>, Lavender Health <<http://lavenderhealth.org>>, and GLMA <<http://www.glma.org/>>. A search of all "LibGuides" <<http://libguides.com>>, online listings of the main resources for a specific topic or discipline, relays only a small sampling of resources, and they do not explain the complexities of finding more comprehensive information on this specialized topic. A 2008 study of college counseling center websites found "LGBT-targeted communications were the exception rather than the norm."¹² McKay published a more current selected list of 12 websites related to LGBT health.¹³

Books are an accessible and almost universally appreciated source of information for health care providers and consumers. In a study that examined the information-seeking behavior of transgender people, almost half of the respondents reported that books on transgender issues were important to them. Almost one-third of the respondents mentioned autobiographical and biographical accounts, which are commonly found in books, as important information resources.¹⁴ In a 1999 study of two public libraries in England, 44% of the LGB respondents used bibliographies of books that had been compiled about LGB topics; all found them useful.¹⁵ However, there are no current bibliographies of books on LGBT health. This suggests a need for bibliographies that organize existing references to books about LGBT health.

In his study of MEDLINE, Snyder concluded that "the health needs of the LGBT cultural group are not well understood by an analysis of the medical literature," finding little on subjects

other than HIV/AIDS and sexually transmitted diseases.¹¹ He encountered difficulties with searching comprehensively for articles on LGBT health due to database structures and the limitations of subject headings and keyword fields. Others have noted challenges in identifying published resources on LGBT health include the multiplicity of terms that are related and the ongoing evolution of the terminology.^{11,16,17,18,19,20} Daley and Mulé studied gender and sexual identity terminology in the first four editions of the *DSM (Diagnostic and Statistical Manual of Mental Disorders)*, which “has grown into a powerful mechanism that has the means of controlling sexual behavior and defining normative gender concepts and labeling anything that falls outside of this restricted purview as pathologically a mental disorder.”¹⁶ Cizek commented that efforts to improve access to information through thesauri, catalogs, and indexes were somewhat successful only for the topics of “gay men” and “lesbians.”¹⁷ Keilty described the issues in standard library classifications of LGBT-related materials stating, “there are countless examples of how LGBT information is consistently misrecognized and miscategorized.”²¹

Health Information Needs of LGBT People and Health Care Providers

Fikar and Keith identified some of the information needs of LGBT health care professionals. Topics of particular interest were: sexual health and practices, coming out, advance directives, marriage, substance abuse, breast cancer, rectal cancer, anal pap smears for men who have sex with men, adolescent depression and suicide, reproduction, adoption, HIV, hepatitis, immunization, parenting, mental health, domestic violence, loss of a partner, preventive health, transgender surgeries and hormone therapy, and aging.²⁰

Most transgender people in a 2002 study obtained information about identity and issues from the Internet, from transgender friends, and from support groups.¹⁴ Information needs of LGBT people varied based on where they were in the ongoing process of coming out: self-recognition, sharing with other LGBT people, telling close friends/family, positive self-identification, and integration of their LGBT identity.⁹ The information needs of transgender people progressively changed from topics such as acceptance and coming out to public policy concerns. Once they had sex reassignment surgery, respondents reported that they no longer had information needs related to transgender issues.¹⁴ A study reported that young gay, bisexual, and questioning men used sources such as search engines, the National Institute of Health, and Mayo Clinic's site for questions about sex and sexual health. Because of the lack of reliable health information available, the authors of the study suggested that public health practitioners needed to create a reliable information resource that could explain sexuality and sexual health practices.²² Lack of reliable health information is not just an issue for men. A study that examined the amount and quality of sexual health information for lesbians on websites concluded that "not only is there a lack of sexual health information available to lesbians on the Internet but also the information that does exist is often incomplete and written at an advanced level."²³

The health information needs and health information-seeking behaviors of LGBT people vary widely in relation to the context of information need, preferred mode of communication of health information, demographic, and type of sexual minority.^{24,25,26} Men who had sex with men reported that they primarily used search engines and LGBT websites to find sexual health information. Less frequently used were government sites, public media, health insurance websites or emailing a health care provider to obtain sexual information.²⁵ Clearly, there is a

need for better-organized and better quality resources that are customized for individual communities and that address specialized topics.

Research Question

The literature on LGBT health for health care providers and for lay people appears in a variety of types of resources and in many disciplines. To begin to address the need for relevant, easily accessible information for LGBT people and health care providers, this pilot study focused on two questions: (1) What are recent popular and scholarly books relating to health and lesbian, gay, bisexual, transgender, and intersexual (LGBT) people; and (2) What characteristics do these publications have, such as prevalent topics; topics that are missing or less well-represented; number of books published per year; the more prolific authors; and primary publishers?

Identifying books and basic characteristics of this body of literature will begin to organize extant information and help to identify information gaps. Relevant associations, government agencies, publishers, and individuals can use these findings to inform decisions about future publications. Individuals, health care providers, social workers, researchers, and libraries can use the bibliography to learn about LGBT health, to refer books to others, to conduct research, and to build collections.

METHODS

To compile a list of references to recent books that would help address the need for relevant, easily accessible information for LGBT people and health care providers, the Worldcat database

<<http://www.worldcat.org>>, a catalog of publications that includes over 340 million records from thousands of libraries globally, was mined as the data source and authority. The criteria for inclusion in the bibliography were: the most current editions of academic and popular books and reports of 20 or more pages in the English language that were owned by five or more libraries and had publication dates between 2005 and mid-2015. The definition of “health” used was broad and included wellness, disease, medicine, nursing, allied health, mental health, disability, social work, family, aging, violence, bullying, homophobia, heterosexism, and health aspects of social services. Excluded were older editions; book chapters; reprints; special issues of journals; annual series; theses; fiction; audio or video recordings; books on law, politics, policy, literature, religion, general books on HIV/AIDS; and works with a primary focus on groups outside of the United States. Examination of the catalog records of relevant works retrieved by searching commonly used terms resulted in the discovery of additional terms that retrieved other unique records. The screening of each record retrieved ensured compliance with the inclusion criteria. The Appendix lists the terms used for the search strategies. The intent was to compile a comprehensive listing; any omissions within the scope described above were unintentional.

The citations were compiled in a spreadsheet, coded by the author, and sorted by author/editor, year of publication, publisher name, type of publisher, and subject. Fikar and Keith’s list of topics that were important to LGBT health care providers²⁰ was adapted for the subject coding, collapsing some of the related terms under one and supplementing with additional terms that applied to this bibliography.

RESULTS

This section describes the results of analyses to determine which books were published on LGBT health between 2005 and mid-2015, the number of books published each year, characteristics of topics, topics that were missing or less well-represented, and the primary publishers. The bibliography of 521 books compiled using the methods described above is available through the Purdue University institutional repository, e-Pubs, at <<http://docs.lib.purdue.edu/>>.

The total number of books published each year on LGBT health between 2005 and mid-2015 was 521, the average number of books published annually between 2005 and 2014 was 48, and the median was 48. One analysis examined the proportion of books published that were about the health of a specific LGBT population. Almost half of the books were about the general LGBT population (46%, n=241). The highest percentages of books about specific populations were 15% that were about transgender people (n=76) and about gay men/MSM (14%, n=75). The lowest percentage was 2% each about bisexuals (n=9) and intersex (n=11). Juvenile literature and books about youth made up 13% (n=67) of the total. Eight percent (n=42) of the books were about lesbians. The term “biomedicine” included technical books published for an audience of medical professionals and researchers. The term “health” included books published for a lay audience. Although there were only 3 (<1%) books about “homelessness,” it was included as a topic because it is an important issue for gay teens and young people, many of whom are evicted from their family homes and cut off from parental financial support when they come out.²¹

Table 1 shows the results of an analysis of genre: advice books, bibliographies, history of LGBT health, books for youth (juvenile works), and personal accounts (including autobiographic and biographic works). The largest proportion (24%, n=125) were personal accounts. These are important to LGBT health because those in this study deal almost universally with some aspect

of mental health, including psychological adjustment, bullying, prejudice, and coping; or with physical health (i.e., violence, surgery, disease). A study by Taylor reported that books were important for transgender people.¹⁴ Five percent (n=27) were books written for youth. There was only one book-length bibliography (*Top 250 LGBTQ Books for Teens: Coming Out, Being Out, and the Search for Community*), suggesting a need for more works of this type.

[PLACE TABLE 1 HERE]

Legend: TABLE 1. Genre

The next analysis examined the percentage of books published on different topics. These were derived from Fikar and Keith's list of topics that were important to LGBT health care providers²⁰ and enhanced with additional topics reflected in the bibliography. Table 2 shows that most of the books were on the topic of some aspect of mental health, or relationships and family (56%, n=290). Less than half of the books (44%, n=231) were published in other areas identified as important in LGBT health, each representing less than 10% for each topic.

[PLACE TABLE 2 HERE]

Legend: TABLE 2. Book Topics

Routledge (including Taylor and Francis and Haworth) was the most prolific publisher of books on LGBT health, with 46 books. But this represented only 9% of the books published. Associations, centers, government agencies, institutes, and university presses published 27% (n=140) of the books. Of those, university presses published 13% (n=67) of the books.

Notably, 38% of the publishers (n=200) produced only 1 book each.

DISCUSSION

Books are a source of information that provide in-depth information, can be read in private, and do not make judgments about their readers. For those who want information on aspects of LGBT health, that privacy and neutrality are key to the pursuit of learning about a topic.²⁷ This was a preliminary study to address a need for bibliographies of books and provided a preliminary analysis of works published within a ten-year period. The lack of standard terminology for concepts related to LGBT health required a highly iterative search process. The terms included in Appendix 1 may be useful for those interested in pursuing new works and those that did not fall within the scope described above. As the terminology further evolves, new terms can be added to this list.

The number of books found when combining the LGBT-related terms with the health-related terms (Appendix) and published from 2005 to mid-2015 was small, consistently at around 48 per year. Many of these were self-published or published by small presses. There is no predominant publisher for this topic, and the major commercial publishers produce little. Since publishers are market-driven, they may not have uncovered a large enough market to publish books on LGBT health. Research influences the academic market, and the National Institutes for Health, the primary government funder of health-related research, funds very little research on this topic.¹⁰

The prominence of personal accounts as a genre in this study is notable. This implies that telling a person's own story through a book-length account is an important and valued way of

publicly communicating their identity and the accompanying issues and helping others to deal with the same.

Compared with the findings of an Institute of Medicine report that “research has not been conducted evenly across sexual and gender minority populations, with more research focusing on gay men and lesbians than on bisexual and transgender people,”² the books on gay men in this study outnumbered those on lesbians and bisexuality. The number of books on transgender people exceeded all of them. The bibliography developed for this study included scholarly works as well as popular works which may account for the difference in findings. The importance of books to transgender people was reported in the results of a survey in which close to half of the respondents “stated that they consulted non-biographical books for transgender related information.”¹⁴

Of the topics of interest to LGBT health care professionals,²⁰ the following were **not** represented in the bibliography:

- Advance directives
- Breast cancer
- Rectal cancer
- Anal pap smears for men who have sex with men
- Hepatitis
- Immunization

The reason for this could be that the topics are too specific for book publication, but may be represented in the journal literature instead. Also, the search strategy used (see the Appendix) did not include these terms because of their specificity.

There were relatively few books on any topic except “mental health” and “relationships/family.” The Institute of Medicine reported that these topics were important but under-researched.² The findings of this study were similar to Snyder’s, who reported that “overall, very little literature exists on other important disease topics that may affect the LGBT population, such as cardiovascular medicine and cancer.... Parenting and aging are important concerns of LGBT persons, yet, there is little discussion of these topics to date.”¹¹ These are areas in which publishers and authors could fill gaps. There is also a need for books for teachers about LGBT students in their classrooms, for education administrators on LGBT-friendly policies for schools, and on including education about LGBT students and issues in teacher preparation programs. LGBT teens experience bullying and stigmatization in school that affects their health.¹² Specialized bibliographies and a database on LGBT health would facilitate access to this information.

RECOMMENDATIONS FOR FUTURE RESEARCH

This study could lead to many other studies of the literature on LGBT health with important, practical applications for access to information for LGBT people and their health care providers.

Some recommendations are:

1. Conduct studies of information needs and information behaviors of people who identify as sexual minorities. Use those studies to develop useful information resources.
2. Develop a comprehensive, open access database of citations to international scholarly and popular books, book chapters, reports, theses, literature, fiction, nonfiction, juvenile works, and data sources on LGBT health. Include topics not included in this bibliography

(i.e., health and religion, arts, law, policy). This has been done for other health-related subjects that are widely dispersed in different disciplines and types of publications, for example, LILACS <<http://lilacs.bvsalud.org/en/>>, Native Health, <<https://hscssl.unm.edu/nhd/>>, and Women's Health Research, <http://www.hsrdr.research.va.gov/for_researchers/womens_health/search.cfm>.

3. Prepare bibliographies on specialized topics, e.g., sexuality and sexual health for young gay males.²²
4. Construct a stable and regularly updated website that provides links to LGBT health resources such as associations, health care providers, and conferences. Advertise widely.
5. Construct a thesaurus of relevant terms for use by those who organize information on LGBT health.
6. Analyze personal accounts to identify common and disparate themes, and to identify areas for further research.

CONCLUSION

The literature on LGBT health is an area that would benefit from convenient and comprehensive compilations of resources and analyses of their content and publication characteristics. This study was a first step and resulted in the development of a bibliography of books (<http://docs.lib.purdue.edu/>) that was fascinating for its complexity. The multitude of terminologies, publications found in the literature of many disciplines, and their appearance and importance in scholarly as well as popular literature posed challenges to comprehensive

searching and required a highly iterative process. These are characteristics of an emerging and multidisciplinary field.

Compilations of information are a first step, but are not sufficient. Better ways to communicate health information need to be identified, and need to vary based on preferences of different gender and sexual minorities, ages, levels of education, and other demographics. Health information can influence health behaviors and can therefore have a positive influence on quality of life.

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Table 1. Genre.

Genre	# (%) Publications
Advice	12 (2%)
Bibliographies	1 (0%)
History of LGBT health	13 (3%)
Juvenile	27 (5%)
Personal accounts	125 (24%)
Other	343 (66%)
Total	521 (100%)

Table 2. Book Topics.

Topic	# (%) Bks
Mental health, identity	165 (32%)
Relationships/family	125 (24%)
Delivery of health care	45 (9%)
Biomedicine	29 (6%)
Coming out	31 (6%)
HIV/AIDS	26 (5%)
Education	21 (4%)
Bullying/stigma/violence	18 (3%)
Health	18 (3%)
Homophobia, heterosexism	16 (3%)
Aging	12 (2%)
Substance use	8 (2%)
Disability	4 (1%)
Homelessness	3 (>1%)
Total	521 (100%)

Appendix

Search Terms Used to Identify Books in the Worldcat Database

These are the terms that are related to the concept, "LGBT." They were searched in various combinations in the subject field of the Worldcat database to identify resources for the bibliography. An asterisk at the end of a word indicates a truncation that would include variations on the word stem. An example is "homosexual*" which would retrieve citations that included the keywords "homosexual," "homosexuals," and "homosexuality."

androgeny	homophob*
berdache	homosexual*
bisexual*	intersex*
closeted	lesbian*
coming out	LGBT*
gay, gays, gay parents	non-binary gender
gender ambigu*	nonheterosexual
gender dysmorph*	queer*
gender identi*	questioning
gender nonconforming	same sex
gender variant	sex* ambigu*
GLB*	sex chromosome abnormalit*
hermaphrodit*	sex differentiation disorder*
heterosexism	sex* fluid*

sex* minorit*

transgender*

sex* orientation

transsexual*

sex reassign*

two-spirit

sexual minorit*

These are the terms combined with the above “LGBT” terms related to the concept, “health:”

adjustment

gerontol*

nursing

adolescent*

grief

old age, older people

age factors, aged, aging

handbook*

pleasure

baby boom

health

pregnancy

behavior*

home care

psychol*

bereave*

homeless*

psychotherapy*

bully*

identity

retirees, retirement

caregiver*

intergenerational

safe/unsafe sex

childrearing

intimacy

sex change

community health service*

life style

sex instruction

counseling

manual*

sex reassign*

disabil*

marriage

social work

disease*

medical

stigma*

drug*

medicine

substance

famil*

menopause

surgery

geriatric*

mental health

young adults, youth