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Bibliometric Trends in AIDS Publications

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Bibliometric Trends in AIDS Publications

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Abstract

A bibliometric approach was used to investigate the status of AIDS publications for young people. The population consisted of all books, fiction and non-fiction, dealing with AIDS and cited since 1981 in "Books in Print." The DIALOG on-line version of "Books in Print" was used to obtain yearly publication numbers for both juvenile AIDS books and adult AIDS books. The numbers were analyzed to determine if the growth of juvenile AIDS books was keeping pace with that of adult AIDS books and also with the growth of juvenile AIDS cases reported in the United States. Findings indicated that the number of AIDS books for young people was growing at a rate comparable to that of adult AIDS books. Findings also indicated that the juvenile percentage share of AIDS books compares well to the current juvenile percentage share of reported AIDS cases.

Bibliometric Trends in AIDS Publications

A Graduate Research Paper
Submitted to the
Division of Library Science
Department of Curriculum and Instruction
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Master of Arts

UNIVERSITY OF NORTHERN IOWA

by

Vicki Jo Shepard

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Abstract

A bibliometric approach was used to investigate the status of AIDS publications for young people. The population consisted of all books, fiction and non-fiction, dealing with AIDS and cited since 1981 in Books in Print. The DIALOG on-line version of Books in Print was used to obtain yearly publication numbers for both juvenile AIDS books and adult AIDS books. The numbers were analyzed to determine if the growth of juvenile AIDS books was keeping pace with that of adult AIDS books and also with the growth of juvenile AIDS cases reported in the United States. Findings indicated that the number of AIDS books for young people was growing at a rate comparable to that of adult AIDS books. Findings also indicated that the juvenile percentage share of AIDS books compares well to the current juvenile percentage share of reported AIDS cases.

This Research Paper by: Vicki Jo Shepard

Titled: Bibliometric Trends in AIDS Publications

has been approved as meeting the research paper requirement for the
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Chapter 1

Introduction

Publishing for juveniles reflects the problems and attitudes of the society in which they are created. In the past, these publications have dealt with such issues as divorce, teen pregnancy, child abuse and suicide. Today's society faces a new and deadly problem -- acquired immune deficiency syndrome, more commonly known as AIDS.

AIDS is an ever-growing problem with constantly changing demographics. What started out as a predominantly homosexual disease has rapidly spread to an epidemic that cuts across all lifestyles and age groups. AIDS victims are a group as diverse as the general population. In 1990, the National Research Council reported:

We do not know what effects this epidemic will ultimately have. The available evidence indicates, however, that the swathe cut by this disease is widening and, despite considerable efforts to retard the spread of HIV infection, it is likely that morbidity and mortality from HIV infection will continue throughout the 1990's. (p. vii)

Most experts feel that the answer to the AIDS epidemic lies in educating the public. This means getting information into the hands of those who are most at-risk. Toward this effort, the number of AIDS publications has grown rapidly since the discovery of AIDS in 1981. Most of the first publications were aimed at the earliest at-risk groups: young homosexual men, intravenous drug users and hemophiliacs.

As the AIDS epidemic has grown and spread, the at-risk groups have changed. Many experts now list children and adolescents among the AIDS-

vulnerable groups. Reported AIDS cases among young people (under the age of 30) have grown from 209 in 1981-82 to 8546 in 1992 (Statistical Abstract, 1993, p. 134). Unfortunately, it does not appear that AIDS publications aimed at young people have kept pace with the epidemic.

Purpose of the Study

This research study attempted to show that there is a dearth of books for juveniles dealing with AIDS and the AIDS epidemic. While many AIDS publications for adults have been written and published in the relatively short history of the disease, AIDS publications for children and adolescents are lacking. How does the number of books published for juveniles dealing with AIDS compare with the number of AIDS books published for adults?

Hypotheses

1. In the years since the discovery of acquired immune deficiency syndrome (AIDS), adult books dealing with AIDS have grown at a rate that is double that of juvenile books dealing with AIDS.
2. Since 1981, the ratio of juvenile books about AIDS to adult books about AIDS has not increased in proportion to the ratio of juvenile cases of AIDS to adult cases of AIDS.

Assumptions

For the purpose of this study, the researcher assumed that the majority of new books published each year are cited in Books in Print. Books are designated by publishers for age groups such as "juvenile" or "young adult" which are reflected in the Books in Print citations. It is assumed these

designations accurately reflect the researcher's use of these terms. Also, the researcher assumed that books are one source that can provide the information needed by juveniles to become educated about the impact of AIDS.

Significance of the Study

Acquired immune deficiency syndrome (AIDS) is a deadly and ruthless disease. As yet, there is no known cure. Until one is found, society's only hope of slowing, or perhaps even stopping, the spread of this disease is education. In order to educate the population information must be available in all locales and at all levels. "One ray of light in all this is that a number of publishers have begun to produce some fine AIDS-related materials" (Eaglen, 1990, p. 105).

Unfortunately, the spread of AIDS is constantly changing. In the early 1980s, when the AIDS virus was first discovered and documented, the majority of victims were young homosexual males. Data from bibliometric studies about the amount of publishing on a subject can provide an indication of society's need for information and concern about a problem. The early publications dealing with AIDS were directed at a specific audience, written by, for or about homosexuals and the homosexual community of the 1980s.

The demographics of AIDS in the 1990s are changing. Medical science is finding that "the two most at-risk groups in the 1990s are projected to be infants and teenagers" (Eaglen, p. 105).

In order to deal with the changing demographics of the disease, AIDS publication trends should be changing as well. This research study attempted to show whether the numbers of AIDS publications are changing to show the new at-risk status of children and young adults. This study attempted to document the growth, or lack of it, in juvenile AIDS publications by investigating the actual

numbers of juvenile AIDS books.

Definitions

Human immunodeficiency virus (HIV) is a virus that attacks selected cells in the human immune system. It is considered to be the causal agent of acquired immune deficiency syndrome (AIDS), which is a progressive and fatal destruction of the human immune system.

In this study, AIDS publications were defined as fiction and non-fiction books dealing with the subject of AIDS.

For the purpose of this study, children were defined as persons under the age of 12. Young adults were defined as individuals in the 12-17 year age range and adults were defined as persons 18 years of age or older.

In this study, juvenile publications were defined as books written for children and young adults and adult publications were defined as books written for persons 18 years of age or older.

Limitations

This research study was concerned solely with AIDS publications, fiction and non-fiction books, written since the 1981 discovery of the AIDS virus and cited in Books in Print. Even though there are growing numbers of pamphlets, videos and films dealing with the subject of AIDS, the bibliographic control of such media is not as complete as that of book publications.

Chapter 2

Literature Review

Acquired immune deficiency syndrome (AIDS) is the medical phenomenon of the Information Age of the late 20th century. It has had a brief, well-documented history and has been the subject of world-wide conferences and seminars. AIDS is a topic familiar to most Americans. In the midst of this Information Age, AIDS continues to spread, death tolls continue to rise and the youth of today are at greater risk than ever before of contracting the AIDS virus. In this literature review, the researcher briefly discusses the history of the AIDS epidemic and its demographics, the need for AIDS publications aimed at children and young adults, and the way bibliometrics can document this need.

AIDS is a relatively new disease. The first documented cases occurred in 1981, when unusual cases of Kaposi's sarcoma (a rare form of skin cancer) and pneumocystis pneumonia were discovered among young homosexual men. These cases were unusual because they occurred in previously healthy young men. Upon further study, doctors discovered that all of these patients suffered from severe immune system damage. In 1982, after many similar cases were documented, the disease affecting the human immune system and causing the pneumonia and sarcoma was termed acquired immune deficiency syndrome, or AIDS (Malinowsky and Perry, 1991).

At first, the disease seemed to be contained to small at-risk groups: young sexually-active homosexual males and intravenous drug users. In late 1982, however, the Center for Disease Control (CDC) reported cases of possible transfusion-related AIDS (Malinowsky and Perry), sending the nation

into a panic. AIDS suddenly became a household word.

America could no longer ignore this disease; it would not go away. News of it was cropping up everywhere. In July 1985, actor Rock Hudson went public with the news that he was suffering from AIDS. His acknowledgement made the public more aware and helped to generate funding for AIDS research.

For a long time the publicity seemed to create more fear than understanding. When AIDS seemed to be no longer restricted to small at-risk groups, the public felt the need for more restrictions and regulations. In many parts of the country schoolchildren carrying the AIDS virus were barred from school (Thomas, 1985, p. 24).

The best known example of this type of discrimination is the case of Ryan White. White was a 13-year old hemophiliac living in Kokomo, Indiana, when he discovered that he had contracted AIDS, probably from a clotting agent administered during an earlier bleeding episode. Returning to school after this discovery was no easy matter. In Ryan White: My Own Story (1991) he recounts:

We began a series of court battles for nine months, while I was attending classes by telephone. Eventually, I won the right to attend school, but the prejudice was still there . . . because of the lack of education on AIDS, discrimination, fear, panic and lies surrounded me. (p. 258)

White and his family eventually moved from Kokomo to nearby Cicero and encountered an atmosphere of educated understanding. White became a sort of "poster boy" for AIDS patients and AIDS research. He attended many fund-raising benefits and was befriended by celebrities, including Michael Jackson and Elton John. White, who died in 1990 at age 18, helped to dispel many fears and myths about AIDS (White and Cunningham, 1991).

Throughout this time period, government officials and the medical

community could not agree on how to handle the nation's fears and misunderstandings about AIDS. In February of 1987, the Center for Disease Control (CDC) suggested mandatory blood testing for pregnant women, couples applying for marriage licenses, people seeking treatment for sexually transmitted diseases and anyone admitted to hospitals. Many people in the medical field feared that this plan would backfire, causing more fear and more reluctance to seek medical help. LeRoy Walters, a bioethicist at the Kennedy Institute of Ethics, stated, "We need public education that is specific, that is pervasive and that reaches down to young people in the elementary-school years" ("Mandatory Testing," 1987, p. 22).

By 1988, the nation's desire and need for AIDS information was so great that an eight-page booklet was mailed to 107 million households in the United States, under the direction of then-Surgeon General C. Everett Koop. Koop reported, "We are taking this step because the epidemic of misunderstanding about how AIDS is spread seems, at times, as difficult to control as the epidemic itself" ("Must Reading," 1988, p. 73).

As the epidemic moved into the 1990s, the demographics shifted toward other groups in the general population. In June of 1990, officials estimated that 6,000 to 20,000 American children were infected with HIV, the forerunner of AIDS (Malinowsky and Perry, 1991, p. 25). In fact, a congressional report issued in April of 1992 warned that HIV is "spreading unchecked among the nation's adolescents, regardless of where they live or their economic status" ("Teenagers and AIDS," 1992, p. 45).

As the demographics shift, so must the thrust of AIDS publications. It is no longer sufficient to aim AIDS materials at just those groups deemed at-risk when the AIDS virus was first discovered. "There is a great need in communities to

have as much information as possible available to them on the subject of AIDS” (Cowen and Rix, 1991, p. 31).

Nowhere is the need for AIDS information more vital than in materials for children and adolescents. With children becoming sexually-active at younger and younger ages, AIDS information is crucial. “Since the introduction of the AIDS virus into both the homosexual and heterosexual populations, death has become an accomplice to sexual ignorance and misinformation. No longer can our discomfort simply confuse our children; it can kill them” (Bradburn, 1990, p. 34). As early as 1988, AIDS had become the sixth leading killer of 15 to 24 year olds (“Trends in AIDS,” 1990). Many experts feel that, given the increase in teen sexual activity and AIDS’ relatively long incubation period (five to ten years), lack of juvenile AIDS publications now could lead to alarming increases in AIDS in the near future. In “Sex, Lies and Young Readers At-Risk,” Francis Bradburn (1990) contends that “providing fiction and non-fiction materials about people living with AIDS or affected by AIDS is one of the most effective tools we can give young people” (p. 37). To the many parents and educators who hope that science and health curricula will fill this need Bradburn points out:

If young people are going to avoid risky behaviors, they must have the information that makes this possible. While human sexuality curricula and books about AIDS for children and teenagers are vital in this quest for information, general library information that youth can check out as the need arises is especially important. (p. 38)

In order to increase and improve the AIDS information available to young people, bibliometric studies need to be undertaken. Bibliometrics, simply put, is “the statistical or quantitative description of a literature - ‘literature’ taken here to mean, simply, a group of related documents” (Nicholas and Ritchie, 1978, p. 9). Very few bibliometric studies have been done in the field of AIDS literature. One

study has been done dealing with the frequency of journal articles on the subject of AIDS. According to the authors, "measures were taken of the numbers and variety of scholarly journals, and the amount, and change in the intensity of clustering" (Brooks, Bierbaum and Brooks, 1990, p. 197). The researchers concluded that during the study period of 1986-1989 the AIDS literature studied showed signs of becoming a maturing literature. This process is "characterized by a large number of tangentially related journals being reduced to a smaller number of heavily productive journals" (p. 197). This researcher did not find, however, any bibliometric studies of book publications dealing with AIDS. A bibliometric study of juvenile books on AIDS could reveal the strengths or weaknesses in the current status of AIDS publications for young people. Although AIDS is a relatively new health threat to young people, the need for ample and accurate information is great.

Chapter 3

Methodology

A bibliometric approach was applied to the study of AIDS publications for children and young adults. The population for this study was all books cited in Books in Print since 1981 and dealing with the AIDS disease. Books in Print is a comprehensive source of information on nearly all books published in the United States. It contains bibliographic records for books in print or about to be printed from 22,000 different publishers.

The researcher employed the DIALOG on-line version of Books in Print (File 470) to obtain the number of AIDS publications cited each year since the discovery of the AIDS virus in 1981. The DIALOG Books in Print database uses a logical search and sort process to obtain the number of publications dealing with an indicated subject released in a given year. In this study, the researcher searched by publication year (1981 through 1993), Library of Congress subject heading (AIDS (w) Disease) and intellectual levels (juvenile, young adult or all). The search and sort procedure for each publication year resembled the following:

S1	AIDS (W) DISEASE	Searches for all books dealing with AIDS
S2	S(ort) S1/1993	Sorts out only AIDS books published in 1993
S3	S2 AND IL=JUVENILE	Searches for 1993 juvenile AIDS books
S4	S2 AND IL=YOUNG ADULT	Searches for 1993 young adult AIDS books

The S3 and S4 numbers were totaled to figure the number of juvenile AIDS publications in 1993. This number was subtracted from the S2 number to figure the number of adult AIDS publications for 1993.

The procedure was continued for each year back to 1981. The subsequent results were sorted and analyzed by the researcher to examine the amount of growth from year to year and to compare the juvenile and adult percentage shares of the total yearly publication numbers to the percentage shares of juvenile and adult AIDS cases.

In order to figure year-to-year growth in AIDS publications for a specific year, the researcher subtracted the previous year's number of AIDS publications from the given year's number of AIDS publications and then divided this difference by the number of AIDS publications from previous year. This yielded the percent gain or loss from the previous year.

To figure the percentage shares of juvenile and adult AIDS publications both the juvenile and adult number of AIDS publications for a given year were divided by the total number of AIDS publications for that year.

In order to find the percentage shares of AIDS cases, the researcher used data gathered by the Center for Disease Control (CDC) as reported in the Statistical Abstract of the United States (1991, 1992, 1993). Due to the way this data was reported, the researcher split the data into two categories: persons under the age of 30, and persons 30 years of age and older. The percentage share calculations were figured in the same manner as with the AIDS publication percentage shares.

Chapter 4

Analysis of the Data

In the course of gathering data for this study, the researcher encountered few unforeseen problems. The DIALOG on-line version of Books in Print allowed quick and relatively easy access to the yearly numbers of AIDS books published. The “intellectual level” feature of the search-and-sort process allowed the researcher to separate juvenile and adult publication numbers.

The only problem the researcher encountered was trying to access yearly reports of new AIDS cases that were grouped by age level. This sort of grouping is necessary in order to compare publication percentage shares to AIDS patient percentage shares. The researcher chose the Center for Disease Control (CDC) figures reported in the Statistical Abstract of the United States (1991, 1992, 1993). This data is grouped by age level; however, the age groups differ from those in the researcher’s definitions of “juvenile” and “adult.” Since the CDC figures are split into numerous age groups (for example: under five years old, 5 to 12 years, 13 to 29 years, 30 to 39 years, 40 to 49 years), the researcher chose to split the figures into two groups: under 30 years of age, and 30 years of age and older. Because of the long incubation period for AIDS, many of those in the upper end of the 13 to 29 year age range may have contracted the disease while still in their teens.

Prior to conducting this study, the researcher hypothesized that adult books about AIDS have grown at a rate that is double that of juvenile books about AIDS. According to the data gathered from Books in Print on the yearly numbers of AIDS books published since 1981, growth for both juvenile and

adult AIDS books has been quite uneven (Table 1). One year may show a growth rate of 80% from the previous year and be followed by a 50% decrease the next year. The large growth and loss rate numbers belie the actual status of AIDS publishing. Whereas the growth and loss numbers are large, the actual numbers of yearly AIDS publications are quite small.

Table 1
Yearly Change in AIDS Book Publications

Year	# Juvenile AIDS Books	% Gain or Loss	# Adult AIDS Books	% Gain or Loss
1981	0	---	0	---
1982	0	---	0	---
1983	0	---	6	---
1984	0	---	8	33%
1985	0	---	13	62.5%
1986	5	---	32	146%
1987	7	40%	39	22%
1988	14	100%	30	-23%
1989	12	-14%	32	7%
1990	15	25%	37	16%
1991	10	-33%	28	-24%
1992	18	80%	33	18%
1993	9	-50%	25	-24%
Mean % Gain or Loss		21%		23%

Source: Books in Print, DIALOG version

Examination of the yearly publication numbers revealed a wide range of growth and loss rates in adult AIDS books (from 146% gain to 24% loss) and a mean yearly gain of 23% over the course of ten years. The situation was quite similar for juvenile AIDS books. The figures ranged from 100% gain to 50% loss with a mean yearly growth rate of 21% over seven years. Upon comparison of mean yearly rates of growth (23% for adult AIDS books to 21% for juvenile AIDS books) the researcher rejected the first hypothesis.

The other hypothesis that the researcher formulated prior to this study concerned the comparison of the juvenile-to-adult ratio of AIDS books to the juvenile-to-adult ratio of AIDS cases. The researcher hypothesized that the ratio of juvenile AIDS books to adult AIDS books has not increased in proportion to the ratio of juvenile AIDS cases to adult AIDS cases.

Table 2

Yearly Breakdown of Number of AIDS Book Publications

Year	Total # AIDS Books	# Juvenile AIDS Books	% of Total	# Adult AIDS Books	% of Total
1981	0	0	---	0	---
1982	0	0	---	0	---
1983	6	0	0%	6	100%
1984	8	0	0%	8	100%
1985	13	0	0%	13	100%
1986	37	5	14%	32	86%
1987	46	7	15%	39	85%
1988	44	14	32%	30	68%
1989	44	12	27%	32	73%

Table continued from page 14

Year	Total # AIDS Books	# Juvenile AIDS Books	% of Total	# Adult AIDS Books	% of Total
1990	52	15	29%	37	71%
1991	38	10	26%	28	74%
1992	51	18	35%	33	65%
1993	34	9	26%	25	74%

Source: Books in Print, DIALOG version

According to the data, the ratio of juvenile AIDS books to adult AIDS books has remained fairly constant (Table 2). The juvenile percentage share of AIDS books has stayed between 26 and 35% of total AIDS publications for the last several years. The figures on yearly reported AIDS cases (Table 3) reveal the same information. Reports of AIDS cases in young people (under 30 years of age) have remained consistent since the discovery of the disease. The percentage share for young people has remained between 19 and 25% since 1981. If any trend is to be noted it is that the yearly percentage share for young people has been slowly decreasing the last few years. Due to this evidence, the second hypothesis is also rejected

Table 3
Reported AIDS Cases, by Year

Year	Total # AIDS Cases	# Cases Under 30 Yrs.	% of Total	# Cases 30 & Over	% of Total
1981-82	839	210	25%	629	75%
1983	2059	489	24%	1570	76%
1984	4442	1006	23%	3436	77%
1985	8210	1809	22%	6401	78%
1986	13,147	3004	23%	10,143	77%
1987	21,088	4681	22%	16,407	78%
1988	30,719	6914	23%	23,805	77%
1989	33,595	7322	22%	26,273	78%
1990	41,653	8837	21%	32,816	79%
1991	43,701	8519	19%	35,182	81%
1992	45,472	8546	19%	36,926	81%

Source: Center for Disease Control

Chapter 5

Conclusions, Recommendations, Summary

Upon examination of the yearly AIDS publication numbers it appears that AIDS publishing for young people (and, for that matter, adults) is still largely an untapped field. Although the number of AIDS books has grown over the years, it hardly seems to reflect the size of the health threat that AIDS poses to our society. In 1993 only 34 books dealing with AIDS were published in the United States and of that number, only nine were books aimed at young people.

This information suggests a couple of possible conclusions. Perhaps, once the initial stage of fear and panic passed, the effort to educate the public worked and people stopped seeking information about AIDS. Or perhaps the public is satisfying its need for information about AIDS through other media - films, videotapes, pamphlets, newspapers and magazines.

Even though the actual numbers of yearly AIDS publications are low, the percentage split between juvenile and adult AIDS books is keeping pace with, if not exceeding, the percentage split of AIDS cases in young people and adults. This could reflect the tremendous effort to educate the public about AIDS and about the risky behaviors that could lead to AIDS. More likely it reflects the long incubation period for AIDS (five to ten years). The number of reported AIDS cases will continue to climb for several years before the efforts at education will show much effect.

The researcher has two recommendations for further study in this area. Since AIDS is a relatively new disease with a long incubation period, it might be interesting and educational to replicate this study in ten or fifteen years and

compare those results to the ones found in this study. It might also be interesting to conduct the same kind of study on AIDS materials in other media formats - videotapes, films, etc. The results could be enlightening and might give a better picture of the true status of AIDS information available to the public.

This study investigated the status of AIDS publications in the United States. The researcher was concerned solely with the growth of books, both fiction and non-fiction, dealing with the subject of AIDS and aimed at young people. A bibliometric approach was used to ascertain how the growth of AIDS books for young people compared to the growth of AIDS books for adults and whether the growth of AIDS books for young people was keeping pace with the growing number of AIDS cases reported among young people. The researcher obtained yearly publication numbers of AIDS books for young people and for adults by utilizing the DIALOG on-line version of Books in Print. These numbers were compiled and analyzed to find year-to-year growth rates in both juvenile and adult AIDS books. The percentage shares for juvenile and adult AIDS books were also compared to the percentage shares of juvenile and adult cases of AIDS. After analyzing the data, the researcher found that the number of juvenile AIDS books has grown at approximately the same rate as the number of AIDS books for adults. Furthermore, the evidence indicates that the ratio of juvenile AIDS books to adult AIDS books compares favorably to the ratio of juvenile AIDS cases to adult AIDS cases.

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