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>
> **Barbara Seitz de Martinez**
>
> SALIS Chair, 2017

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The *Substance Abuse Library and Information Studies* is the eProceedings of the 39th Annual Conference, entitled *Real Health: The Importance of Professionals in Today's Information Climate,* organized by the Substance Abuse Librarians and Information Specialists (SALIS) partnering with the Association of Mental Health Librarians in Worcester, MA, May 3-6, 2017.

SALIS is an international association of individuals and organizations with special interests in the exchange and dissemination of alcohol, tobacco, and other drug (ATOD) information (salis.org).

Climate change: History in the making

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> "*Life is not what one lived, but what one remembers and how one remembers it in order to recount it*"
>
> (Gabriel García Márquez)

Introduction

"We are making history!" This enthusiastic comment, though announced solemnly by a conference attendee at the 36th Annual Conference of the Substance Abuse Librarians and Information Specialists (SALIS), was one of the key factors that inspired founding the *Substance Abuse Library and Information Studies* (or SALIS Journal for short). The history of the field was the theme of the successful event hosted by the Rutgers Center of Alcohol Studies in 2014.

The main purpose of launching the publication was, and still is, to make available some of the vast knowledge and experience each conference reveals for those members who are unable to attend. True to its original mission, the *SALIS Journal* has grown over the years, adding a scholarly perspective to the conference issue of *SALIS News*. Most recently, the *SALIS Journal* also includes publications by our colleagues from the Association of Mental Health Librarians following the first joint conference of the two organizations in Denver, Colorado in 2016.

It is my great honor and pleasure to welcome readers to browse the fourth issue of *Substance Abuse Library and Information Studies*. Partnering with the Association of Mental Health Librarians for the second time in 2017, the joint conference was hosted by AMHL in Worcester, MA, May 3–6, 2017, with the title "Real Health: The Importance of Professionals in Today's Information Climate."

Climate change in ATOD libraries

Since the inception of the *SALIS Journal,* our field has seen a lot of changes in just four years. The founding editors are obviously biased to point out first the one that had caused the biggest transformation in their careers, i.e., shutting down the Information

Services Division and Library at the Center of Alcohol Studies at the end of 2016. Originally at Yale, the birthplace of what we know as modern-day addiction studies, the Rutgers Center had to sacrifice significant portions of its operations, due to a change of the reporting structure to Rutgers, the State University of New Jersey. The ripple effect of a major change like this on the profession in general and on SALIS specifically is to be mapped for a long period.

The conference venue in 2017, however, also brings up pleasant memories from the 2014 Rutgers conference. A panel discussion was dedicated to one of the founding fathers of alcohol studies, E. M. Jellinek, who spent a significant amount of his time in Worcester, MA before becoming renowned about his new scientific approach to alcohol. It was an extremely sad moment to realize that none of the librarians chasing *Bunkyana*, as we have come to refer to artifacts related to Jellinek's life, would be able to make it to the conference. No one would have the chance to breathe the air at the former Worcester State Hospital in Massachusetts, where Bunky pursued his research and creative interests at the psychiatric facility.

The founding editors of the *SALIS Journal* were not the only ones unable to attend in 2017. Other members of the editorial board and many "frequent flyers", i.e., seasoned SALIS conference presenters might have experienced similar difficulties and missed the event. Additionally, a fair amount of the presenters chose to opt out of publishing in the *SALIS Journal,* which is understandable, given the circumstances and the various stages the presenters are in their career. Hence this skinny fourth volume: it is significantly shorter than any of the previous three.

Missing the opportunity to present a paper or poster at a conference is one thing, but it probably damages individual careers only. Failing to be there for other presenters as an editor during the discussion also results in missing out on the advantages of informal solicitations of articles. Without a face-to-face opportunity to encourage presenters to write up their talks and convince them to submit to the *SALIS Journal* soon after the conference, the momentum seems to have been lost in 2017 for both the author and the editor.

Even though it was a joint conference of two "small but influential" organizations, as we often call them, the question might arise as to whether there is a genuine need for a journal, a conference, or, *horribile dictu*, the organization in the current information climate with a relatively low level of output. It is outside the scope of a short editorial to answer the question, however, a significantly shorter issue of the conference proceedings might be a telltale sign that calls for concern and further discussion on the survival of SALIS and AMHL in the current information climate.

How is the current information climate?

Before considering the options and potential solutions, any organization in a similar situation will probably have to do their homework first. It seems, however, that assessment criteria for success of scholarly societies and professional organizations are few and far between. In addition, there lingers the eternal question for the overworked information professional: Is this the best use of my time? At the end of the day, it boils down to the everlasting dilemma: Are we making a difference? Or if we wish to overstress, no pun intended, is it even possible to make a difference in the current information climate? What is the current information climate like anyway? How is it changing? How does it change our field?

Similar questions were in the focus of the presentations and discussions at the 39th SALIS/AMHL conference in 2017, as reflected by the articles and short communications in this issue. Serving as prime opportunities for professional development, SALIS conferences in the past were traditionally divided into two main tracks: addiction science and library and information science. Local conference hosts always excelled in finding the perfect local experts to match the interest of their audiences and fulfill the professional needs of attendees. The conference program in 2017 continues this tradition.

Section 1: On the current information climate

Among the presentations by researchers, a group from Harvard focused on the pressing issue of the 21st century plague of information science, "fake news", by offering their own emerging hypothesis. In their paper entitled "Public health, social networks, and the digital media ecosystem: Emerging hypotheses" authors Brittany Seymour, Natalie Gyenes, Hal Roberts, Sands Alden Fish II, Fernando Bermejo, and Ethan Zuckerman compare online public health information ecosystems to complex social networks in terms of behavior. Using Media Cloud, a global archive of more than 500 million online publications, they completed over 150 case studies, including public health topics, benefiting from the open source platform developed by the Harvard Berkman Klein Center for Internet and Society and MIT Center for Civic Media. In a world of rapid and extensive spread of misinformation, the Media Cloud project in public health research should definitely remain on the SALIS/AMHL radar.

Written by Amy L. Harrington, the second paper in this section entitled "The opioid epidemic: History and current treatment" gives an overview of the current opioid epidemic including both background and treatment options. Shedding light upon the significant role of physicians and pharmaceutical companies, the author suggests personalized treatment plans combining available treatments based on the individual needs of their patients, selecting from options of medication-assisted and psychosocial methods as well as other strategies, such as harm reduction.

The third article entitled "Activist Librarian II: Engaging in LGBTQ Cultural Competencies" by Juan Carlos Vega provides the reader a glimpse of the author's journey during his career as a librarian and activist in understanding LGBTQ cultural competencies. Highlighting LGBTQ health disparities is followed by the discussion of the role of librarians and information specialists as catalysts with the strong potential of bringing competency to reduce these health disparities in their communities. One of the reviewers had a comment worth mentioning, she expressed her wish to read the article "Activist Librarian", a lost opportunity for a publication that could have been written based on the author's presentation at the 32nd Annual SALIS Conference, if the *SALIS Journal* had been in business at that time.

Section 2: Follow-up and brief reports

The next section of this issue follows a tradition established at SALIS conferences and adopted by the *SALIS Journal*. In general, these brief communications follow up on previous presentations, projects, and other sessions of interest to SALIS and AMHL members.

Len Levin and Zlatina Kostova share their experience with "Designing a web portal for persons with serious mental illness." As their subtitle "Design considerations based on the literature, focus groups and an expert users survey" suggests, they have been

accumulating invaluable knowledge while working on their three-year project supported by a grant from the National Library of Medicine/National Institutes of Health. As participants of one of their focus groups, many SALIS/AMHL members are looking forward to the deliverable, an online resource that persons with mental illness can use to learn skills to more fully understand and address physical health issues they experience.

Last but not least, members will probably give a hearty welcome to a new installment from the SALIS Digs Team, an update on the SALIS Collection at the Internet Archive. With a noble aim to create an ATOD digital archive of books and government documents, the SALIS Digitization Project has been going on for over four years now in partnership with the San Francisco-based Internet Archive. Written by Sheila Lacroix, Andrea L. Mitchell, and Barbara S. Weiner, "Creating a SALIS legacy: Building an Alcohol, Tobacco and Other Drug (ATOD) archive with knowledge for all" points out the importance of this project in the current information climate. Amidst the closures of ATOD libraries and other climate changes, the small, international team is strongly committed to promote this innovative method of providing access to the literature.

Calling all SALIS members, again

Augmenting, perhaps ambitiously, the original aim to offer valuable content for those unable to attend the conference, the founding editors of the *SALIS Journal* wish to express their desire to engage more members to contribute to the next issue with their scholarly articles. If supported and approved by the SALIS Board,

a more inclusive call for publication might invite authors to submit their articles either on a theme presented at the annual conference or on their own ATOD-related original research conducted during the year.

As shown by the previous three issues, the variety of topics, perspectives, styles, language and tone in the *SALIS Journal* is meant to represent SALIS, a group of librarians and information specialists proud to belong to an international, multicultural, and multi-disciplinary organization. Bridging gaps between continents and languages, connecting people from a variety of institutions and backgrounds, hopefully, SALIS will continue to make history and a difference in the lives of others. Embracing and promoting all missions of the organization, this SALIS publication, the *Substance Abuse Library and Information Studies*, along with the *SALIS News*, is committed to remain a key contributor to it.

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Public health, social networks, and the digital media ecosystem

Emerging hypotheses

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The rapid far-reaching spread of misinformation has posed challenges for public health. Media Cloud, a global archive of more than 500 million online publications (mainstream media, blogs, advocacy pieces, original research articles, etc.) is an open source platform developed by the Harvard Berkman Klein Center for Internet and Society and MIT Center for Civic Media. Designed to evaluate the media's framing of issues online, the project maps information ecosystems publishing about given topics. To date, we have performed approximately 150 case studies using Media Cloud, including on public health topics such as vaccines and Ebola. Our work supports emerging hypotheses that online public health information ecosystems may behave more like complex social networks, and not merely unidirectional information distributors. Social norms are a strong determinant of group behavior, and future research can assist in addressing the determinants of online health misinformation by studying the dynamics of the digital media ecosystem.

Keywords

Misinformation, Health Communication, Internet, Digital Media, Social Networks

Introduction: Digital Pandemics

Dr. Julio Frenk, while Dean of the Harvard Chan School of Public Health, proclaimed in a 2009 NIH Barmes lecture, "During the 20th century alone, the world as a whole experienced a larger gain in life expectancy than in all the previously accumulated history of humankind." This increase is largely attributed to the success of vaccination, named one of the great public health achievements of the 20th century.[1] However, in 1998, a new publication alleged an association between the MMR vaccine and autism.[2] The authors disclosed in the article that they could not claim a causal link,[2] and the paper was eventually found to be faulty and was retracted.[3] Nonetheless, a digital assault on the safety and efficacy of vaccines was eventually triggered, one that began with autism and has since ballooned to numerous other concerns. Celebrities, bloggers, and advocacy groups continued to perpetuate myths and misinformation online. [4] Exemptions from the recommended vaccination schedule nearly doubled in California between 2007 and 2013,[5] and as a result, the U.S experienced the largest measles outbreak in nearly a generation, traced to a case in Disneyland.[6]

Digital assaults do not occur only for vaccines. A controversial article released in 2014 recommended that fluoride (another CDC 'great'[1]) be designated as a developmental neurotoxin in children.[7] Numerous scientists and more recent studies have debunked the claim,[8,9] yet, communities continue to cite the article and related online misinformation as a reason to cease water fluoridation in their municipalities.[10] Misinformation about "quarantines" and "waiting periods" led a New Jersey school to request two healthy children who had moved from Rwanda, a nation with zero cases, stay home during the 2014 Ebola outbreak.[11] A story describing how pharmaceutical companies purposefully engineered the Zika virus to start the outbreak for profit permeated online social networks.[12] These digital assaults, or perhaps more aptly named digital pandemics,[13] and their rapid far-reaching spread of misinformation have posed severe challenges for public health, and corrective information is consistently ineffective.

Methods: The Media Cloud project

Media Cloud, a global archive of more than 500 million online publications (mainstream media, blogs, advocacy pieces, etc.) is an open source platform developed by the Harvard Berkman Klein Center for Internet and Society and MIT Center for Civic Media. The platform was developed to evaluate the media's framing of issues online and to map the information sources publishing about given topics. To date, we have performed approximately 150 case studies using Media Cloud, on topics ranging from Islamophobia to substance abuse to climate change. For each case study, we developed a query using Boolean keyword strings within a defined date range. For example, in our vaccine case study, we searched for content online containing words that begin with the stem 'vaccin', from June 1, 2014 to March 1, 2015. We built on the initial set of content by identifying each hyperlink citation embedded within the text and downloading additional relevant content into our dataset. This hyperlink technique was repeated to produce a comprehensive 'spidered' database.

Media Cloud tools have been validated through previous studies and are now automated to allow for large volume data sets (i.e., several thousand to millions of publications). Research team members perform manual validation checks for each case study. Using this technology, we performed hyperlink and word frequency analyses to determine sources citing others through hyperlinks, the frequency with which

these citations happened, and which key terms were commonly used by sources in the information network generated. This allowed us to visually map communities of sources that both linked to one another most frequently, and shared common language to describe the topic at hand. Quantitative analysis of network characteristics allowed us to determine which sources and content were most influential within this media ecosystem for a given case topic.

Results: Network clustering

We have detected preliminary patterns from our case studies. First, we identified sub-communities that formed within each topic

network, based on citations through hyperlinks between content publishers and common language (similar framing) used to describe the topic. Second, we detected information authorities —publishers that are cited or referenced most frequently by others in the network — within each sub-community. Third, we identified that information authorities in different sub-communities linked to one another less frequently than to sources within their own sub-communities. Fourth, each information network contained a distinct and isolated public health sub-community, primarily comprises public health authorities such as the CDC. Figure 1 illustrates three examples by topic of this digital network clustering.
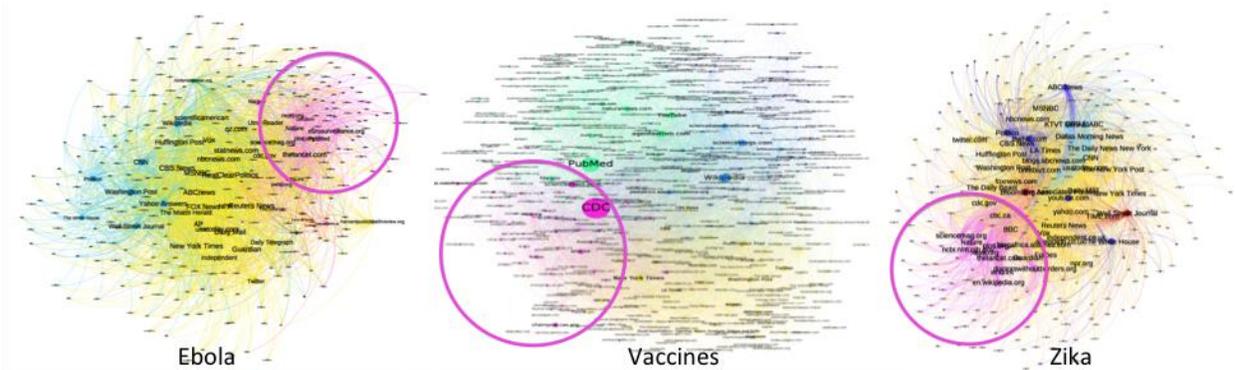

Figure 1. *Three example information networks for public health topics: Ebola, Vaccines, and Zika. Color-coded sub-communities within each topic network demonstrate which sources are linking to one another most frequently and sharing common language and framing of the topic. The distinct public health sub-communities within each information network are circled.*

(Vaccine information network adapted from Getman R, Helmi M, Roberts H, Yansane A, Cutler D, Seymour B. Vaccine hesitancy and online information: The influence of digital networks. Health Education and Behavior 2017; Dec 1.)

Discussion: Social networks in the digital media ecosystem

We were able to visualize these data in information network maps (Figure 1), where digital sources that link to one another most frequently, and utilize similar language to describe a given topic, cluster together. The tight linkage of these sub-communities may make it possible for existing opinions, based more on shared language and values than on fact, to propagate and reinforce each other. The public health sub-communities largely consisted of public health sources linking to other public health sources, which may mean, consequently, insufficient reach to audiences beyond the public health sub-communities. While public health sub-communities are helpful for building public health consensus, their closed nature may prevent the wider dissemination of evidence-based, and corrective information.

When investigating media ecosystems, we can identify information authorities deeply embedded within a given sub-community, indicating that their content is not reaching other sub-communities effectively. Information authorities likely generate a narrative around each topic that dominates their own sub-communities but not others. Our analyses have shown that information echoes from one source to another source within a given sub-community, even when counter to fact. Seemingly, information moves within the digital ecosystem based not on its 'scientific proof' but rather on its 'social proof,' a form of imitation where people ascribe to the behavior of their peers, such as sharing particular content, in order to resolve uncertainty.[14] These are perhaps the reflections of a shared set of social norms within sub-communities.

Conclusion

Our case studies support emerging hypotheses that online public health information ecosystems may behave more like complex social networks, and not merely unidirectional information distributors. We are reminded of Geoffrey Rose's epidemiological thought piece, Sick Individuals and Sick Populations.[15] With sick individuals, he asks, "Why did *this* patient get *this* disease at *this* time." We look at the exposure, and the relative risk of contracting a disease compared to those who weren't exposed. Rose then asserts that for populations, we need to look not at individual risk, but at the determinants of incidence of disease for a population as a whole, and how incidences vary among different communities. "Why do some populations have high rates of a particularly disease while in others, it is rare?" Initially, in the face of digital pandemics, we've been asking, "If the Internet is the exposure, what is the relative risk that someone will encounter misinformation?" However, perhaps we need to take Rose's advice and ask, "For a given topic, why might one online sub-community have higher rates of health misinformation than another? What distinguishes the two groups?" To find the determinants of the illness, he says we must study characteristics of populations, not individuals. He states social norms are a strong determinant of group behavior, and to shift the determinants of incidence of disease, in modern form, we must attempt to alter modern forms of society's behavioral norms.[15] Translating to online networks, we are hopeful the Media Cloud project can assist in addressing the determinants of misinformation by studying the dynamics of the digital media ecosystem.

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The Opioid Epidemic: History and Current Treatment

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The current opioid epidemic in the United States was fueled, in part, by aggressive prescribing of narcotic pain medications in the preceding decade. In addition to heroin, health care professionals are seeing patients who are addicted to prescription opioid medications such as oxycodone and fentanyl. There are many different medications and psychosocial treatments available to treat opioid use disorder. Healthcare professionals can create a personalized treatment plan using a combination of the treatments available based on the individual needs of their patients.

Keywords

Opioids, Buprenorphine, Methadone, Harm Reduction

How did we get here?

Opioids have been used by humans for both euphoric and medicinal reasons for almost 5000 years. Morphine is a naturally occurring opioid synthesized in both plants and animals. Heroin, also known as di-acetyl morphine, is a synthetic drug that is broken down into morphine by the liver after being ingested.

Because opioids are highly addictive, there have been repeated epidemics of abuse. The most recent opioid epidemic stands out for several reasons, including the role that physicians played in the increased rate of prescription of opiates late 1990's. In addition, health care professionals today have many medications and psychosocial treatments

available to them when designing a treatment plan for a patient.

Pain as the 5th Vital Sign

In 1980, a brief letter to the editor was published in the *New England Journal of Medicine.* (Porter and Jick, 1980) The writers of this letter had reviewed 11,882 patient charts of patients prescribed opiates, and found only four cases of documented addiction. The summary sentence of this letter stated "We conclude that despite widespread use of narcotic drugs in hospitals, the development of addiction is rare in medical patients with no history of addiction."[1]

In the 1990's, pain doctors began to advocate for more aggressive treatment of pain, citing the low risk of addiction if opioid pain medications were taken as prescribed for a medical condition. The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) identified "pain" as the fifth vital sign, along with blood pressure, heart rate, respiratory rate and temperature. All patients were asked to rate their level of pain, regardless of the reason that they were seeking health care services. Pharmaceutical companies who used to only market opioid pain medications to oncologists, orthopedic surgeons and other specialists, began to market these medications to general practitioners (Atlantic Monthly, 2017).

The result of these various factors was that prescription of opiates in the United States nearly tripled from 76 million in 1991 to 207 million in 2013. As sales of opioids increased, so did the rate of death attributed to opioid overdose. The rate of death in 2008 for opioid overdose was almost four times the rate of death in 1999 (CDC, 2011).

The Rise of Fentanyl

One aspect of this particular epidemic that has been unique is the increased recreational use of fentanyl and related drugs. Fentanyl is a synthetic opiate that has a potency 50-100 times greater than morphine (NIDA, 2016). It was designed to be used for cancer pain and other forms of severe pain. Someone who is ingesting fentanyl when he believes that he is ingesting heroin is at greater risk of overdose and death. The rise in the rate of overdose from opiates has coincided with the increased rates of recreational use of fentanyl. Other forms of the drug are being seen more in the recreational opioid supply. This includes carfentanil, a drug 10,000 times more potent than morphine that is used as a general anesthetic for large animals, such as elephants (DrugBank, 2017).

What do we do now?

Medication-Assisted Treatment

Medication assisted treatment involves using a prescribed medication to prevent cravings for a drug of abuse, thereby preventing relapse. Medication options for opioid use

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[1] EDITOR'S NOTE: *It should be noted here that in June 2017 NEJM published a critical follow-up letter and an unprecedented editor's note on the online version of the original warning readers that it had been "heavily and uncritically cited" as evidence of the evidence of the rarity of addiction in opioid users. See the follow-up letter here:*

https://www.nejm.org/doi/full/10.1056/NEJMc1700150

and the original letter with the Editor's Note here:
https://www.nejm.org/doi/10.1056/NEJM198001103020221

disorder include a collection of medications like buprenorphine and methadone referred to as Opioid Replacement Therapy, as well as Opioid Antagonist Therapy with medications like naltrexone.

Med	Action at mu opioid receptor
Naltrexone/Naloxone	Antagonist
Buprenorphine	Partial agonist
Methadone	Full agonist

Table 1. Medications used to treat opioid use disorder

Opioid replacement therapy is predicated on the concept that replacing a short-acting opioid like morphine, the active ingredient in heroin, with a long-acting opioid will allow the opioid to be present in the brain at a steady state. The brain does not experience the cycles of intoxication and withdrawal; therefore the patient does not go through the behaviors associated with obtaining opioids that cause the significant morbidity.

Methadone is an opioid with a long half-life, roughly 22 hours. Therefore it can be taken once a day while still maintaining a steady concentration in the body. It is a full agonist, meaning it binds to the mu-opioid receptor and activates it fully. Methadone is dispensed in federally regulated clinics, which means that most patients need to come to the clinic on a daily basis in order to obtain their dose (CSAT, 2005).

Buprenorphine is also an opioid, however it is a partial agonist. This means that it binds to the mu-opioid receptor and only activates it partially. This has the benefit of lower rates of side effects like sedation, as well as lower risk of overdose. Buprenorphine has been available for a long time as a pain medication,

however, if a physician is prescribing it for the purpose of treating opioid use disorder, she must have a special waiver from the federal government.

When buprenorphine is prescribed for the purpose of treating opioid use disorder, it usually contains a second medication called naloxone. The common medication Suboxone is one example of the combination of buprenorphine and the opioid antagonist naloxone. If the medication is taken under the tongue as intended, the naloxone is not absorbed and has no pharmacologic activity. It only becomes active if the medication is taken by another route, such as inhalation or injection. (Chiang and Hawks, 2003)

The combination of naloxone and naltrexone is an opioid antagonist, meaning it binds to the mu-opioid receptor and blocks any activity from happening. Naltrexone is available both as a pill that is taken orally every day as well as a once a month injection known as Vivitrol. Naltrexone has been shown to be effective in reducing use of both opioids as well as alcohol (Krupitsky E, 2011).

Psychosocial Treatment

Medication assisted treatment works best when it is paired with non-medication therapies that focus on changing behavior related to addiction. 12-step programs like Narcotics Anonymous and other mutual support groups such as Smart Recovery have been available for many years. Though research on their effectiveness is mixed (Ferri, 2006), there are a large number of people in recovery who credit these kinds of groups with their success.

Relapse prevention therapy is a form of therapy focused on increasing self-control in order to reduce drug and alcohol use. Contingency management is a form of behavioral therapy that uses positive reinforcement (i.e., financial incentive) to

reward a desired outcome (i.e., negative urine toxicology screen.)

Harm Reduction

Harm Reduction is a strategy that does not aim to eliminate opioid use altogether, rather the aim is to reduce negative consequences and secondary harm from use. Syringe exchange programs are one harm reduction strategy. These are programs where someone can exchange used syringes for new, sterile ones, which decreases the risk of infectious disease transmission from IV drug use (CDC, 2007). Supervised injection facilities (SIFs) are monitored locations for injection drug use where staff can assist in maintaining the safety of the people using the facility. SIFs have been shown to decrease the rates of fatal overdose as well as the risk of victimization and criminal activity (Marshall, 2001).

An important public health development that has been implemented with great success during this opioid epidemic is the dissemination of by-stander administered intranasal naloxone. Naloxone, also known by the brand name Narcan, is like naltrexone in that both are opioid receptor antagonists. Naloxone is used in emergent situations to reverse an overdose. Naloxone can be distributed to non-medical people in the community, and there have been wide-spread efforts to train people on how to use it correctly. Communities where naloxone is being widely disseminated have lower rates of death from opioid overdose than other communities (Walley 2013).

Conclusion

Health care professionals have a number of treatments, both pharmacologic and psychosocial, available to them today. Treatment for opioid use disorder is not "one size fits all." Different people are going to respond better to certain interventions. Some people benefit from the structure of attending a methadone clinic every day. Others do better with the flexibility of an office-based treatment like buprenorphine. People who have problems with adherence may find a long-acting injectable like naltrexone to be beneficial. Some people benefit from the 12-step model of peer support while others have better results with the more therapy-based interventions like relapse prevention therapy. Healthcare professionals can create a personalized treatment plan using a combination of treatments available based on the individual needs of their patients.

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Activist Librarian II

Engaging in LGBTQ Cultural Competencies

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Outside of traditional academic, research, and public library spaces, we can find many opportunities to share with avid information seekers experiences and endless knowledge of available resources; ranging from databases, to websites, to journals, to a community resource, to a chapter in a book. Since my beginnings in alcohol and tobacco control and prevention work in 2001, I have submerged myself in trying to understand LGBTQ cultural competencies to properly serve LGBTQ community members looking to quit smoking and/or how to support the frontline workers looking to serve LGBTQ communities. This paper will explore: 1) the librarian's role as health activist and "real information" facilitator; 2) current LGBTQ health disparities and realities affecting ATOD consumption; 3) cultural competencies to work in LGBTQ communities; and 4) non-traditional health resources available to work with LGBTQ communities.

Keywords

LGBTQ, Tobacco control, Health disparities, Cultural competency, Intersectionality

Introduction

Librarians and information specialists are trained to search databases, identify sources of information, and support the research needs of their clients. In this uncertain moment, when people are questioning what is "real information," we realize librarians have been finding real information already for centuries. What is a reliable source? Who has

authority or subject expertise? Is the author or his/her publications cited frequently by others? Many of us go to traditional sources of information, others go online, while others rely on their personal/professional experiences in the field to identify the resources to answer the user's questions.

As a librarian and information specialist, can you identify a moment when you provided a library user or information seeker with a reference to a resource that you know because you are a member of a community, because you think it is "real information," or because of your own knowledge? Can you identify a community-based organization in your city/county or a leader in a specific community that can be a reference for your patron? Perhaps a spokesperson or champion in a cause that can provide knowledge beyond the graphs and statistics found in journal articles? Do you know your communities' "key informants?"

Back in 2010, during the SALIS 32nd Annual Conference, I provided a broader overview of how librarians can work in their communities and contribute to the national and local public health debate by presenting, *Activist Librarian: Experiences/Observations from an Independent Information Consultant Navigating the Public Health Field*. Seven years later, the call for us to consider how our current work continues to address the health information needs of the substance use and mental health fields allowed me to insert the reduction of health disparities among LGBTQ communities in this year's conversation.

About LGBTQ Communities

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities use a wide range of terminology to identify themselves. Depending on the geographic location, LGBTQ communities use a variety of acronyms and terminology that changes as new generations

of LGBTQ individuals empower themselves to fight homophobia and heterosexist environments. However, most funded research on LGBTQ communities usually does not go beyond LGBT. For the purpose of this paper, the Q signifies *queer* or *questioning* and it was included in recognition of all those individuals that do not identify with the LGBT acronym, but are members of the community, such as intersex and gender fluid. It is important to note that most sources cited here do not include the Q in its findings, data collection efforts, or reports.

But how do LGBTQ communities in your city or state identify themselves? To better understand that, public health advocates and service providers need to insert themselves in the LGBTQ community to identify sexual orientation (lesbian, gay, bisexual), gender roles (masculine, feminine), gender identifier (transgender, transsexual, queer), and other terminology representative of the racial/ethnic, social, and economic variables present in each location. Each of these categories and descriptors vary within each LGBTQ community across the country. National standards only provide a general overview.

Intersectionality is a term coined by civil rights advocates and scholars who recognize that an individual has multiple layers or identities that create the whole. Every individual carries different identities. These identities include race, gender, sexual orientation, age, religion, mental and physical disabilities, among other forms of identity. Recognizing these differences allows for better understanding of the individuals and communities we are trying to serve. LGBTQ communities are diverse and represent more than one single community.

Throughout the world, LGBTQ people face isolation, violence, overt discrimination, and inequitable benefits and policies, affecting

access to health and social services. LGBTQ communities carry a heavy burden of a history that even criminalizes homosexuality, yet strong grassroots structures exists to offer social support, legal assistance, health services, and provide an organized platform to advocate for what LGBTQ communities need. Even with the lack of trust LGBTQ communities feel regarding institutions and the government, partnership with LGBTQ communities continues to be an untapped resource to make changes. Private companies and governments are recognizing the importance of LGBTQ communities by establishing policies that are inclusive. However, the struggle to achieve equality continues to be a barrier, as presented by the nondiscrimination policies showcased in Image 1.
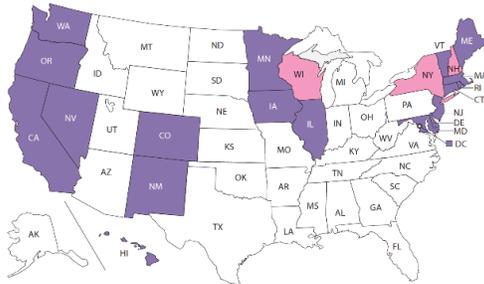

Image 1. The National Gay and Lesbian Task Force State NonDiscrimination Laws in the US map shows in purple the states banning discrimination based on sexual orientation and gender identity. The states in pink shows the states with laws banning discrimination based on sexual orientation.

Hospital and healthcare facilities receiving federal funding are mandated by Obama-era policies that expanded protection for LGBTQ communities. However, current federal government policies seem to be dramatically changing this landscape.

LGBTQ Health Disparities

Research suggests that LGBTQ people face barriers to health care that profoundly affect their overall well-being. Fear of stigma and discrimination because of their sexual orientation or gender identity from healthcare providers and institutions makes it harder for LGBTQ individuals to access care, much less culturally competent healthcare (Institute of Medicine, 2011).

Additionally, national health reports are showing tendencies for higher use of alcohol, tobacco, and drug use as well as higher risk of depression, anxiety, and suicide among LGBTQ communities, especially among youth, trans, and communities of color (US Dept. of Health and Human Services, 2012; Fenway, 2016).

Much is needed to reduce LGBTQ health disparities. The few research studies looking to understand LGBTQ health are limited in scope and many are compromised by the national and state policies that rule the funding. These realities are even more present for LGBTQ youth, who are often left out of the limited current research agenda making their health realities less visible to the public health agenda. Issues like cancer, diabetes, and other chronic conditions, especially among LGBTQ elders, should be studied to maintain a health profile of LGBTQ communities and understand the most appropriate strategies to approach the issues. Due to the lack of research available, libraries and information centers have limited content to share regarding LGBTQ health disparities and need to be creative to satisfy user needs.

LGBTQ Tobacco-Related Disparities

The Centers for Disease Control and Prevention Consortium of National Networks to Impact Populations Experiencing Tobacco-Related and Cancer Health Disparities supports eight national networks that are working to advance the prevention of commercial tobacco use and cancer in populations experiencing tobacco-related and

cancer health disparities. Among network findings, tobacco use is 71% higher among adults with mental illness while African Americans smoke menthol cigarette at nearly three times the rate of Whites (LGBT HealthLink, 2016).

According to the 2009-2010 National Adult Tobacco Survey, LGBT tobacco use is over 50% higher than in the general population. Issues like stigma and youth coming out process are triggers associated with initiation. Bars and clubs have always been a place where LGBTQ individuals gather safely. Yet, these are "safe" spaces with high alcohol, tobacco and drug consumption.

Decades of oppressive policies and institutions make other issues more relevant among LGBTQ communities. Fighting for basic rights like adoption, marriage, hospital visitation, inheritance, bathroom rights, prison treatment of trans individuals, and serving in the military make tobacco control and prevention a secondary issue.

Although the HIV/AIDS epidemic has stabilized for the general population, certain sectors are still experiencing higher rates of HIV infection than others (Gay and Lesbian Medical Association, 2001). The same happens with smoking. While the general population has decreased its cigarette smoking prevalence, LGBTQ communities continue to smoke at alarming rates (LGBT HealthLink, 2016). Unlike other pressing policy issues, smoking is not a priority for LGBTQ communities nor for the government. According to CDC-funded LGBT HealthLink (2014), it took fifty years since the first US Surgeon's General Report on smoking to clearly delineate LGBTQ communities as a population experiencing disparities.

Image 2. Tobacco continues to find ways of maintaining a presence as an ally of the LGBTQ community. Vaporshark Electronic Cigarette is a sponsor of Miami Beach Gay Pride in 2015.

Industry Targeting

For decades, the tobacco industry has been targeting different populations to attract new smokers. They lure LGBTQ individuals to smoke by appealing to the communities with high quality campaigns. Like the alcohol industry, they adorn their campaigns with fight for equality messages and rainbow flag images. Magazine advertisings in LGBTQ publications and financial support to LGBTQ organizations have been some of the tactics used to showcase support to LGBTQ communities. But in reality, these are campaigns to lure new smokers and drinkers. Today, the tobacco industry shows up to LGBTQ Pride events and bars to distribute cigarettes in exchange for contact information to send coupons to purchase cigarettes at a discount.

Before brands and campaigns are released, the industry has performed a detailed marketing study to understand LGBTQ habits and preferences. Dating back to the 1990s, R. J. Reynolds' intentions were to target alternative lifestyle consumers to boost cigarette sales by implementing Project SCUM. Standing for Sub Culture Urban Marketing, it targeted gay men and homeless individuals in San Francisco neighborhoods (Engardio, 2001).

Engaging in LGBTQ Cultural Competency

Any search in journal databases will yield results about what is cultural competency and its importance. Each of the layers of an individual's identity could require a specific cultural competency needed to best deal with their health concerns. Beyond any recommendations provided by researchers, librarians and information specialists can be catalysts who bring competency to reduce health disparities. Traditionally, libraries and information centers have been safe spaces for LGBTQ communities, and beyond any available research on the stacks, our diligence can contribute to inclusiveness. Beyond adding more books with content on LGBTQ issues and bringing LGBTQ speakers to events and programs, institutional policies and administrative procedures can begin inserting data collection language inclusive of sexual orientation and gender identities. Websites, trainings, reports, and funding can be inclusive of LGBTQ needs. Internal hiring, promotion and personnel practices can also institutionalize competencies within an institution.

Departments of health across the country are integrating LGBTQ perspectives and realities into their work. These include the celebration of Pride month, LGBTQ targeted prevention campaigns, LGBTQ specific cessation programs like The Last Drag, and the development of promising practices to target LGBTQ communities. California, Idaho, New York, and Pennsylvania are leading the way in reaching out to LGBTQ communities. Even North Carolina, a state recently perceived as aggressive towards LGBTQ communities due to their restroom policies, is reaching out to LGBTQ smokers using smart phones.

LGBTQ Health Resources

Today's journal databases provide a limited amount of research to understand health disparities as an intersection of various aspects of one individual. Even less information will be available to understand the needs of a geographically limited LGBTQ community unless you are from Chicago, New York, San Francisco or other urban centers. Yet, the best book or journal in the library many times does not come in that format. For librarians and information specialists in any setting, identifying your local resources can be the best sources of information. Following is some recommendations:

- Find out what programs or services your local department of health offers to LGBTQ communities.
- Identify support for you and your clients at the closest LGBTQ community center by searching CenterLink's Directory of LGBT Community Centers at https://www.lgbtcenters.org/
- Find a healthcare professional in the Gay and Lesbian Medical Association Online Provider Directory at http://www.glma.org
- Contact LGBT HealthLink for tobacco and cancer related information at http://www.lgbthealthlink.org, including a Tobacco Free Queers educational campaign.
- Identify culturally competent resources in the Center of Excellence for Transgender Health at http://transhealth.ucsf.edu and the National LGBT Health Education Center at www.lgbthealtheducaiton.org

Conclusion

The current political and economic realities we face today have led me to explore various strategies for my career as a Librarian. Engaging in LGBTQ communities has been an essential part of my career as I strive to reduce health disparities. Identifying LGBTQ communities has not always been easy outside the bars, clubs, and Pride events I visit or find online. LGBTQ resilience to survive discrimination led to the establishment of social and support groups, open-door churches, as well as an extensive media network (print and digital) targeting LGBTQ communities, which today includes social media, LGBTQ health directories, online platforms, and mobile applications that can be accessed for health prevention efforts.

It is important to remember that LGBTQ health goes beyond testing for HIV/STDs or establishing support groups. LGBTQ communities need culturally competent preventive services for substance abuse, cancer, diabetes, and other health conditions, including mental health issues. Therefore, how can we commit as librarians to present "real information" to our users and communities? This paper looks to encourage librarians and information specialists working in ATOD, mental health, and public health to understand diverse perspectives when approaching the work and to learn of innovative public health development approaches, programs, and opportunities to support effective information access and dissemination.

Librarians and information specialists need to inform themselves about LGBTQ communities to ensure that the information they need for their users is readily available and accessible. They can also contribute to the national and local public health debate by supporting their local community based LGBTQ organizations, becoming allies, and by seeing themselves as social justice activists within the information highway.

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Designing a web portal for persons with serious mental illness

Design considerations based on the literature, focus groups and an expert users survey

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People with serious mental illness die 25 years earlier, on average, than the general population. Much of this disparity in life expectancy can be attributed to modifiable lifestyle factors or psychotropic medications that increase the risk for developing obesity, diabetes, and/or cardiovascular diseases. (Parks, Svendsen, Singer, & Foti, 2006; Viron & Stern, 2010) While many websites and mobile apps have been developed to support persons with mental illness, very few link this information with similar resources on physical health. Plus, research shows that persons with serious mental illness often have a more difficult time using online resources. (Cohen & Adams, 2011; Nicholson & Rotondi, 2010; Swan, 2009)

In 2015, the University of Massachusetts Medical School's Lamar Soutter Library, in conjunction with the university's Department of Psychiatry and the Dartmouth Psychiatric Research Center, received a three-year grant from the National Library of Medicine/National Institutes of Health to address this issue. The end product of this

grant will be an online resource that persons with mental illness can use to learn skills to more fully understand and address physical health issues they experience.

In order to build an effective tool for this population and this purpose, significant research and preparation was conducted. Year one (2015-2016) of the grant was dedicated to information and data gathering. In order to learn specifically what persons with serious mental illness would want to find in this type of online resource, focus groups were convened. Three focus groups (N=42) were conducted with people having lived experience. One was conducted in an inpatient psychiatric facility, another is an outpatient setting and a third with young adults that are part of a social psychiatric research group. Three additional focus groups were conducted with mental health professionals. These groups consisted of librarians working in mental health academic institutions or hospitals, researchers, educators, and practitioners. One of these focus group was held at a conference of health information professionals and the other two were conducted at universities. Results of these focus groups are currently being reviewed using Dedoose, an online qualitative data analysis tool. It is anticipated that these results will be published in 2018. A poster documenting this process and initial findings was presented at the annual meeting of the American Psychological Association and can be found at

http://escholarship.umassmed.edu/lib_articl es/202/.

While the focus groups helped the project team understand need, an online survey was also created and distributed to experts in mental and physical health seeking input of best practices in website formatting, navigation and content. A 64-question survey was designed using RedCAP, an online survey

and database application. The initial design of the survey was based upon a validated tool entitled the DISCERN survey, which was designed to evaluate web sites created for our target population. Additional questions were developed based on design and format elements that would be vital to address as part of this project. 68 responses were received. Highlighted findings from this survey can be found in a poster discussing this project that was presented at the annual meeting of the Medical Library Association in Seattle, Washington in May of 2017. The full text of the poster can be found at http://escholarship.umassmed.edu/lib_articl es/199/.

In late 2017 – early 2018, this project will enter the design phase. By mid-2018, it is anticipated that we will initiate usability testing with potential users, these being groups similar to those that participated in the focus groups and the survey. The site will be launched by the fall of 2018 and marketing and training efforts will get underway.

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Creating a SALIS Legacy

Building an Alcohol, Tobacco and Other Drug (ATOD) Archive with Knowledge for All

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The SALIS Digitization Project, or Digs, as it is called by the SALIS Advocacy Committee project members, is an ongoing activity to create an ATOD digital archive of books and government documents in partnership with the San Francisco based Internet Archive. This report provides an update of the project including the status and projected growth of the collection, strategies for growth that include both fund raising for digitization and uploading existing digital documents, and the challenges and solutions for dealing with monitoring workflow and applying meta data. With the continuing closures of ATOD libraries and the loss of key databases and catalogs, this project provides a way to preserve the literature of the field, as well as making it more accessible.

Keywords

Digitization, Preservation, Alcohol History, Drug Abuse History, Substance Abuse

Introduction

The SALIS 2017 conference in Worcester, MA provided an opportunity to report on the status of the SALIS Collection (the Collection) in the Internet Archive (IA), strategies for growth of the Collection, and the challenges and proposed solutions. In addition, a workshop was given to demonstrate the interface and the process of how materials are acquired, tracked, scanned or uploaded, and tagged with meta data. The two sessions updated previous presentations provided by the Digs (SALIS Internet Archive Digitization) Project team (Mitchell et al., 2015) at the SALIS 2015 conference in San Diego, CA and at the 2016 SALIS Conference in Denver, CO (Mitchell et al. 2016).

The Collection depends on the SALIS membership to identify and locate resources for scanning and, for those with appropriate authorization, to upload digital documents, a means for adding government and research reports from our diverse membership.
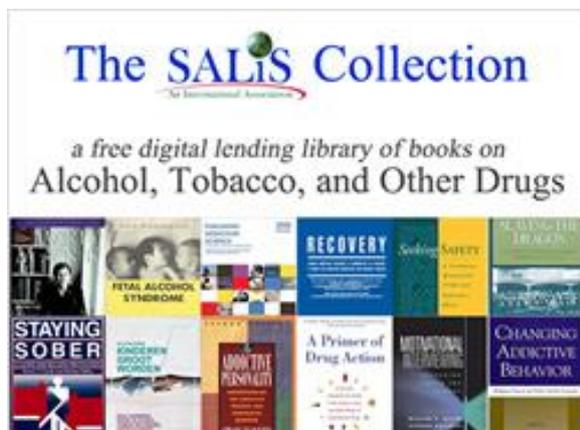

Figure 1 The SALIS Collection:
http://archive.org/details/salis

Building the Collection: Status and Goals

Andrea Mitchell began with an overview and update. The formal partnership with the IA began in 2014 with a contract. Growth and use of the collection increased dramatically over the past two years, from approximately 300 books and 532 views recorded in May 2015 to over 1300 documents (books and reports) and more than 52,000 views recorded in May 2017.
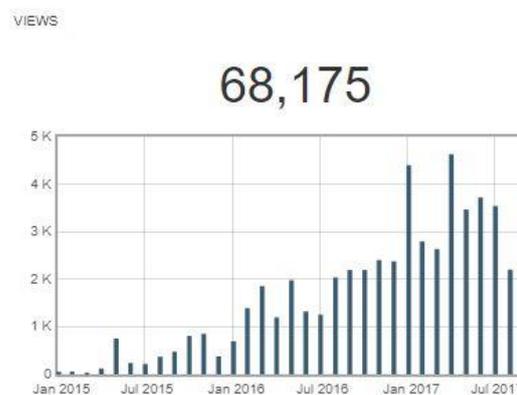

Figure 2. SALIS Collection Views over time

This growth could not have happened without the support of partners and dedicated SALIS members working behind the scenes. An early supporter, Joel Fort, (Joel and Maria Fort Foundation) funded the first mini proposal for seed money in 2013.

Following that, support came from the National Institute on Alcohol Abuse and Alcoholism (NIAAA), when it donated its library and provided more seed funding to begin digitizing these holdings.

Five librarians worked diligently to select the most relevant titles from the NIAAA list of books to add to the SALIS Collection in the first phase. With additional support from Hazelden Betty Ford Foundation, NIAAA, the SALIS Treasury, and individual SALIS members, nearly $20,000 was accumulated. With these monies and the volunteer work of ten dedicated SALIS members actively identifying and uploading digital resources and editing records, the Collection has witnessed a healthy growth.

Mitchell presented the analogy of the Collection as being like a forest with trees

representing libraries such as those at the Alcohol and Drug Abuse Institute (ADAI), the Hazelden Betty Ford Foundation, the Centre for Addiction and Mental Health (CAMH), and NIAAA, the leaves of the trees represent the potential resources for building the collection, book by book. A goal of 1800 books by year end was set, how will this be accomplished?

Building Blocks

Books are shipped to the most convenient IA scanning center, where the content is scanned and metadata is added, provided by the contributing SALIS member, usually from the most suitable WorldCat record. A spreadsheet with the metadata for each book accompanies the shipment. The approximate cost to SALIS for each book to be scanned is $30. The first additions to the Collection were books scanned at the Internet Archive in San Francisco in 2015-2016.

Another growing source of the SALIS Collection holdings comes from grey literature and out-of-copyright books that members can scan and upload, or simply upload, if born digital or an electronic copy can be located. This is a great way to add grey literature such as government and research reports, current and historical, from various jurisdictions representing the diverse membership of SALIS. Barbara Weiner explained the process of uploading and provided examples. One example highlights the advantage of working in a center that published documents. She has been actively uploading *Research Updates* from Hazelden Betty Ford Foundation's Butler Center for Research. Another example she provided highlights other sources, such as copyright-free government reports accessible through the internet. Weiner stressed some important points: uploading not only adds to the Collection, but incurs no cost to SALIS, permission must be obtained for items in copyright, to be authorized to upload, one must have an Administrator Account, if one does not have an account, PDFs of documents can be forwarded to SALIS Home.

Fortunately, there are Digs Team members in various locations, including Belgium, France, the UK and the US actively uploading documents. Adding grey literature from a variety of sources and jurisdictions is a way of enhancing the collection and making it more valuable to the ATOD community.

Sheila Lacroix reported on the benefit of sharing resources already in other IA collections and the value of forming partnerships. Concerning sharing, it was discovered this year that resources already in the IA can be tagged as part of the SALIS Collection. This is something that IA staff must do, so it is the task of SALIS members to identify possibilities. Through sharing, the Collection now has a few turn-of-the-last-century books tagged from the Cornell University IA Collection that fit our collection policy. This includes the *Royal Commission on Opium* reports from Great Britain, a valuable historical resource.

Lacroix presented a case study of how partnerships can help to build the Collection. The Addiction Research Foundation (ARF) of Ontario was a founding partner of CAMH. It was a center of research in epidemiology, treatment, prevention, and education, and had a mandate to disseminate research-based knowledge and develop policy. As a result, it had an active publishing arm and many of its publications were collected by the University of Toronto (UofT) Libraries. As IA Canada is located at Uof T, Lacroix approached the librarian responsible for digitization and the result was a win-win solution. UofT, which has an aggressive, well-funded digitization project underway through IA Canada for its out-of-copyright holdings, agreed to digitize, and cover the cost, of its holdings published by ARF when copyright clearance was provided. Items are tagged as part of The SALIS Collection as well as UofT's Addiction Research Foundation (ARF) Special Collection. This has resulted in over 230 digitized books, all of the volumes of the periodical *Alcoholism Research / Alcoholism Research Treatment Education / Addictions* (1953 – 1977) as well as most of

the issues of *The Journal (ARF): Addiction News for Professionals* (1972 – 1998).

Challenges

Without doubt, the two main challenges are fundraising and dealing with the practical and time-consuming collection building activities required for a project of this magnitude. The purpose of the workshop was to introduce members to existing protocols and procedures required to manage workflow from beginning to end, ensuring some standardization and no costly duplication.

Monitoring: At the workshop, the Digs Project Database was demonstrated and discussed. Through this, the team can track every item selected and added to the Collection. Standardized bibliographic information as well as the ISBN, if available, must be added to the database for each item, and once added to the Collection, the IA URL is inserted. This database is accessible to SALIS members through the SALIS website.

Discovery: Having these resources in a single collection is an admiral goal, but like any library, in particular as it grows, search capacity is a necessity. Unfortunately, because metadata is used from various sources, there is no consistency in subject headings. As yet, a standard list of Subject Headings has not been selected or applied. There remains much work to be done in this area. In the short run, member contributors are encouraged to use the most appropriate WorldCat record to accompany the book when sent for scanning. Standards for author, title and series have been established, but not always used. The prospect of going in and adjusting records to ensure consistent field values is daunting, but will have to be considered some time in the future.

Scope: Thus far, given the NIAAA library donation, the collection is heavily weighted with alcohol books. However, the Project team plans to expand the Collection to include more resources on other drugs in the near future.

Fundraising and Promotion: These are related, as the more the ATOD community becomes familiar with the SALIS Collection, the easier it is to generate support for its growth. Goodair and Lacroix (2016) presented at the 2016 Society for the Study of Addiction's (SSA) annual conference held in York, UK. At the time of the SALIS 2017 conference, plans were underway to apply for a grant from SSA. Also, a fundraiser through a crowdfunding provider was under investigation. SALIS members have been charged with promoting the Collection at their institutions and through any relevant newsletters, presentations and social media channels they support.

The SALIS Legacy

Dedicated SALIS members continue to work on building the SALIS Collection with an ultimate goal of at least 10,000 items. This will be an important contribution towards preserving and making accessible the resources in our field. The impetus for this was the continuing closures of ATOD libraries and the loss of key databases and catalogs, essential for the preservation of the ATOD knowledge base, a diverse, multidisciplinary and complex literature. (Mitchell et al., 2012).

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