

A COMMUNITY RESOURCE GUIDE FOR PEOPLE LIVING WITH HIV/AIDS IN
WESTERN MONTANA

by

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TABLE OF CONTENTS

1. INTRODUCTION 1

 Statement of the Problem.....2

 Purpose.....3

 Background and Significance3

 Effects on Society4

 Effects in the Nursing Profession5

 Effects on Individuals Living with HIV/AIDS6

 Theoretical Framework.....6

 Assumptions.....8

 Limitations9

 Definitions.....9

2. REVIEW OF LITERATURE 10

 Community Resources10

 Social Isolation.....12

 Rural United States13

 HIV/AIDS and Theory of Health Promotion.....14

 Summary14

3. METHODOLOGY 16

 Development of the resource Guide17

 Data Collection18

 Pilot Testing of the Resource Guide19

 Rights of Human Subjects and Consent Process20

4. RESULTS 21

 Layout and Content of the Resource Guide21

 Pilot Study Results.....24

5. DISCUSSION 26

 Strengths26

 Limitations27

 Implications.....30

 Conclusion31

REFERENCES CITED.....32

TABLES OF CONTENTS – CONTINUED

APPENDICES36

 APPENDIX A: Montana County Map37

 APPENDIX B: Total Reported HIV/AIDS Cases by Major County39

 APPENDIX C: Key Informant Questionnaire.....41

 APPENDIX D: Pilot Test of Resource Guide Questionnaire.....43

 APPENDIX E: Certificate of Completion45

 APPENDIX F: Resource Guide.....47

ABSTRACT

The number of people becoming infected with HIV has surpassed the number of people who die each year with HIV/AIDS in the United States. In the past decade there has been an increase in the incidence of HIV/AIDS diagnoses among rural populations. As of June 2011, there were 532 known cases of people living with HIV in Montana.

A literature review was performed to better understand the needs of rural dwelling people living with HIV/AIDS in Montana. Specifically, needs related to improving psychological, social, and emotional health and ultimately overall quality of life.

Once common needs were identified for improving quality of life for people living with HIV/AIDS, a community resource guide was created. Resources were gathered through an Internet search and interviews with professionals who work with people living with HIV/AIDS in Montana.

The need for community resources for people living with HIV/AIDS has been increasingly recognized as this population lives longer. While medications continue to be developed, the mental health and well-being also needs to be addressed. It has been recognized that rural dwelling people living with HIV/AIDS have a unique set of needs related to the potential for social isolation. Lack of community resources and community involvement has been shown to have a direct negative correlation on outcomes of PLWHA in rural areas. Current research shows that access to community resources and social interaction can lead to better physical and mental health outcomes for rural dwelling people living with HIV/AIDS.

CHAPTER 1

INTRODUCTION

According to the Centers of Disease Control and Prevention (CDC), at the end of 2009, it was estimated more than one million (1,178,350) adults and adolescents in the United States were living with Human Immunodeficiency Virus (HIV) infection (CDC, 2011). This is a seven percent increase from the previous 2006 estimate. The number of people becoming infected with HIV has surpassed the number of people who die each year with HIV/AIDS. “While the federal government’s investment in treatment and research is helping people with HIV/AIDS live longer and more productive lives, HIV continues to spread at a staggering national rate” (AIDS United, 2010, p.1). The investment in research is resulting in better drug treatment options for people living with HIV/AIDS; and as a result, “has extended the life for many people with HIV disease and will allow, as never before, individuals who were infected in midlife to live into old age” (Emlet, 2006, p. 299). Consequently, HIV/AIDS in the United States is now considered a chronic illness as opposed to a disease that was previously thought of as a death sentence (Cabral et al., 2007).

Throughout the United States, people living with HIV/AIDS (PLWHA) are living longer and the number of people becoming infected is increasing. In the past decade, there has been an increase in the incidence of HIV/AIDS diagnoses among the rural populations (Basta, Shachman, & Reece, 2009). As of June 2011, there were 532 PLWHA in Montana (Department of Public and Human Services, 2012). Access to care

and support for this population is uniquely different than care for their urban counterparts due to the very nature of rural living which is usually not in close proximity to clinics and resource centers.

Statement of the Problem

The need for community resources for PLWHA has been increasingly recognized as this population lives longer. It has also been recognized that rural dwelling PLWHA have a unique set of needs related to the potential for social isolation (Basta, Shachman, & Reece, 2009).

In 2009 Montana received 1.43 million dollars from the United States Department of Housing and Urban Development to create low-income rural housing for individuals living with HIV/AIDS (United States Department of HUD, 2009). According to AIDS United (2010), Montana also received an additional 2.8 million dollars from the Health Resources and Services Administration to be used towards direct support services for PLWHA.

PLWHA in rural and remote areas as well as healthcare workers may be unaware of such resources if they are not linked into a larger support network that functions on a state or national level. The aim of this project is to increase awareness of resources and encourage interaction within this population as well as between healthcare workers. Thus, the question that will be addressed for this project is: what community resources are available to people at risk for social isolation related to living with HIV/AIDS in Western Montana.

Purpose

While the prevalence of HIV/AIDS is measurable, it is somewhat more difficult to quantify the number of community resources available to rural dwelling PLWHA in Montana. This is difficult because resources come from various networks across the state, ranging from formal government sponsored programs to less structured word of mouth gatherings. Currently, it has been difficult to find a resource that identifies all the available community resources that exist for this population. If this information is not identified and compiled, a knowledge deficit may result due to unawareness of the available resources. In addition, it is not only this population but also providers, outreach workers, and nurses living in rural areas that may not be aware of resources.

The purpose of this project is to develop a comprehensive list of community resources that are available to PLWHA in Western Montana. The list will not only act as a resource for PLWHA but will also act as tool for outreach and healthcare workers to use when making referrals. This formal list also has the capability to act as a vehicle to promote HIV/AIDS awareness within this population and also within the communities in which they live. Furthermore, it is not evident that there is a formal current compilation of community-based resources available to PLWHA in Western Montana.

Background and Significance

Lack of community resources and community involvement has been shown to have a direct negative correlation on outcomes of PLWHA in rural areas. Many times this lack of community involvement leads to a decreased quality of life in terms of physical

and emotional health (Basta, Enbal, & Reece, 2009). Alternately, among this same population, there is a positive correlation between contacts with outreach and health care workers and the likelihood of consistently adhering to scheduled medical primary care visits (Carbral et al., 2007). Caring for this population by providing links to resources has direct effects on not only this population but potentially on the United States as a whole.

Effects on Society

The United States contributes financially to the prevention of HIV/AIDS and also to the cost needed to care for the population living with HIV/AIDS. In 2007, 212,892 PLWHA were enrolled in Medicaid. In the same year, the United States spent \$5,294,006,640 or \$24,867 per capita in Medicaid on this population, (Kaiser Family Foundation, Medicaid enrollment spending, 2011). In 2009, the United States government spent \$3,102,544,704 on HIV/AIDS. This money was allocated state by state, and helped support the prevention of HIV/AIDS and also supported PLWHA (Kaiser Family Foundation, total HIV/AIDS federal spending, 2011). One focus of this financial spending is to provide support to PLWHA. It is imperative these resources do not go unused due to a lack of awareness.

Hutchinson et al. (2006) conducted one of the first studies in the United States that included the overall economic productivity losses in terms of the total estimated cost of HIV/AIDS. In 2002, the total lifetime cost of illness for Americans newly diagnosed with HIV was estimated to be approximately 36.4 billion dollars. Furthermore, it was found that the high cost of HIV/AIDS medications was eventually offset by extended

productivity within this population as they aged and stayed healthy enough to contribute to society through the workforce (Hutchinson et al., 2006). This being said, it is in society's best economic interest to care for and support this population to enhance long term economic return.

Effects on the Nursing Profession

Continued education is a necessity for nurses in order to remain professionally competent. Being aware of the resources for patients aligns with remaining competent as a nurse. Building professional connections with the available resources also promotes professional development. "Nursing care is also directed toward meeting the comprehensive need of patients and their families across the continuum of care" (ANA, 2010, p. 4). It is important for nurses to develop the level of education that is needed to maintain and promote health in the population living with HIV/AIDS. The idea of promoting health is also consistent with Pender's model of Health Promotion (Pender, 1982), the guiding theoretical framework in this project. One of the Ten Essential Public Health Services is to "link people to needed personal health services and assure the provision of health care when otherwise unavailable" (American Public Health Association, 2012). Nurses are in a vital position to work with the HIV/AIDS population in a health promotion capacity by improving links within this population as well as links to the community with the goal of promoting interaction and overall well being. Public health nurses and other healthcare workers would also be able to utilize this information when helping patients navigate resources as well as when making referrals. Overall, the addition of this information to the existing body of nursing knowledge in Montana makes

the profession stronger as it improves patient care through the expanding knowledge of resources.

Effects on Individuals Living with HIV/AIDS

As stated previously, it was estimated more than one million (1,178,350) adults and adolescents were living with HIV in the United States at the end of 2009 (CDC, 2011). Currently, in Montana as of June 2011, there were 532 known cases of people living with HIV (Department of Public Health and Human Services, 2012). On a National level, the CDC estimates that 1 in 5 people or 18.1% of people are unaware that they are infected with HIV (CDC, 2012). Based on this national statistic, the prevalence of HIV in Montana is likely to be underestimated as well. It is probable that the actual number of PLWH in Montana is greater than 532.

The population of PLWHA in Montana would benefit from this project in two different ways. First, they would have a comprehensive list of community resources available. Second, seeing a comprehensive list of all the resources could elicit a sense of community within this population. Being aware of other rural areas and the fact that they have community resources has the potential to relieve some of the stigma that may surround this population. Furthermore, the heightened awareness of the links that already exist within this population can lead to a greater cohesion within this population.

Theoretical Framework

Pender's Health Promotion Model (HPM) (Pender, 1982) will provide the framework for this project. One major reason for choosing this framework is Pender's

holistic background which incorporates: nursing, human development, psychology and education (Sakrida, 2010). The HPM takes into consideration patterns of development, the psychology of change, the various ways people learn, and applies these ideas to nursing practice. The central construct of the HPM is self-efficacy (Pender, 1996). The resource guide will act as a tool for health care practitioners and outreach workers to use in order to instill a sense of self-efficacy within individuals living with HIV/AIDS. PLWHA can use the resource guide as the first step to seeking out community resources and community involvement.

The HPM is applicable to the population living with HIV/AIDS as it does not include fear or threat as a source of motivation for health but it looks to prior related behaviors and personal factors such as biological, psychological, and sociocultural (Pender, curriculum vitae, 2000 as cited in Sakrida, 2010). The HPM offers a holistic approach to working with rural dwelling PLWHA. This holistic approach will help guide the types of resources that will be included in the Resource Guide.

A key component of the HPM is the idea that individual characteristics and experiences influence health actions. One of the components of this idea is the concept of health promoting behaviors. “A health promoting behavior is an end point of action outcome that is directed toward attaining positive health outcomes such as optimal well being, personal fulfillment, and productive living” (Sakrida, 2010 p.439). The idea of optimal well being is particularly important when working with people in rural areas living with HIV/AIDS as enhancing well being can lead to an enhanced quality of life as this population ages. The guiding principles for this project will come from Pender’s (1996) idea that health promotion encompasses the lifespan. As PLWHA age their needs

change. Pender (1996) outlined assumptions that surround the HPM; these assumptions will also act as guiding principles of this project and are outlined in the following section.

Assumptions

It is important to examine Pender's (1996) assumptions regarding the Model of Health Promotion, as it is the theoretical framework providing the foundation for this project. Pender's (1996) HPM is based on seven major assumptions. Particularly critical to this project is the following assumption: "Persons seek to create conditions of living through which they can express their unique human health potential" (Pender, 1996, p. 54). This assumption can be applied to this project as PLWHA have the potential to express their human health potential through the use of social resources. Another assumption of Pender's (1996) theory is: "individuals in all their biophysical complexity interact with the environment, progressively transforming the environment and being transformed over time"(Pender, 1996, p. 54). This assumption reflects the aspect of chronic illness that people living with HIV/AIDS face and the adaptation that is necessary to obtain a certain level of health for this population.

This project is based on the assumption that living in a rural area has the potential to become socially isolated. In other words, living in an area where one has to travel long distances to clinics or resource centers can limit personal contact with health care professionals, outreach workers, and other people living with HIV/AIDS. The last assumption that is key to this research is the idea that people with HIV/AIDS living in rural areas, have a limited knowledge of the community resources available throughout the rural western state.

Limitations

The primary limitation of this project is access to information. Community resources are at times informal, word of mouth, and not published. Another limitation is that the Author is not a part of the HIV/AIDS community in Western Montana. To attempt to control for these limitations, it will be helpful to have a key informants within various counties that have worked with this population and are aware of a variety of available resources.

Definitions

- 1.) *HIV/AIDS Population*. HIV/AIDS population was defined as any person with a confirmed positive diagnosis of HIV or AIDS.
- 2.) *Rural*. The definition of rural includes any county labeled as “frontier” (6 or fewer persons per square mile) and any county labeled as rural (6-50 persons per square mile). (United States Department of Agriculture Economic Research Service, 2003).
- 3.) *Community Resources*. Community resources were defined as any formal government or state program or financial resource available to PLWHA. Any formal or informal programs, meetings, or support groups that promote psychosocial health and physical health for PLWHA. Any laypersons or health professionals who primarily focus on working with people living with HIV/AIDS.
- 4.) *Social Isolation*. Social Isolation was defined as one’s self-perceived level or an external persons perception of level of geographic, physical, or psychological degree of isolation that effects daily functioning.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this chapter is to provide an analysis of the current state of the research regarding resources for PLWHA in rural areas. This review contains a summary of the literature findings regarding PLWHA and the relationships between community resources, social isolation, rural United States, and the Theory of Health Promotion.

Community Resources

It has been found that “there is little information about the impact of interventions on engagement or retention in HIV primary care among the hard to reach” (Cabral et al., 2007 p. 59). Despite this lack of information, a positive correlation has been identified between the level of engagement in community outreach interventions and retention in the medical care system for PLWHA (Rajabium et al., 2007; Cabral et al. 2007). The use of social intervention as a support for PLWHA has been shown to result in better adherence to medication regimes (Cabral et al., 2007 and Rajabium et al., 2007). Despite the availability of community resources, there are often perceived barriers when it comes to utilizing such resources. Barriers that stand in the way of achieving a high level of engagement in community resources and medical care for PLWHA include; 1.) level of acceptance of HIV, 2.) coping with substance abuse, 3.) health care provider relationships, 4.) presence of external support, and 5.) ability to address external barriers to care (Rajabium et al. 2007).

Engagement in health care and community resources for a person living with HIV/AIDS is cyclical rather than a linear progression. People fall in and out of engagement in medical care and community resources at different points in the care cycle. Vulnerable points in the health care engagement cycle can be pinpointed as opportunities for interventions from outreach workers (Rajabium et al., 2007). PLWHA must have a link to care and also be prevented from falling out of care. The numerous barriers identified can be overcome by helping PLWHA utilize multiple resources, engage in their community, and connect with peers.

Implementing support programs for PLWAH at the community level comes with barriers. The Real AIDS Prevention Project (RAPP) was a nationally spread prevention effort realized by the HIV/AIDS Prevention division of the Center for Disease Control and Prevention (CDC) (King et al., 2008). The project began in March, 2003 and ended in May, 2007. This program was developed based on CDC data depicting AIDS as a “growing and persistent health threat to women in the United States, especially young women of color” (King et al., 2008 p.1055). The main goal of RAPP was to mobilize community agencies and outreach workers to implement core community level interventions. Interventions of note that RAPP utilized included; peer and community networks, small group activities, role models, and one on one discussions. Barriers to community implementation of RAPP included; difficulty reaching the intended population, lack of community attendance at sponsored gatherings due to lack of child care, transportation, fear of identification, and problems gaining the trust of the communities (King et al., 2007). These barriers need to be considered when implementing resources at the community level.

Social Isolation

“The advent of highly active antiretroviral therapies (HAART) in the 1990’s has extended the life for many people with HIV disease and will allow, as never before, individuals who were infected in midlife to live into old age” (Emlet, 2007, p. 299). Grove et al. (2010) also recognizes “advances in treatment of HIV have resulted in a large growing population of older adults with HIV” (p. 630). While antiretroviral therapies continue to be developed, the mental health and well being of a person living with a chronic disease also needs to be addressed. “Social support networks have been consistently acknowledged as important elements in the lives of people living with HIV/AIDS, adequate social support has been associated with physiological and treatment aspects of HIV” (Emlet, 2007, p.300).

When considering the aging population living with HIV/AIDS researches have found a negative correlation between experienced stigma and emotional support. (Emlet, 2007; Grove et al., 2010) This stresses the importance of combating stigma experienced by people living with HIV/AIDS by building social networks that involve emotional support.

Loneliness and HIV-related stigma were found to be significant independent predictors of major depressive symptoms. Interestingly, it was found that HIV stigma and loneliness were not associated with objective indicators of health such as an official AIDS diagnosis, it was the extent of these psychosocial factors rather than the physical symptoms or objective data that contributed to depression. This finding suggests the

magnitude of the psychosocial aspect of living with HIV/AIDS may determine the degree of experienced depression. (Grove et al., 2010)

Rural United States

In order to provide adequate resources for rural dwellers one must understand and take into consideration individual health practices, as these practices are influenced by perceptions of health and illness (Bales, Lee, & Winters, 2010). The healthcare needs of rural dwellers require unique approaches that take into consideration the special needs of this population. Nursing models developed in urban or suburban areas do not adequately take into consideration such needs (Long & Weinert, 2010).

According to Basea et al. (2009) few studies have been conducted that examine psychosocial distress among rural individuals living with HIV. Rural dwelling people living with HIV/AIDS have been found to have higher levels of symptoms of psychological distress than their urban counterparts. When hostility levels were measured in both HIV/AIDS populations it was found that rural dwellers displayed higher levels than urban dwellers. Regardless of access to care, rural participants are less likely to identify the need for mental health care as an integral component in their HIV care. One possible reason for the difference in distress symptoms included a look at Internet based resources. Basta et al (2009) also found that rural participants earned lower incomes and therefore did not have access to specific HIV/AIDS support online resources than their urban counterparts utilized. Beyond reasons related to income, many rural areas do not have the infrastructure in place to provide Internet connection. This often makes it difficult to bring telemedicine or online support for people living in rural areas.

HIV/AIDS and Theory of Health Promotion

Exploring perceptions of PLWHA through the lens of Pender's Health Promotion Model (HPM) can be both empowering and therapeutic for this population (Mandias & Parr, 2007). The HPM framework allows for a holistic look at the lives of PLWHA. Mandias & Parr (2007) found that PLWHA expressed interest in communicating with others about HIV and are also interested in learning about being healthy or staying healthy. When it came to assessing the preferred learning modalities of this population, the least preferred method was found to be a home visit from a clinician or outreach worker to the house of the participant. The top barriers to health care include distance to the clinic, travel or supply costs, and confidentiality (Mandias & Parr, 2007). By looking at the needs of this population through the lens of the HPM one can begin to identify perceived control of health, perceived barriers, and perceived benefits of engaging in health promoting behaviors. By taking into account the perceived ideas of this population nurses can gauge the likelihood of an individual to engage in health promoting behaviors (Pender, 1987)

Summary

“Advances in treatment of HIV have resulted in a large growing population of older adults with HIV” (Grove et al., 2010 p. 630). The medical world continues to develop medications that have changed HIV/AIDS into a chronic condition. Living life with HIV/AIDS comes with barriers both physical and psychological. It has been speculated that the United States is a heavily allopathic nation that continues to work to

prolong the lives of people living with HIV/AIDS through new drug developments. As people live longer with HIV/AIDS an equal effort is warranted to help this population cope with the psychological effects of depression, loneliness, stigma, and overall lack of connectedness as this population ages. The rural dwelling population living with HIV/AIDS comes with its own set of barriers that are clearly defined in the literature.

Currently, it is evident the state of the research surrounding community resources for PLWHA in rural areas displays consistent themes. The main theme that has surfaced within the literature is the need for interaction within this population. This identified theme encompasses a need for social support and interaction within this population and also with the surrounding community. Realizing the best way to form these interactions is a warranted direction for research in this area.

CHAPTER 3

METHODOLOGY

The steps that took place to create the resource guide are outlined in this chapter. The idea to create a resource guide came after an informal conversation with an employee at a local HIV/AIDS resource center in Missoula MT. This conversation revealed that there are multiple informal gatherings and resources for PLWHA in rural Montana, and knowledge of these resources is often passed through word of mouth. This conversation also revealed that there are multiple formal State and National resources for PLWHA in Montana. At this point, it is not apparent that there is an easily accessible comprehensive guide or listing that contains all of the current available resources in Montana.

The intended goal of this professional project was to compile a resource guide that lists community based resources for PLWHA in Western Montana. This resource guide can be used by PLWHA and also by people who work with this population.

The paper-based guide will be distributed to clinics, HIV/AIDS resource centers, and community centers. A paper-based guide was thought to be the most accessible medium for distributing this information to the largest population. The resource guide will also be available as a pdf on the Internet.

The guide was created using Microsoft Word Document so changes or updates can be added at any time in order to keep information current. The most conveniently available paper size is 8 ½ x 11 inches, thus this was the size paper chosen for the resources guide in order to simplify mass reproduction. The guide was distributed via

email, or hand delivered to clinics, hospitals, and centers that serve PLWHA in Western Montana.

Development of the Resource Guide

Formal Nationwide and Statewide resources such as Ryan White funded centers, and public health departments made up a small portion of the resource guide, these resources were found through a simple Internet search. The majority of information in this resource guide was obtained through interviews. This project was heavily qualitative in nature because it generated “narrative findings for the purpose of providing an in depth description” (Norwood, 2010, p. 45) in order to promote understanding of the resources available to people living with HIV/AIDS. To gather these narratives the sampling procedure of network sampling was used.

The target population included people who currently work with those living with HIV/AIDS in Montana. Within the total target population an accessible population was determined, which is the “portion of the target population to which the researcher has a reasonable access for data collection” (Norwood, 2010, p.222). Individual interviews were conducted with a portion of the accessible population. Inclusion criteria for the population interviewed was as follows: interviewees live within 22 counties that make up the western part of Montana (see Appendix A) and include working physicians, nurses, public health workers, caseworkers, and people who work at HIV/AIDS related resource centers.

The western 22 counties were chosen because they contain nine of the top ten counties with the highest reported HIV/AIDS cases in the state (AIDS Action, 2005) (see

Appendix B). They were also chosen to limit the area from which data is collected to ensure a detailed comprehensive list of community resources for the western part of State. Of note, one of the top 10 counties, Yellowstone County, was omitted because it is not located within the western 22 counties in the state.

The goal sample population consisted of one interview from one professional who works with the HIV/AIDS population in each of the top nine out of ten counties with the highest reported cases of HIV/AIDS in Western Montana. The rationale for the goal of these nine interviews was decided based on data that included the number of HIV/AIDS cases per county. It was assumed that counties with the highest number of cases of PLWHA will have workers who work with this population. If no workers were found within these counties it was a significant finding in terms of lack of support for this population. By paralleling the information gathered from the nine workers who work with this population in nine separate counties, an accurate geographical measure of resources was obtained. Common themes and community support organizations that were found throughout the interviews were grouped together to promote readability and overall organization of the resource guide.

Data Collection

To begin to form the sample population an Internet search of key informants who currently work with the HIV/AIDS population was conducted. Specifically, the websites of State agencies that serve this population were reviewed and phone calls were made to obtain information from key informants who work within these agencies. To compile informal resources, the Open Aid Alliance in Missoula was first contacted via telephone

to find key informants to provide information regarding community-based resources for this population. A heavy reliance was placed on network sampling at this point, the sample population was expanded via word of mouth through original contacts that were made. A specific effort was made to expand to contacts throughout the nine target counties

Each participant was asked the same open-ended question; “What is your knowledge of available resources for people living with HIV/AIDS”. Follow up questions were also used to gain more specific insight and to elicit a greater variety of available resources. Specifically, follow up questions explored participants knowledge of social support in the form of formal and informal meetings and community gatherings. Participants were also asked specifically about their knowledge of financial resources. The stopping point of the compilation of resources became apparent when the point of saturation was reached. It was at this point the sample population continued to report resources that had already been recorded.

Pilot Testing of the Resource Guide

Before pilot testing of the resource guide took place, credibility of community resources was confirmed. In order to confirm credibility of information, telephone or email contact was made with persons responsible for specific community events and resources that were mentioned by participants. Once credibility was established, the resource guide was created and emailed to the sample population for review. Included with the preliminary resource guide was a questionnaire that asked participants to rate and comment on: readability, organization, and usefulness of information (see Appendix

D). Questionnaires were reviewed and suggestions for change were taken into consideration.

Rights of Human Subjects and Consent Process

This professional project did not proceed with any data collection until approval was received from the Montana State Institutional Review Board (IRB). An application for request for exemption was submitted to the review board. An exemption was requested as this study falls within the exempt guidelines stated by the Montana State Institutional Review Board. Specifically, this project falls under the exempt example stating; “Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these materials are not generated at the request of the investigator and if information concerning the materials is recorded by the investigator in such a manner that the subjects cannot be identified” (Montana State IRB, 2010, p.1). A certificate of completion, “Protecting Human Research Participants” was obtained from the National Institutes of Health (NIH) Office of Extramural Research web based training source (NIH, 2011). See Appendix E.

CHAPTER 4

RESULTS

The outcome of this project was the development of a resource guide for PLWHA in Western Montana. A pilot test of the resource guide consisted of sending the resource guide along with a survey to the sample population and organizations that work with PLWHA in Western Montana. The sample population consisted of 12 key informants. This number exceeded the initial goal of nine key informants because three additional key informants were found and contacted during data collection. This chapter contains details of the layout and content of the resource guide, and the results of the survey.

Layout and Content of the Resource Guide

To determine the most logical layout for the resource guide various HIV/AIDS resource guides from other states were reviewed. A variety of HIV/AIDS resource guides were found ranging from one-page quick reference guides to detailed 10 page booklets. Based on the limited number of organizations that solely provide resources for PLWHA in western Montana it was decided to keep the guide to a two-page document that can be printed on both sides of one sheet of paper. The resource guide contains five sections; community or social support based resources, state resources, online resources, phone resources, and websites. Online resources, websites, and phone numbers are a mix of local, and national resources.

National resources were included in the guide based on frequency of occurrence on various websites. For example, HIV/AIDS resource pages from universities, hospitals,

and research organizations were reviewed. The most frequently occurring national resources for PLWHA on the websites reviewed were included in the final resource guide.

State resources were taken from the Montana Department of Public Health and Human Services HIV/AIDS treatment program webpage. This webpage lists state run HIV/AIDS case management programs by county. In almost all cases, the phone numbers listed on the state website were not direct numbers to the HIV/AIDS case managers. It was found that by calling the numbers listed on the state website one could be easily be connected with the case managers for each county. Thus, it was decided to leave the main numbers listed instead of including actual names and phone numbers of case managers.

Local community or social support based resources include organizations such as the Open Aid Alliance in Missoula, MT and the community based services they offer. It was also decided to include an organization in this section that is not based in the western region of Montana. The Yellowstone Aids Project (YAP) “is a not-for-profit organization committed to increasing HIV/AIDS awareness and providing prevention and client services in Montana” (<http://www.yapmt.org>). YAP is based in Billings, MT, which is out of the service area indicated for the resource guide. After talking to a contact at the Bozeman Health Department it was found that she often refers people to YAP. After then talking with a contact at YAP, it was verified that YAP does provide services for PLWHA from Great Falls and Bozeman eastward. Thus, YAP was included in the resource guide.

The goal is that the resource guide acts as a start for people to be linked with services and events. PLWHA can use the guide to find contacts and organizations in their

area to further link them with specific resources based on individual need. For example, some case managers reported they often link PLWHA to churches for food donations. Often times the specific names of the churches were not revealed when speaking with case managers. In terms of food resources for PLWHA it was not feasible to list every church that offers food to people in need. As a result, case managers and organizations are listed that will link people to food resources in their area if warranted. Another example is that one organization holds support groups and dinners for PLWHA, up to date information regarding dates, times, and locations of these functions can be obtained by contacting the organization. As a result the resource guide does not list specific times or locations of community based functions but rather the organizations that sponsor them.

The resource guide contains phone numbers, addresses, and website links to organizations. Under each organization specific services that the organization provides are listed. In term of privacy, some organization contacts asked that their direct phone numbers and names not be included on the resource guide. As the guide came together it was decided to not include any specific names on the guide to keep uniformity. Names are also omitted in order to respect privacy of individuals and organizations.

During data collection it was found that there is a lot of overlap of resources for PLWHA and the lesbian, gay, bisexual, transgender (LGBT) population. It was decided to keep the resource guide to organizations and programs that serve specifically PLWHA. This was decided because although there may be some overlap in these two populations, they are, after all, two distinct populations.

Pilot Study of Resource Guide Results

Pilot study results consisted of answers to the survey that was e-mailed to contacts regarding: readability, organization, and usefulness of the resource guide (see Appendix D). The survey consisted of four yes or no questions with space below each question to explain answers. The final question had a space below for people to provide additional resources that were not listed on the resource guide.

The survey along with the resource guide was distributed via e-mail to 12 professional key informants who work for organizations that serve PLWHA. A total of 10 surveys (83%) were returned. All of the surveys returned were filled out completely. Everyone who completed a survey answered, “yes” to the first three questions with the exception of one participant. In this case, the participant answered “no” to the question: “Do you think the resource guide was organized in a logical way”. This participant elaborated in the space provided by stating; “I don’t like how community resources is split on two pages. Can they be combined? Maybe put online resources on back page”. This suggestion was taken into consideration and prompted a change in the overall order of the resources listed on the guide. Under the fourth question that read, “Are you aware of additional resources specifically for people living with HIV/AIDS in western Montana that are not listed on the resource guide” two participants listed additional resources. The resources were then verified and included on the final guide.

In addition to completing the survey participants wrote back via email with suggestions and comments. One participant stated that most of the community organizations listed on the resource guide also offer condoms for PLWHA and that this

would be a helpful resource to add. This information was verified and condom availability was added below two organization headings. Another participant stated that as of January 1, 2013 one of the state run hotlines was no longer in service, this information was verified and the hotline was taken off the resource guide. The case manager for one of the community organizations listed the specific wording of bullet points to be included under the heading of the organization she works for. The wording she requested was then changed on the resource guide. One participant suggested taking the prefixes “http://” off of all of the websites to improve readability and for a cleaner look. Prefixes were taken off as it did contribute to an over cleaner look.

According to the survey, participants found the resource guide to be easy to read, logically organized, useful, and comprehensive. Most participants expressed enthusiasm and were in support of the resource guide. One participant wrote, “ We’re looking forward to having this resource to offer our clients”. Other participants wrote, “I like the layout of the guide”, and “thank you for taking an interest in this topic, not many people do”. Many of the participants provided their direct phone numbers should further questions arise.

CHAPTER 5

DISCUSSION

Strengths

The overall content of this project including the Statement of the Problem, Background and Significance, Review of the Literature, and the Outcome of the Project was the result of an overview of findings from a variety of scholarly research. The studies that contributed to the project consisted of current research within the last 10 years. Although a review of the literature did not reveal any specific studies that focus on rural dwelling PLWHA in western Montana, qualitative and quantitative studies were found that dealt with various connections within the statement of purpose. For example, Rajabium et al (2007) and Cabral et al. (2007) conducted studies that looked at the connection between degree of engagement in community outreach interventions and retention in the medical care system for PLWHA. Basta, Enbal, & Reece (2009) examined the connections between availability of community resources, degree of community involvement, and health outcomes among rural dwelling PLWHA. In order to find these connections in the literature, the project topic was broken down into categories that were viewed in the context of living with HIV/AIDS. These categories included; community resources, social isolation, rural United States, and health promotion. By looking at each of these categories through the lens of living with HIV/AIDS, a comprehensive literature review evolved despite the lack of specific studies involving rural dwelling PLWHA in western Montana. The review of the literature allowed for a

complete look at barriers rural dwelling PLWHA face in achieving their optimal quality of life. Social and community support proved to be important aspects to improving overall health outcomes in this population.

Once the resource guide was developed a pilot study of the guide provided professionals the opportunity to approve the content of the guide as well as make recommendations for improvement. An 83% return on the pilot study surveys proved to be a great strength of the final guide. Survey participants provided constructive criticism regarding content and layout of the guide; this information improved the overall quality of the guide. A leading figure at the Montana Department of Public Health who works with statewide HIV programs and surveillance conducted a final edit of the resource guide. In addition to editing the guide, this key informant also made recommendations for improvement. Having this key informant edit the resource guide also proved to be an important step in the overall quality of the guide, this was a major strength of the pilot study.

Limitations

Western Montana, for the purpose of this project, is defined as the 22 most western counties in the state. Western Montana counties are each unique in terms of population, geography, and access to existing resources. Because of the uniqueness of these counties, this project is not generalizable beyond the specific counties of interest. This is a limitation, as this project cannot be utilized by other states or even by other counties within Montana.

The final resource guide will be available at organizations that work with

PLWHA, clinics, and public health centers. Beyond these locations the resource guide will also be available via the Internet, this assumes people have access to the Internet. This is also a possible limitation as not everyone has access to one of the physical venues listed above or access to the Internet.

The lack of informal community resources is a limitation apparent at first glance of the resource guide. Examples of informal community resources include, support groups, informal dinners or potlucks, or recreational outings involving PLWHA. During the data collection of this project it was found that these types of informal gatherings do exist throughout western Montana. Individual meeting dates and times of such occasions are not listed on the resource guide because it was found that many of these dates, times, and locations change. Furthermore, it was found that informal community resources are usually sponsored by one of the organizations listed on the guide. Under each organization listed there are bullet points that list these types of informal community gatherings. It is assumed that if someone reading the guide is interested in one of the gatherings, they will contact the organization to find the accurate date, time, and location.

Another limitation of the guide is the lack of healthcare providers listed on the guide. Names and contact information of specific healthcare providers who work with PLWHA are not listed on the guide for two reasons. The first reason was the fact that a comprehensive list of these providers was found to be difficult to generate. There is a current list of providers in Montana labeled as “LGBT friendly”, but not a list of those who serve specifically PLWHA. Initially, the beginning of a list was generated at the start of the data collection. It was found that most caseworkers and organizations had specific health care providers in their area that they typically refer PLWHA to. It was also noted

that at times, in certain locations, many caseworkers refer PLWHA to family practice or general practice providers. It was decided that individuals who utilize the guide and are looking for a provider will contact one of the organizations or case managers in their area and then be connected to a provider through that initial contact. This process of finding a provider is not optimal but is seemed like the most logical solution. The second reason for not including a list of providers was limitation of space. It is assumed that the resource guide will be printed and distributed by organizations, for this purpose information was restricted to what could be legibly printed on front and back of one sheet of paper.

The final limitation of the resource guide is the ability to keep the guide updated and current. With a variety of resources it is inevitable that some of the information will change overtime. One way to attempt to overcome this limitation was to email the resource guide to the ten survey participants in the form of a Google document. The ten participants are all people who work at the organizations listed on the guide. The purpose of a Google document is that information on the guide can be updated and changed as needed. As additional copies of the resource guide are needed they can be printed from the updated Google document and distributed as needed. This method does not insure that the guide will be always be continually updated but it will allow involved persons to make updates when they choose to.

Implications

The advances in HIV/AIDS research have extended the lives of many PLWHA (Emlet, 2006). Because PLWHA continue to reach the later stages of life, more so than before, HIV is now considered a chronic illness (Cabral et al., 2007). Along with the chronicity of HIV comes new set of needs for this population. With this, comes the need for continued research in caring for this population. In terms of healthcare needs, the rural dwelling population requires unique approaches that take into consideration the individual needs of this population (Long & Weinert, 2010). When the two unique factors of living with HIV/AIDS and living rurally are combined, an even more unique population evolves with an entirely different set of needs. Currently, few studies have examined the distress among the rural dwelling population living with HIV/AIDS (Basta et al., 2009). Furthermore, it is not apparent that the needs of the rural dwelling HIV/AIDS population in western Montana have been formerly studied. Additional research in this specific population will bring forth a better understanding of ways to overcome barriers and improve quality of life for this population.

As organizations throughout western Montana adapt services in order to continue to best serve PLWHA, updates will also need to be made in ensure continued accuracy of the recourse guide. Ideally, it would be best to have one representative or organization responsible for making changes and updates to resource guide.

Conclusion

The purpose of this project was to explore and compile the community resources available for PLWHA in western Montana. More specifically, this project assessed the barriers that rural dwelling PLWHA experience and ways to overcome these barriers. A review of the literature revealed that lack of community involvement in the population living with HIV/AIDS leads to a decreased quality of life in terms of physical and emotional health (Basta, Enbal, & Reece, 2009). PLWHA in rural areas have different needs related to potential for social isolation than their urban counterparts (Basta, Shachman, & Reece, 2009). The resources guide is a tool to help to overcome these challenges that PLWHA face in terms of making connections within their communities to improve their quality of life. The aim of the resource guide is to promote connections by linking PLWHA to community and state resources that will help build a sense of optimal physical health and emotional well being.

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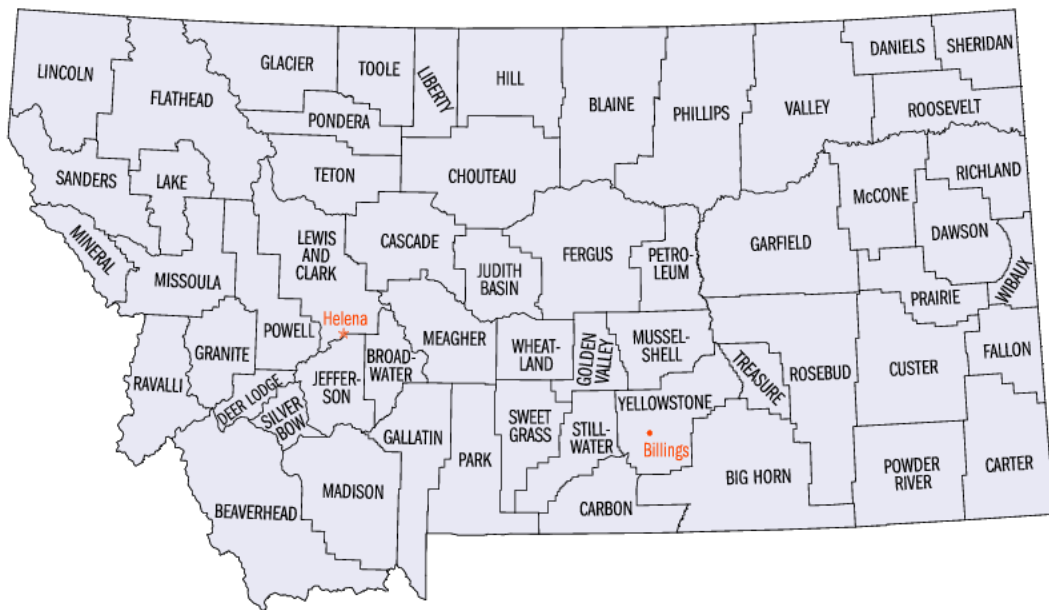
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APPENDICES

APPENDIX A

MONTANA COUNTY MAP

The counties to the left of the line are 22 western countries involved in the resource guide.



APPENDIX B

TOTAL REPORTED HIV/AIDS CASES BY MAJOR COUNTY

Total reported HIV/AIDS cases by major counties, 2005.

Yellowstone County	181
Missoula County	106
Cascade County	79
Lewis and Clark County	52
Silver Bow County	47
Flathead County	41
Gallatin County	42
Powell County	17
Lake County	18
Ravalli County	13

APPENDIX C

KEY INFORMANT QUESTIONNAIRE

- 1.) What is your knowledge of available resources for people living with HIV/AIDS?
- 2.) In terms of social support for people living with HIV/AIDS, are you aware of any specific formal or informal meetings, or community gatherings?
- 3.) Are you aware of any financial support resources for people living with HIV/AIDS?

APPENDIX D

PILOT TEST OF RESOURCE GUIDE QUESTIONNAIRE

1.) Did you find the Resource Guide easy to read? Yes No

If you answered no, please state why.

2.) Do you think the Resource Guide was organized in a logical way? Yes No

If you answered no, please state why.

3.) Did you find the content of the Resource Guide useful? Yes No

If you answered no, please state why.

4. Are you aware of additional resources specifically for people living with HIV/AIDS in western Montanan that are not listed on the Resource Guide: Yes No

If you answered yes, please share additional resources.

APPENDIX E

CERTIFICATE OF COMPLETION

Certificate of completion for the National Institutes of Health Office of Extramural Research web-based training course “Protecting Human Research Participants”

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Katrina Brucker** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.


Date of completion: 09/07/2009

Certification Number: 271977

APPENDIX F

RESOURCE GUIDE


Front Cover and Back Page




State Resources

AIDS Drug Assistance Program (ADAP) (406) 444-4744
Health Insurance Continuum of Coverage Program (HICCP) (406) 444-4744.
Early Intervention Program (406) 444-3565.
Partner Notification Services (406) 444-2678
HIV Case Management - 406) 444-3565 or the contact number for your area listed below.


- Butte/SilverBow Health Department: (406) 497-5016
25 W Front Street, Butte, MT 59701
- Cascade City-County Health Department: (406) 791-9279
115 4th Street South, Great Falls, MT 59405
- Flathead City-County Health Department: (406) 751-8154
723 5th Avenue East, Kalispell, MT 59901
- Gallatin City-County Health Department (406) 582-3100
215 West Mendenhall Rm 117, Bozeman, MT 59715
- Lewis and Clark City-County Health Department (406) 457-8952
1930 9th Avenue, Suite 207, Helena, MT 59601
- Partnership Health Center (406) 258-4165
323 West Alder, Missoula, MT 59802



[Street Address][City], [State][Postal Code]



Western Montana HIV/AIDS Community Resource Guide



First and Second Page

Know your HIV Status go to www.getcheckedmt.org to find a testing site.

Community Resources

AIDS Outreach: (406) 451-5718
202 S Black Ave, Bozeman, MT 59715

- Support Group facilitated by a licensed therapist and certified HIV educator.
- Direct outreach, support and assistance to/for HIV positive persons and their families/caregivers.
- Education, safe sex information.
- HIV testing, condoms, and lubricant

Butte AIDS Support Services:
www.buttebassonline.org

- Prescription drug co-pays
- Assistance with utilities and rent
- Transportation expenses to the doctor
- HIV Help/Info Hotline 406-490-6125
- Christmas gift cards
- Referrals in finding a doctor or mental health care provider.
- Up-to-date drug and treatment information
- Peer counseling
- HIV men's support group
- HIV Testing

FDH and Associates: (406) 829-8075
127 North Higgins 203-205 Missoula, MT 59802

- HIV positive partners' health retreat
- HIV positive gay men's health retreats
- HIV testing

The Lewis and Clark AIDS Project:
(406) 457-8952

(Serves Lewis and Clark, Broadwater, Jefferson Counties)

- Support Group facilitated by a licensed therapist and certified HIV educator.
- Direct Outreach, support and assistance to/for HIV positive persons and their families
- Education
- Annual HIV+ Women's Retreat
- Christmas gift cards
- Assistance with utilities and rent
- Prescription drug co-pays

Partnership Health: (406) 258-4121
323 West Alder, Missoula, MT 59802

- HIV primary medical care
- Integrated behavioral health services and
- Dental services
- Ryan White case management

Open Aid Alliance: (406) 543-4770
500 N Higgins Suite, 100 Missoula, MT 59802

- Housing assistance
- Needs Pantry
- Support groups
- Social activities (Friends and family dinner, movie night, book club, men's/women's group)
- Comprehensive case management services
- Client Lounge area
- HIV Testing, condoms, and lubricant

Open Hands Foundation: Great Falls
www.open_hands_foundation.home.bresnan.net

- Utility Assistance
- Food and non-perishable assistance
- Transportation Assistance

Tribal BEAR (Building Effective AIDS Response) Project: (406) 275-4913
Salish Kootenai College PO Box 70, Pablo, MT 59855

- Education
- HIV Testing

YAP (Yellowstone AIDS Project): (406) 245-2029
(Serves clients from Great Falls and Bozeman eastward)
2906 1st Ave. N., Billings, MT 59101

- GOAL Program (Get Out And Live)
- Tri-state HELP HOPWA (Housing Opportunities for Persons With AIDS)
- HIV testing

Questions/Comments contact: katrinabruckner@gmail.com



Online Magazines/Blogs

HIV Plus Magazine
www.hivplussmag.com

Positively Aware
www.positivelyaware.com

POZ Magazine
www.poz.com

From Eternity to Here (A Blog written by a "Gay HIV+ native Montanan"): www.dgsmith.org

Phone Resources

CDC National AIDS Hotline
1-800-342-2437

Project Inform National Hotline
1-800-822-7422

Online Resources

Just diagnosed with HIV? Start here:
www.aegis.org/Basics/diag1.aspx

The Body: The Complete HIV/AIDS Resource:
www.thebody.com

AEGIS: AIDS Education Global Information System: www.aegis.org

AIDS meds: Your Ultimate guide to HIV Care:
www.aidsmeds.com

AIDS.gov: <http://aidsinfo.nih.gov>

AIDS.gov: www.aids.gov

US. Dept. of Housing and Urban Development:
HIV/AIDS Housing website:
www.portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/aidshousing

Centers for Disease Control
www.cdc.gov/hiv/

