

COMMUNICATION AND INFORMATION EXCHANGE IN LIBBY, MONTANA:  
A SECONDARY DATA ANALYSIS OF COMMUNITY ADVISORY GROUP  
MEETING SUMMARIES

by

Natasha Nicole Blata-Pennock

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Sandra W. Kuntz, PhD, PHCNS-BC

Approved for the College of Nursing

Helen I. Melland, PhD, RN

Approved for the Division of Graduate Education

Dr. Carl A. Fox

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## ABSTRACT

Residents of the rural town of Libby, Montana are impacted by what has been called the worst case of community wide asbestos exposure in United States history. Over a decade after cleanup of the asbestos-contaminated vermiculite began, Libby area residents continue to experience the related aftermath of widespread asbestos exposure, including asbestos-related disease (ARD) and other chronic illnesses, an ongoing environmental cleanup effort and the conduct of multiple research studies. Effective communication is an essential element of trust and confidence in community-based activities. Although the Libby Community Advisory Group (CAG) was established as a two-way forum for communication and information exchange between the community and agencies involved in providing services to the community, little is known about the community's preferred modes of communication and the community's awareness, knowledge, acceptance and resistance to biomedical and behavioral research. The purpose of this study was to identify concerns, perceptions and preferences of Libby area residents related to research communication, information exchange and other issues pertinent to the community's health and well-being. A retrospective, qualitative analysis of CAG meeting summaries was conducted to identify themes that could lead to a better understanding of critical communication issues between community members and health service providers, policymakers, researchers and agencies involved with the environmental investigation and cleanup of the Libby area. A total of 53 meeting summaries from four years (2001, 2003, 2006 & 2008) representing seminal events in the community were examined. Eleven primary topics of discussion emerged from the data. Libby residents use a variety of communication and information exchange methods, including letters, newspapers and CAG meetings. Face-to-face communication is valued by the community. The community generally has a positive and supportive view of research, and coordination between researchers and local healthcare providers is important to community members. Rural traits and concepts were present in the CAG meetings, including independence, self-reliance, hardiness/resilience, distance/isolation and insider/outsider. Results support research in the Libby community, and emphasize the importance of communication of research opportunities, updates and results and the coordination of research activities with local healthcare agencies. Implications for practice and future research also are presented.

## CHAPTER ONE

## INTRODUCTION

Introduction

The residents of Libby, Montana are impacted by what has been called the worst environmental disaster in United States (U.S.) history (Environmental Protection Agency [EPA], 2007; Carr & Hawes-Davis, 2004). Twenty years after the closure of the W.R. Grace vermiculite mine and over a decade after cleanup of the asbestos-contaminated vermiculite began, Libby area residents continue to experience the related aftermath of widespread asbestos exposure, including asbestos-related disease (ARD) and other chronic illnesses, an ongoing environmental cleanup effort, and the conduct of multiple research studies. Effective communication is an essential element of trust and confidence in community-based activities. Although the Libby Community Advisory Group (CAG) was established as a two-way forum for communication and information exchange between the community and agencies involved in providing services to the community (Lux, 2003), little is known about the community's preferred modes of communication and the community's awareness, knowledge, acceptance and resistance to biomedical and behavioral research. This study will use CAG meeting summaries to identify concerns, perceptions and preferences of Libby area residents related to research communication, information exchange and other issues pertinent to the community's health and well-being.

## Background

The small rural town of Libby is located in the Northwest corner of Montana, in a forested valley between the Kootenai River and the Cabinet Mountains. Libby has a population of less than 3,000, with 12,000 people living within a ten-mile radius of the town (Kuntz, 2009). With a total population density of less than six persons per square mile, the county qualifies as “frontier”- a sparsely populated rural area far from population centers and services (Rural Assistance Center, 2008). The community boasts breathtaking scenery and numerous recreational opportunities, such as fishing, hiking and hunting. Libby, Montana is also the site of what has been called the worst environmental disaster in U.S. history (EPA, 2006) and the location of the first public health emergency declaration by the Environmental Protection Agency (EPA) in U.S. history under the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA) (EPA, 2009).

The world’s largest deposit of vermiculite is located near the town of Libby, Montana. Mining and processing of the naturally occurring silicate material began in the early 1920’s and continued until the closure of the mine in 1990. Vermiculite is a material that is capable of expanding to 8-12 times its normal size when rapidly heated, creating small, light weight granules. Vermiculite from this mine was used in a variety of construction, commercial and agricultural applications, including loose-fill insulation, fireproofing, gypsum plaster, packing material, fertilizer and potting soil mixes, brake shoes and sealants (Peipins, et al., 2003; Sullivan, 2007). While most vermiculite ore and products do not pose a health hazard, vermiculite from the Libby mine was contaminated

with a form of naturally occurring asbestos called “Libby amphibole asbestos” (Horton, et al., 2006; Peipins, et al., 2003). Asbestos contaminated vermiculite ore from the Libby mine was also shipped to over 200 processing and receiving facilities located in cities throughout the U.S. (Horton, et al., 2006). The W.R. Grace Company acquired the mine from the Zonolite Company in 1963, and operated it until the closure in 1990 (Peipins, et al., 2003).

For several decades, asbestos-contaminated vermiculite was mined, handled, processed, and used personally and commercially in Libby, leading to historical levels of occupational and environmental exposure and the widespread contamination of the community (Noonan, 2006; Peipins, et al., 2003). Asbestos-contaminated insulation remains in homes and buildings in the Libby area, and across the United States, Canada and other countries. Not only were the Libby vermiculite mine workers exposed, but so, too, were their family members, household contacts, and individuals living or visiting the Libby community who used or were exposed to the asbestos-contaminated vermiculite. Wives of the mine workers were exposed during the process of shaking out and laundering their husband’s work clothing. Children who played near the mine tailings or experimented with “popping” (expanding) pieces of vermiculite over a heat source inadvertently exposed themselves to the toxic substance (Peipins, et al., 2003; Sullivan, 2007). Numerous other occupational, recreational, household and environmental exposure routes have been documented (Noonan, 2006; Peipins, et al., 2003). Asbestos exposures in the community are ongoing, insidious and widespread (Pfau, Pershouse & Putnam, 2006).

Asbestos exposure in the Libby community has resulted in significant health problems, including asbestosis, mesothelioma, pleural abnormalities and lung cancer (McDonald, Harris, & Armstrong, 2004; Peipins, et al., 2003; Pfau, Sentissi, Weller, & Putnam, 2005; Sullivan, 2007). From 2000-2001, The Agency for Toxic Substances and Disease Registry (ATSDR) conducted an extensive medical screening program in response to reports of respiratory illness among people exposed to asbestos-contaminated vermiculite in the Libby area. A total of 7,307 individuals, who had lived, worked or played in the Libby area for more than 6 months prior to December 31, 1990, were included in the study. Of those, 6,668 participants received chest radiographs to assess the prevalence of lung abnormalities and a large percentage (17.8%) of individuals were found to have pleural abnormalities. Results of the study revealed significantly elevated rates of mesothelioma, asbestosis and lung cancer compared to Montana and U.S. populations (Peipins, et al., 2003). Several additional studies, some conducted before the ATSDR study and some after the study, demonstrated significantly elevated rates of asbestos-related disease (ARD) and death in the Libby community (McDonald, et al., 2004; Pfau, et al., 2005; Sullivan, 2007).

The scope of the problem goes beyond morbidity and mortality. This historic case of community-wide asbestos exposure has also resulted in a significant emotional, social and financial impact on the Libby community (Cline, Berry-Bobovski, Coleman, et al., 2006; Cline, Berry-Bobovski, Silk, et al., 2006; Cline, et al., 2007; McDonald, et al., 2004; Peipins, et al., 2003; Pfau, et al., 2005; Sullivan, 2007). With the closure of the W.R. Grace mine in 1990, many Libby area residents lost their jobs. Ironically, though, environmental cleanup and restoration is now one of the largest contributors to Libby's

economy. Cline, et al. (2007) found that in a community that otherwise values “taking care of its own,” a significant amount of stigma exists associated with ARD. Cline also found that conflict surrounding the asbestos contamination issue in the Libby community has created a rift in this self-described close-knit and supportive community.

The EPA has had a presence in Libby since 1999, collecting air, water and soil samples, as well as conducting extensive cleanup of the area. Libby was added to the EPA’s National Priorities List in October, 2002 enabling government funding for clean-up of asbestos-tainted-vermiculite in Libby and the surrounding area. On June 17, 2009, the EPA administrator Lisa Jackson determined that the conditions in Libby constituted a public health emergency (EPA, 2009). The declaration was based upon the uniqueness of exposure in Libby and the nearby community of Troy due to a number of factors, including the existence of multiple exposure pathways, the limited availability of health care providers and the high incidence of ARD. The historical emergency health declaration is the first such declaration made in the United States, and underscores the seriousness of the impact of the contamination on Libby and Troy communities and the need for healthcare for residents (EPA, 2009). The EPA’s cleanup efforts are ongoing in attempts to make Libby a safer place to live, work and visit (EPA, 2008).

The Libby community provides a rich source of data and a unique opportunity to bring together researchers from across a wide range of disciplines to study asbestos and the impacts of asbestos exposure. As Pfau, Sentissi, Weller and Putnam (2006) stated, “It is a unique population with both occupational and environmental exposures, excellent ongoing monitoring and demographic data, enthusiasm for participation in these studies and sufficient numbers of exposed individuals...for statistical analyses of many

parameters (p.28).” With asbestos-contaminated insulation in an estimated 15-30 million U.S. homes, the study of asbestos related issues is essential not only to the Libby community, but also for ensuring public health in communities across the United States (Pfau, et al., 2006). Understanding the issues surrounding asbestos exposure in the Libby community will require significant and ongoing interaction between researchers and the community. By developing functional partnerships, researchers will be better able to design and conduct studies that will yield the maximum benefit to the community with the least amount of impact on research subjects (Pfau, et al., 2006). Therefore, there is a need to understand the reciprocal communication between community members and research members.

#### The Community Advisory Group

EPA sponsored CAGs are rooted in CERCLA, which was established by Congress in 1980. Congress established this program to make public involvement in decision making an important part of the Superfund process. The intent was to ensure that the people whose lives had been affected by hazardous waste and materials would have a say in the actions surrounding the cleanup of these substances. This mandate was strengthened by the Superfund Amendments and Re-Authorization Act of 1986. CAGs are usually found in communities with hazardous waste sites where community interest is high and cleanup is expected to take several years to complete (EPA, 2008).

A CAG is made up of representatives with “diverse community interests” (EPA, 2008) and provides a forum for community members to discuss their needs and concerns related to the Superfund decision making process. While the CAG does not have any

decision making power with regard to EPA cleanup, the CAG informs the agency and decision makers of the opinions of the community. The size of the CAG depends on the needs of the affected community, but they typically have 15-20 members. Membership of the CAG should represent the composition of the affected community as closely as possible, and members should be drawn from among local residents, property owners, businesses, government units, environmental or public interest groups, and minority and low-income populations. CAG members may be selected in a variety of ways, including self selection, selection by local government in a fair, open manner, or by the EPA administrator with assistance of local government (EPA, 2008).

The Libby CAG was developed in 2000 by the EPA to provide a public forum for the community to come together and address questions, needs and concerns related to Libby asbestos issues and the Superfund decision making process. The meetings focused on exchanging information between the community and representatives from the EPA and other pertinent state and federal agencies. According to EPA representatives (2008), the purpose of the Libby CAG was to (a) provide a conduit for formal and regular communication between the people of Lincoln County and the EPA, (b) provide advice and/or recommendations to EPA and others such as Montana's Congressional delegation, (c) facilitate the creation of a new organization as needed, (d) facilitate the release of information, and (e) serve as a point of contact with Lincoln County for Montana's governor and others.

The CAG initially held bi-monthly meetings until mid-2002, at which times the meetings were then held monthly. Meetings were open to the public. Public

announcements containing the date, time and location of the meetings, along with the agenda, were displayed in the local newspapers in advance of each meeting (EPA, 2008). Meetings were held until February, 2009, when regular meetings were discontinued. The CAG dissolved secondary to a lack of productivity and community involvement. CAG meetings became increasingly unstructured and unproductive, with some individuals dominating the group and using the forum as a “gripe session” and to “agency bash,” rather than working toward common goals of solutions and resolutions to community issues and problems. The EPA left the CAG, stating that they were hoping to restructure the CAG toward more constructive information sharing (K. Rowse, personal communication, October 26<sup>th</sup>, 2009). The CAG is currently working toward re-organizing and resuming regular meetings, and the EPA has hired a new facilitator for the group. The individuals that have stayed involved believe that the CAG is a needed forum to allow information exchange between the community and the various agencies involved in investigation, cleanup and research in the community. (M. Giesy, personal communication, January 21, 2010).

#### The National Institutes of Health Public Trust Initiative

The National Institutes of Health (NIH) Public Trust Initiative was developed in 2007 in an effort to increase public awareness, understanding and confidence in the research the NIH conducts and supports (NIH, 2005). The initiative focuses on improved communication and interaction with the public, making public trust a top priority. It includes the assumptions that public input into NIH decision making and research leads to better research, and that quality research is necessary for optimal health (NIH, 2005).

The Public Trust Initiative seeks to provide the public with (a) information about how NIH conducts and supports research, (b) opportunities to participate in priority setting and other NIH activities, (c) opportunities to participate in clinical research and (d) access to, and understanding of, research results (NIH, 2005).

The NIH Public Trust Initiative posted a call for proposals and funded the Libby Partnership Initiative. The goal of the Libby Partnership Initiative is to raise the level of public awareness, understanding, acceptance and involvement in research in the Libby community (Winters, Rowse, Kuntz & Weinert, 2008). The research team consists of academic researchers from Montana State University College of Nursing and clinicians from Libby's Center for Asbestos Related Disease (CARD). To raise the level of public awareness, understanding, acceptance, and involvement in research in the Libby community, the Libby Partnership Initiative applied case study research methods and community based participatory research (CPBR) principles to address three project aims. The first project aim was to determine the research milieu in Libby by conducting a focused community assessment to include (a) history of research in the community, (b) infrastructure (services and resources) available to support the communication and translation of research in the community, (c) Libby resident's awareness, knowledge, acceptance, and/or resistance to biomedical and behavioral research and (d) Libby resident's preferred method(s) of communication about research. The second project aim was to design, implement and evaluate strategies for communicating research opportunities and results to Libby residents to (a) be used by researchers to facilitate research communication in Libby, Montana, (b) increase the community resident's awareness, knowledge and acceptance of research and (c) enhance the existing research

infrastructure for the communication of research to community members. The third aim of the project was to develop the foundation for a rural CPBR model that fosters community involvement in research and guides researchers working in rural communities (Winters, et al., 2008).

### Statement of the Problem

Effective communication is an essential component to the success of community-based activities. Although the Libby CAG was developed as a forum for two way communication and information exchange between the community and agencies involved in the clean-up efforts (Lux, 2003), little is known about preferred modes of communication and the community's acceptance and resistance to biomedical and behavioral research.

### Purpose of the Study

The purpose of this study was to use existing documents (CAG meeting summaries) to identify concerns, perceptions and preferences of rural Libby residents related to research communication and other issues critical to the population's health and well-being. CAG meeting summaries are one mechanism of communication between the Libby community and agencies involved in research, healthcare and cleanup. A retrospective, qualitative analysis of CAG minutes was conducted to identify themes that could lead to a better understanding of critical communication issues between community members and health service providers, policymakers, researchers and agencies involved with the environmental investigation and cleanup of the Libby area.

### Theoretical Basis for the Study

Two theoretical models, Covello's Risk Communication Model (Covello & Allen, 1988) and Long and Weinert's (1989) Rural Nursing Theory, were used to help frame this study. According to Covello's Risk Communication Model, risk communication is one form of communication between Libby community members and agencies involved in providing services to the area. This model stresses public involvement and emphasizes and addresses communication principles, including the model's seven cardinal rules for risk communication with people affected by disaster (Covello & Allen, 1988).

Rural nursing theory concepts and constructs were also used to inform this study (Lee & Winters, 2010; Long & Weinert, 1989). Several traits have been attributed to rural dwellers. These include: hardiness, self-sufficiency, independence, work oriented, religious, of traditional moral values, distrusting of "outsiders" and "newcomers," and trustful and respectful of "old timers" (e.g., persons who have lived in the community for an extended period of time). When dealing with health issues, rural persons tend to consult with a lay network of family and friends before seeking formal healthcare. Rural dwellers also face issues related to lack of anonymity and distance and isolation (Bushy, 1993; Boland & Lee, 2006; Lee & Winters, 2010; Long & Weinert, 1989).

Understanding the traits and characteristics of rural dwellers helped guide and inform this study. Understanding the unique characteristics of a community, including information about community member's knowledge, attitudes, perceptions, behavior, beliefs, values, needs and concerns, as well as information about social networks, opinion leaders, and community dynamics, is necessary for effective risk communication and

interaction with communities (Covello, McCallum & Pavlova, 1989). Kuntz, et al. (2009, p.72) reported that, “Knowledge of the uniqueness of rural persons is necessary for the development and implementation of effective health care policy in sparsely populated areas.”

### Research Questions

1. What are the primary information exchange topics among participants of the Libby CAG?
2. What are the communication characteristics among participants of the Libby CAG?
3. What are the primary themes related to community awareness, concerns, perceptions, preferences, knowledge, acceptance and resistance to healthcare, cleanup and biomedical and behavioral research?
4. What characteristics of rural people are evident among participants of the Libby CAG?
5. Is there evidence of Covello’s Seven Cardinal Rules of Risk Communication seen in the CAG meetings?

### Significance of the Study

The Libby community offers a unique and important opportunity to study the aftermath of an environmental disaster on a rural community (Kuntz, et al., 2009). Additional research is necessary to ensure the ongoing health and welfare needs of Libby area residents are met (Peipins, et al., 2003; Sullivan, 2007). Effective understanding of

potential health risks requires significant interaction between researchers and the community. Education, outreach and coordination of projects is necessary in order to minimize the impact on the exposed community (Pfau, et al., 2006). Effective communication and exchange of information among the Libby community and the multiple agencies involved in research, healthcare, and cleanup efforts in the community is essential for establishing trust and confidence in these agencies.

As additional research is planned in the community, care must be taken to coordinate efforts so as to reduce research burden on participants and community members. A better understanding of communication preferences and characteristics, and of primary information exchange topics of Libby CAG meeting participants, may provide information that could be used to help frame the direction for future asbestos research and to more effectively integrate the community in research, education and outreach efforts. By studying Libby area resident's awareness, knowledge, acceptance and resistance to research and their preferred method(s) of communication, future research opportunities and results can be more effectively designed, implemented and communicated.

#### Operational Definition of Terms

The operational definition of terms used in this study is presented below.

1. Acceptance: "approving reception; approval; acceptability" (*Webster's New World College Dictionary*, 2009, p.7).
2. Asbestos: "Asbestos" is the name of a group of similar minerals with separable, long, and thin fibers. Significant exposure to asbestos fibers increases the risk of

lung cancer, asbestosis, mesothelioma, and non-malignant lung and pleural disorders (ATSDR, 2008 (b)).

3. Asbestos exposure routes: Exposures can generally be categorized as ambient, occupational, household, residential and recreational.
4. Awareness: “aware: knowing or realizing; conscious; informed” (*Webster’s New World College Dictionary*, 2009, p. 55).
5. Biomedical research: Research conducted for the purpose of biomedical science.
6. Behavioral research: Research conducted for behavioral science.
7. Communication characteristics: Methods of communication and information exchange used, preferred or suggested, including by electronic means (website, e-mail), mail, newspaper, public meeting (i.e. CAG meetings), television, telephone, word of mouth or other sources (i.e. EPA Information Exchange Center).
8. Concern: “a matter of interest or importance to one; that which relates to or affects one; affair; matter; business” (*Webster’s New World College Dictionary*, 2009, p. 175).
9. Frontier: “Frontier areas are the most rural settled places along the rural-urban continuum, with residents far from health care, schools, grocery stores, and other necessities (RAC, 2009).”
10. Knowledge: “acquaintance with facts; range of information, awareness, or understanding” (*Webster’s New World College Dictionary*, 2009, p. 492).

11. Perception: “the act of perceiving or the ability to perceive; mental grasp of objects, qualities, etc. by means of the senses; awareness; comprehension” (*Webster’s New World College Dictionary*, 2009, p. 662).
12. Resistance: “the act of resisting, opposing, withstanding, etc.” (*Webster’s New World College Dictionary*, 2009, p. 771).
13. Risk communication “the exchange of information about the nature, magnitude, significance and control of a risk (Miller & Solomon, 2003, pg. 211)” and “an iterative co-orientation process among scientists and non-scientists about risk assessment, risk characterization, risk management and risk policy (McComas, 2004, pg. 62).”
14. Rural: The U.S. Census Bureau characterizes rural areas as open country and settlements with fewer than 2,500 residents or a population density of 2-6.9 persons per square mile (RAC, 2009).
15. Rural traits and concepts: Traits of rural dwellers include the following: hardiness, resilience, independence and self-reliance. Rural concepts include the concepts of isolation, distance, lack of anonymity, familiarity, the “old-timer/new-comer” concept and the related “insider/outsider” concept.
16. Vermiculite: A naturally occurring mineral geologically related to silica. Mined vermiculite ore is milled and processed to produce various materials used in the construction industry and in consumer, agricultural and industrial products (Sullivan, 2007; U.S. EPA, 2006).

### Assumptions and Limitations

The following assumptions apply to this study.

1. It is important to have effective communication regarding cleanup, healthcare and research between the Libby community and EPA, researchers and other agencies involved in Libby.
2. CAG meeting minutes will provide information on Libby area resident's preferred methods of communication and their awareness, knowledge, and perception of research.

The following limitations apply to this study.

1. Time constraints limited the amount of documents that could be reviewed.
2. Views of CAG meeting attendees may not represent the views of the Libby community as a whole.
3. Possible missing or incomplete data is a limitation in secondary data analyses (Polit & Beck, 2008; Szabo & Strang, 1997).
4. Due to time constraints and the need to minimize research burden in this community, member checks with CAG participants was not performed.

### Organization of the Remainder of the Thesis

This research study is presented in five chapters. Review of the literature is presented in Chapter II. A description of the methodology used for this research study will appear in Chapter III. The study's findings are included in Chapter IV. A summary of the entire study, discussion of the findings, implications for findings for theory and

practice, recommendations for future research, and conclusions are presented in Chapter V.

## CHAPTER TWO

## LITERATURE REVIEW

Introduction

All disasters are unique in that each affected community or area has different social, economic and baseline health conditions (Landesman, 2005). Likewise, communities affected by disaster have unique public health needs and concerns (O’Fallon, et al., 2003). An understanding of community conditions is an important first step toward effective interaction and communication with residents in these communities (ATSDR, 2008; O’Fallon, et al., 2003). The purpose of this study is to explore existing documents (CAG meeting summaries) to identify concerns, perceptions, and preferences of rural Libby residents related to research communication and other issues critical to the community’s health and well-being. An analysis of CAG meeting summaries was used to search for themes that could lead to a better understanding of critical communication issues between Libby community members and health service providers, policymakers, researchers, and agencies involved in the Libby community disaster. This study builds from and expands research being conducted funded by the National Institutes of Health (NIH) and National Institute of Nursing Research (NINR) that aims to learn about information exchange and research communication in Libby (Winters, et al., 2008).

In order to better understand the topic of interest, it is necessary to explore what is already known and unknown about the topic. In this chapter, current and relevant research and literature was examined as it relates to risk communication, research

communication, rural nursing theory, community-based participatory research (CBPR) and other topics related to this study. This literature review will provide important background information necessary to better understand the topic of interest, and will serve as a foundation for the remainder of the study.

A number of authors have written on the topics of environmental risk communication and communicating with communities affected by disaster (ATSDR, 2008; EPA, 1988; Landesman, 2005; Noji, 1997; Parkin, 2004; Peters, Covello, & McCallum, 1996). The NIH and others have outlined the importance of effective communication with the public in the areas of research planning and decision making, research participation opportunities, and dissemination of research results to participants (NIH, 2005; O'Fallon, et al., 2003; Parkin, 2004). Other authors have addressed rural nursing concepts, theory and practice, including characteristics, health needs and perspectives of rural dwellers (Bales, Winters & Lee, 2010; Finholdt, 2010; Lee & McDonagh (a), 2010; Lee & McDonagh (b), 2010; Long & Weinert, 1989). Still other researchers have specifically studied aspects of the Libby experience. Cline, Berry-Bobovski, Coleman, et al. (2006) explored the impact of a slow-motion technological disaster on the community image and dynamics. In two related studies, Cline, Berry-Bobovski, Silk, et al. (2006) analyzed social support processes associated with a slow-motion disaster and stigmatizing responses to asbestos-related disease as a barrier to health (Cline, Berry-Bobovski, Sayir, et al., 2007). However, no literature exists that reported on research communication and information exchange in the Libby community and little is known about the Libby community's preferred methods of communication

and the community's awareness, knowledge, concerns, perceptions, and acceptance or resistance related to biomedical and behavioral research.

For this chapter, pertinent literature was reviewed related to the key topics and themes of the study including: environmental risk communication; communication with communities affected by environmental disaster (importance and factors affecting communication, CAG role); research communication and dissemination; CBPR; and secondary analyses of qualitative data. Research and communication themes interrelated to rural nursing constructs were explored. Principles of risk communication and rural nursing were used as the conceptual framework in the literature search and in the development of this paper.

#### Description of the Literature Search

A review of journal articles, books and government resources was conducted to explore the literature on the topics of interest. Medline via First Search, PubMed and CINAHL were the search engines used to search for scholarly journal articles. These search engines were accessed through the Montana State University library's online access portal. The search engine "Google Scholar" was used to discover professional journal articles, books, manuals and government and organizational resources as they pertain to the topic of interest. Full text articles and materials were obtained either for free online through these databases, or were obtained through the Montana State University Interlibrary Loan service.

Websites of known environmental and public health organizations, such as the Centers for Disease Control (CDC), EPA, NIH, and the ATSDR were examined directly.

These sites provided valuable information, including expert opinion summaries, research studies, guidance material, information on principles and practices, and reference and fact sheets (for example, a reference fact sheet on CAGs was obtained from the EPA site). Additional studies and research proposals were obtained through investigators of the Libby Partnership Initiative (Winters et al., 2008). Search terms used included the following: communication, community, community advisory group, CAG, environmental disaster, technological disaster, community-based participatory research, Covello, risk communication, research communication, research dissemination, rural, rural nursing theory.

### Risk Communication

Risk communication is one form of communication between Libby community members and agencies involved in providing services to the area. This model was chosen because it emphasized and addressed communication principles with people affected by disaster and emphasizes public involvement. Risk communication principles and guidelines suggested that effective communication and public participation are essential for ensuring the health and well being of communities affected by disaster (ATSDR, 2008(a); ATSDR, 2008(b); Graffy & Booth, 2008; Peters, Covello & McCallum, 1996). As defined in chapter one, risk communication is “the exchange of information about the nature, magnitude, significance and control of a risk (Miller & Solomon, 2003, pg. 211)” and “an iterative co-orientation process among scientists and non-scientists about risk assessment, risk characterization, risk management and risk policy (McComas, 2004, pg. 62).” Risk communication is a vast and rapidly growing area of study and development

among academic researchers, government agencies and the public (McComas, 2004; Wardman, 2008). The evolution of risk communication principles and the transfer of power from the government to the public over environmental policy can be seen in legislation of the past thirty years, including the Emergency Planning and Right to Know Act of 1986, CERCLA of 1980 and the Superfund Amendments and Reauthorization Act (SARA) of 1986.

Despite the increasing prevalence of risk communication among academic researchers and government policy makers, some suggest that there exists a lack of clarity related to the definition, requirements and implementation of risk communication (Wardman, 2008). According to Chess, Salomone and Hance (2006), there is evidence that government agencies' risk communication practices lag. McComas (2006) indicated that while research on risk communication is diverse and multidisciplinary in nature, the field suffers from few integrative frameworks, making it difficult to capitalize on this diverse knowledge base.

### History of Risk Communication

According to Covello and Sandman (2001), there are four stages of risk communication. The first stage, the pre-risk-communication stage, was prevalent in the United States until the mid 1980's. This stage simply involved ignoring the public, and was replaced by the second stage when a movement began by communities to take back power over environmental policy. The second stage of risk communication involved learning how to explain risk data better. Risk communicators discovered that motivation is the key to learning, and that when people are sufficiently motivated, they can learn

very complex material. On the other hand, information can be presented, but an unmotivated audience may not be willing to process the information. From this evolved the third stage of risk communication, which is built around dialogue with the community. The publication of the Seven Cardinal Rules of Risk Communication by the EPA in 1988 was seen as a sentinel third stage event. A paradigm shift took place in this stage, and a new, expanded concept of risk was developed. Risk was seen as consisting of basically two elements, hazard and outrage. Stage four of risk communication involves treating the public as a full partner. This stage requires a shift in organizational values and culture. Limited progress has been made in this stage, mainly due to the difficulty of achieving individual and organizational change. However, a more forward CBPR approach may facilitate necessary cultural shifts.

#### The Seven Cardinal Rules of Risk Communication

The “Seven Cardinal Rules of Risk Communication” (Covello & Allen, 1988) was published by the EPA as a policy guidance document in 1988. These “cardinal rules” have been used by government organizations and academic researchers involved with environmental risk communication and center around the public’s right to be involved in decisions that affect their lives, property and things they value. According to the cardinal rules, the goal of risk communication is not to diffuse public concern or avoid action, but to create an informed public.

The first cardinal rule of risk communication is to “accept and involve the public as a legitimate partner (Covello & Allen, 1988).” Involving the public includes demonstrating respect for the public by involving the community early, involving all

stakeholders, clarifying decisions about risk and taking into account factors of concern to the public. The highest moral and ethical standards must be adhered to at all times.

The second cardinal rule is to “listen to the audience (Covello & Allen, 1988).” People must perceive that they are being heard if they are expected to listen. Effective risk communication is a two-way activity. Social, cultural, economic, and political factors should be taken into consideration, and people’s emotions should be recognized. Techniques such as facilitated discussion groups, advisory groups and surveys should be used to explore what people are thinking.

The third cardinal rule is to “be honest, frank and open (Covello & Allen, 1988).” The first goal of risk communication is to establish trust and credibility. Trust and credibility are a risk communicator’s most precious assets, however, they are often difficult to obtain, and once lost, nearly impossible to regain. Errors should be corrected promptly. Risk information should be disclosed as soon as possible, and if in doubt, sharing more information, not less, is better.

The fourth cardinal rule is to “coordinate and collaborate with other credible sources (Covello & Allen, 1988).” Effort and resources should be devoted to building partnerships and alliances with other organizations. Allied sources can be effective in helping communicate risk information. Conflicts or public disagreements with other credible sources can make risk communication more difficult.

The fifth cardinal rule is to “meet the needs of the media (Covello & Allen, 1988).” The media plays a critical role in transmitting risk information, setting agendas and determining their outcomes. Risk communicators should be open and accessible to

the media. Establishing long-term, trusting relationships with specific editors and reporters can be helpful.

The sixth cardinal rule is to “speak clearly and with compassion (Covello & Allen, 1988).” Technical language and jargon can be barriers to effective risk communication. Empathy and caring can often carry more weight than statistics and numbers. Risk communicators must be sensitive to local norms and culture, such as speech and dress. Pictures and graphics should be used to clarify risk information. Emotions must be acknowledged and responded to. A discussion of actions currently being taken, or that should be or can be taken, should be always be included. Risk communicators should only promise what can be delivered, and must follow through with any and all promises.

The seventh cardinal rule of risk communication is to “plan carefully and evaluate performance” (Covello & Allen, 1988). Effective risk communication requires careful planning and evaluation. Different goals and audiences require different risk communication strategies. Messages should be pre-tested. Risk communication efforts should be carefully evaluated and altered if needed.

### Risk Perception

Covello and Sandman (2001) outlined several important social and psychological determinants of risk perception. These social and psychological determinants affect how risk information is processed and how the actual magnitude of a risk is judged.

Determinants pertinent to this study and to the environmental disaster in Libby include voluntariness, controllability, delayed effects, trust, media attention, reversibility and

human versus natural origin. Risk from activities judged to be involuntary or under the control of others (versus the individual) are perceived to be greater, and thus less readily accepted. Risks with irreversible consequences (such as birth defects) are judged to be greater than those with temporary or reversible effects. Risks from activities that may have delayed effects (e.g., long latency periods between exposure and adverse health effects) are judged to be greater than risks from activities viewed as having immediate effects (e.g., poisonings). Risks from activities associated with individuals or organizations lacking in trust and credibility are judged to be greater than risks from activities associated with those that are trustworthy and credible. Risks from activities that receive considerable media coverage are judged to be greater than risks from activities that receive little attention. Risks generated by human action or incompetence are perceived to be greater and less readily accepted than naturally occurring risks (such as hurricanes or tornadoes).

### Trust and Credibility

Trust and credibility are key components of effective environmental risk communication (McComas, 2004; Peters, et al., 1997; Wireman & Long, 2001). Perceptions of trust and credibility are dependent on three factors: perceptions of knowledge and expertise; perceptions of openness and honesty; and perceptions of concern and care (Peters, et al., 1997). These perceptions can be either positively or negatively affected by activities performed by groups involved in environmental risk communication. Active disclosure of information and risk management activities increases the trust in groups performing these activities. Providing appropriate and

effective environmental risk communication demonstrates that the communication source is forthcoming and forthright (Peters, et al., 1997).

A major obstacle to effective risk communication is distrust. Sources of distrust are abundant, and include disagreements among experts; lack of coordination among risk management organizations; inadequate training of experts and spokespersons in risk communication skills; insensitivity to the requirements for effective communication, public participation, dialogue and community outreach; and mismanagement and neglect on the part of information providers. Once trust and credibility are lost, they are nearly impossible to regain (Covello & Sandman, 2001).

Tajik, Gattlieb, Lowndes and Stewart (2007) conducted a case study of community contamination due to activities of an oil refinery in Casper, Wyoming. Data were collected from multiple sources, including public testimonies, public hearings and meeting minutes, and archived records obtained from federal and state environmental health agencies. The authors identified and explained factors that affected the community's perception of risk related to industrial contamination, as well as the community's distrust of government agencies regarding the investigation of environmental contamination. The study identified that there was a lack of trust in government agencies due to several critical events and factors, including no response or delay in response time to community concerns, lack of transparency, perceived "cover up," perceived unfair treatment, perception of pro-industry stance or industry influence, and poor communication by government and state officials. The authors concluded that environmental risk perception and willingness to accept explanations and investigations of environmental contamination are strongly influenced by the community's direct

experience with government agencies and the perception of industry influence over the investigation.

Eisenman, Cordasco, Asch, Golden and Glik (2007) conducted a qualitative study of the experience of Hurricane Katrina evacuees to better understand factors that influenced evacuation decisions in vulnerable communities. The authors found that distrust of authorities led to the minimization of the perceived risk associated with Hurricane Katrina. Participants also reported mistrusting hurricane warnings, which influenced their decision whether or not to evacuate.

### Community Involvement in the Research Process

Research participants and communities increasingly feel that they have the right to be equal partners in the research process and to have access to studies to which they have contributed (Parkin, 2004). This has led to greater community participation in the research process over the past decade and a half. This type of partnership ensures that research program development is congruent with the public health needs of the community, and that research is responsive and applicable (O'Fallon, et al., 2003).

It is essential for researchers to foster relationships with communities to understand and respond to their unique public health needs. Researchers must be able to respond to communities concerns, demonstrating that they value the community's views, are committed to protecting participants' input, and are open to issues that may not have been included in the original research design (Parkin, 2004). Researchers also need to be able to communicate research advances in a manner that is understandable and culturally appropriate. This two-way dialogue is a fundamental building-block to the development

and implementation of effective research and intervention efforts in communities affected by environmental health risks (O'Fallon, Wolfe, Brown, Dearth & Olden, 2003).

Recent studies of community-based participatory research (CPBR) have substantiated the positive outcomes from research partnerships established with communities (Israel, Schulz, Parker & Becker, 1998, O'Fallon & Dearth, 2002). All partners benefit if a community partnership is truly a collaborative partnership (O'Fallon, et al., 2003). Communities benefit from improved health, increased knowledge of health risks, policy change, and advanced knowledge, skills and abilities related to research processes. Researchers benefit with increased participation and retention of research participants and with enhanced research design as new and different community needs and environmental concerns are identified. Local, state and federal organizations benefit from the data collected and an increased awareness of community environmental health issues (O'Fallon, et al., 2003; Parkin, 2004). By listening, acknowledging and responding to participants' and community issues and by developing effective partnerships with communities, researchers can reduce suspicion, build trusting relationships and increase support for current and future research efforts and health interventions (Parkin, 2004).

Studies are conducted in communities every year to measure environmental contaminant exposure and assess for related health impacts. Many of these studies involve local and state agencies and/or involve community based participatory research (CPBR) (Israel, et al., 1998). The dissemination of data and results from these research studies to study participants varies in execution and efficacy. Participants may be provided with environmental and/or health data gathered from their involvement in the study. In other cases, participants may be provided with the overall study results and the

interpretation of their personal results in the context of the entire findings of the study.

Yet another example of research dissemination involves providing research results to the communities from which participants are identified (Parkin, 2004).

There is a growing recognition among researchers and their sponsors that communicating research results to participants and communities is an important part of designing a study and ensuring positive and sustainable relationships (Parkin, 2004). Funding institutions have begun to encourage grantees to develop partnerships with communities in order to have a greater overall impact on the public health of the community (O'Fallon, 2003).

Several barriers exist to effective research communication with research participants and communities. One of these issues is related to the fact that research communication is rarely taught at academic programs or discussed at professional meetings. This lack of focus and attention on research communication has led to a lack of clarity on the part of investigators regarding their duties to communicate the results of their research to the community. It is important to address this issue because researcher's lack of communication fosters a climate of distrust in science and implies disinterest or disrespect for research participants and communities (Parkin, 2004).

Research communication problems may also be partly due to Institutional Review Board (IRB) prohibitions governing contact with research participants, or because of the lack of awareness on the part of the researcher regarding their responsibility in communicating research results. It is evident that researcher's practices in communicating research results to participants and communities are quite variable. These discrepancies can lead to anger, distrust and communities expectations not being met.

This distrust in researchers can doom follow-up efforts, interventions and future research studies (Parkin, 2004).

Two challenges for researchers are to determine what “research communication” is in their projects and to identify the “community” that is affected by or may be interested in their studies. Communities may recognize and define themselves quite differently as compared to researchers. This discrepancy in definition may be one of the most important but frequently unexplored issues that can undermine the design of appropriate and effective communication of research planning, opportunities and results. Researchers must be fully aware of their potential stakeholders to avoid potential skepticism and criticism of their research (Parkin, 2004).

The National Institute for Environmental Health Studies (NIEHS) has found Town Meetings to be a successful model for bringing researchers together with community residents and community, state and federal organizations (O’Fallon, et al., 2003). Models such as this help to ensure that affected communities have a voice in identifying environmental health research priorities. The NIEHS has supported 16 Town Meetings across the country since 1998. These meetings have addressed a range of environmental health issues, including particulate matter and health in Syracuse, New York (April, 2003) and in Chicago, Illinois (June, 2003); environmental health implications of pollution in Nashville, Tennessee (November, 1998); and Pacific Northwest environmental health issues in Seattle, Washington (September, 2000) (O’Fallon, et al, 2003).

The purpose of the town meetings is to bring together community members, academic partners, advocacy groups and local, state and federal groups, representatives

and organizations (O'Fallon, et al., 2003). The meetings provide a platform for an open dialogue to establish better coordination among health professionals working on various environmental exposure issues. The meetings also provide an opportunity to broaden public awareness and understanding of environmental health issues. Through these open discussions, NIEHS leaders learn about the issues that are important to the community (O'Fallon, et al., 2003).

There are many note-worthy outcomes of these NIEHS Town Meetings. An immediate outcome is an increased awareness of environmental health research carried out by the NIEHS and its grantees. Communities also learn of valuable resources that a NIEHS Center may offer. These Town Meetings may also help establish trust between researchers and the community (O'Fallon, 2003). Sometimes partnerships emerge from Town Meetings that develop into successful research projects. A crucial outcome is often establishing new methods of working with the community. Public health and policy impacts are anticipated outcomes of Town Meetings. Educational development is yet another outcome of the process of increasing awareness of environmental health issues (O'Fallon, 2003).

### Rural Nursing Concepts

Understanding the unique characteristics of a community, including information about community member's knowledge, attitudes, perceptions, behavior, beliefs, values, needs and concerns, as well as information about social networks, opinion leaders, and community dynamics, is necessary for effective risk communication and interaction with communities (Covello, McCallum & Pavlova, 1989). The more that is known about those

with whom you are communicating, what their concerns are, their perceptions, and whom they trust, the greater the likely hood that communication efforts will be successful (Landesman, 2005). Therefore, understanding the unique traits and characteristics of rural dwellers will help guide and inform this study of this unique rural community.

Rural dwellers are unique and distinct in their characteristics, perceptions, values and beliefs (Boland & Lee, 2006; Lee & McDonagh, 2010; Long & Weinert, 1989). Health definitions, needs, perceptions and behaviors of rural dwellers are also distinct and unique compared to their urban counterparts (Bales, 2010; Bales, Winters & Lee, 2010; Long & Weinert, 1989). Understanding rural dweller's definition of health and unique health care needs can assist nurses, researchers, and healthcare providers in providing care appropriate to and congruent with the rural culture, needs and lifestyle.

### Rural Definition of Health

Long and Weinert (1989) outline several key theoretical statements related to rural nursing theoretical concepts. The first relational statement is that rural dwellers primarily view and define health as "the ability to work, to be productive, and to do usual tasks (Long & Weinert, 1989, pg. 120). Winters, et al. (2010) further expand upon this statement with their identification of a rural health definition that adds to the original definition by including "the ability to play (pg. 51) and by identifying the importance of mental and emotional health. Lee and McDonagh (2010b) assert that rural resident's definition of health is changing to a more holistic view of health that includes physical, mental, social and spiritual facets.

Traits, Characteristics and Health  
Behaviors of Rural Dwellers

The second of Long and Weinert's (1989) relational statements is that "rural dwellers are self-reliant and resist accepting help from those seen as 'outsiders' or from agencies seen as regional or national 'welfare' programs (pg. 120)." The rural characteristics of self reliance and independence is a theme widely seen throughout literature about rural persons (Bales, Winters & Lee, 2010; Bushy, 2003; Collie, et al., 2005; Cudney, Sullivan, Winters, Paul & Oriet, 2005; Winters, et al., 2010). Rural dwellers tend to prefer the familiarity of individuals who know them, rather than 'newcomers' or specialists with whom they are unfamiliar with (Winters, et al., 2010). The 'outsider/insider' concept is pertinent in terms of the acceptance of researchers, healthcare providers, and others in rural communities.

A corollary to Long and Weinert's (1989) second relational statement is that "help, including needed health care, is usually sought through and informal rather than a formal system (pg. 120)." Rural dwellers primarily rely on self-care, family and close friends for help, accessing more formal healthcare systems when and if the situation is deemed serious or life threatening (Winters, et al., 2010; Bales, Winters & Lee, 2010). Family care traditions and a commitment to the community help to strengthen these informal networks (Harris, 2006). According to Lee and McDonagh (2010), the informal system is still frequently used, but there appears to be a change in this cultural barrier toward accessing knowledge and healthcare, with more and more rural dwellers seeking more 'formal' resources such as the internet.

Resilience and hardiness are also prevalent characteristics seen in rural dwellers. According to Bales, Winters and Lee (2010), rural research participants demonstrated several characteristics of hardiness, including adaptability, positive attitude and endurance. This finding has been supported by Leipert (2010). In this study, rural northern Canadian women were found to engage in processes that lead to hardiness and resilience. These processes involve taking a positive attitude, following spiritual beliefs and establishing self-reliance. The development of resilience was also seen in women who used and developed available opportunities and resources. Women also developed resilience through education and information seeking from healthcare professionals, colleges, and distance education programs.

#### Distance and Isolation

The concepts of distance and isolation are important in understanding rural health and health seeking behaviors of rural dwellers (Long & Weinert, 1989). Winters, et al. (2010) define distance as “separation (space, time and behavior) between the rural population and healthcare resources (p. 37).” It is recognized that the distance to all resources (not just healthcare resources) is greater for rural residents.

Despite the long distances that rural dwellers must often travel for both routine and emergency care, studies show that rural dwellers tend to see these services as accessible and do not view themselves as isolated (Bales, 2010; Long & Weinert, 1989). Finholdt (2010) noted that some respondents of her study believed that their communities isolation was a positive factor in that community residents realize they need to work together to solve problems. However, isolation can also make it difficult for rural

communities to solve problems because their access to resources is limited. In the same study, it was also noted that isolation and distance contributed to feelings of collective depression, skepticism and disenfranchisement.

### Lack of Anonymity

Lack of anonymity, another important concept in rural nursing, “implies a limited ability for rural persons to have private areas of their lives (Long & Weinert, 1989, p.120).” Finholdt (2010) found that rural community members serving on a health planning team were reluctant to express opinions that conflicted with others in the group, thus reducing openness during discussions, because the team members knew each other well and interacted often.

### Rural Communication

In order to be effective, communication with rural dwellers must take into account the rural culture, rural traits and the rural way of life. Rural communication has unique bridges and barriers that must be taken into account.

In their study of chronically ill rural women, Cudney, et al., (2005), poor communication with healthcare professionals was identified as a problem. Participants reported feelings of not being taken seriously or listened to. In their study of rural community leaders’ perceptions of environmental health risks, Larsson, Butterfield, Christopher and Hill (2006), participants emphasized that environmental health messages “needs to get out in a lot of different ways (p. 109).” Participants also emphasized that

communication and interventions must be compatible with and sensitive to the rural culture and regional identity.

Rural market places have been found to be a unique and effective communication medium in rural Mexican villages (Spain, 1992). According to Larsson, et al. (2006), word of mouth communication is strength of rural communities, and should be utilized as a culturally appropriate and effective communication medium.

### Research in Rural Communities

There are many unique challenges, opportunities and rewards of conducting health research in rural communities. As discussed previously, rural dwellers are unique in their culture, health needs and health behaviors, which may be both challenging and rewarding. Researchers may face the challenge of dealing with the often harsh physical environment of rural areas. Accessibility to these communities can be affected by the physical landscape (mountains, desert) and weather conditions that are often harsh and unpredictable (snow, floods, wildfire). There are often limited resources in rural communities (Lightfoot, et al., 2008).

Early stakeholder involvement is important in rural research. Spending time in the community and with key community leaders helps to build interest, support and rapport. Research in rural communities is more likely to be successful if there is collaboration with the community (Lightfoot, et al., 2008).

In their research with rural Mexican-American women, Mann, Hoke and Williams (2005) outline several recommendations related to working with rural research participants. The authors note that multiple avenues should be used to recruit research

participants. Using a local contact for screening and scheduling potential participants proved to be the most successful recruitment method. Research in rural areas must take into consideration when the research is conducted. For example, research conducted during the busy chile harvest season in the rural southwest and Mexico areas would not be appropriate. The authors also noted that compensation for research participants must convey the value placed on their participation.

Maintaining confidentiality is an issue that must be addressed. Participants may not want to reveal their involvement in research to their friends or family. However, in rural communities where lack of anonymity is an issue, this may be a difficult task to accomplish. A plan should be devised a head of time to help keep information confidential from curious community and family members (Mann, 2005).

It is desirable if the community identifies the research topics of interest. This builds on the advantage of a vested community interest in the study. It is essential that researchers adhere to local customs, tradition and culture. Local “experts” on the research topic should be included whenever possible. It is also important to keep the community engaged as research partners throughout all phases of the study, and to disseminate research findings to the community (Lightfoot, et al., 2008).

## CHAPTER THREE

## METHODOLOGY

Introduction

The purpose of this study was to use existing documents (CAG meeting summaries) to identify concerns, perceptions and preferences of rural Libby residents related to communication pertaining to research and to other issues critical to the community's health and well-being. The Libby CAG is one method of communication between community members and agencies involved in providing services to the community. A retrospective, qualitative analysis of CAG meeting summaries was used to search for and identify themes that could lead to a better understanding of critical communication issues between the Libby community and researchers, healthcare providers, policy makers and agencies involved in environmental cleanup of the area.

Given the importance of effective communication pertaining to research and other issues critical to the health and wellbeing of the Libby community, this study specifically sought to answer the following research questions.

1. What are the primary information exchange topics among participants of the Libby CAG?
2. What are the communication characteristics among participants of the Libby CAG?
3. What are the primary themes related to community awareness, concerns, perceptions, preferences, knowledge, acceptance and resistance to healthcare, cleanup and biomedical and behavioral research?

4. What characteristics of rural people are evident among participants of the Libby CAG?
5. Is there evidence of Covello's Seven Cardinal Rules of Risk Communication seen in the CAG meetings?

### Method and Design

This retrospective, descriptive study used content and thematic analysis of existing documents to search for and identify themes related to research communication and other issues critical to the health and wellbeing of the Libby community. The existing documents that were used were CAG meeting summaries. Four years (2001, 2003, 2006, and 2008) of meeting summaries were analyzed.

Qualitative research methods seek "...to have the researcher look deeply into the world of individuals and phenomena" (Lunenburg & Irby, 2008, p. 88). The researcher attempts holistic understanding of a phenomena by closely examining peoples words, actions and records and searching for patterns and connections that emerge (Lunenburg & Irby, 2008; Polit & Beck, 2008). Qualitative studies use a design "...that emerges as researchers make ongoing decisions reflecting what has already been learned" (Polit & Beck, 2008, p. 219). In general, qualitative methods are flexible and researchers are able to adjust data collection and analysis strategies in response to what is learned during data collection.

Secondary analysis of qualitative data is an efficient way to generate new knowledge and insights from existing knowledge, and is considered a valid mode of clinical inquiry. Secondary analysis involves the utilization of existing or previously

gathered data, which may or may not have been collected for research purposes, to test new hypotheses, explore new relationships or create new insights. Secondary data analyses provide opportunities for the nurse researcher to exploit rich data sets (Polit & Beck, 2008) and the opportunity to participate in interdisciplinary research and knowledge development (Magee, et al., 2006). The process of data collection is time consuming and expensive, and with shrinking grant dollars and a growing interest in outcomes management, secondary data analyses offers the researcher a legitimate, cost-efficient and time-effective mode of clinical inquiry (Fain, 2004, Magee, et al., 2006; Nicoll & Beyea, 1999, Pollack, 1999, Szabo & Strang, 1997).

Several advantages exist for secondary analysis of qualitative data, including cost, efficiency, convenience, and the reduction of respondent burden (Fain, 2004; Szabo & Strang, 1997). The reduction of respondent burden is one advantage of secondary data analysis that is particularly pertinent in working with communities such as Libby that have been subject to repeated research studies. The use of existing data to answer new research questions allows for research to continue on a topic related to the population, but does not require the recruitment of additional study participants. By maximizing the use of data already collected, secondary analyses may avoid overburdening individuals and the community with repeated requests to participate in research studies. The use of existing data can also help facilitate the translation of knowledge to nursing theory and practice. Magee and colleagues (2006) explain that, "Use of large data sets can accelerate the pace of research by saving time and resources on data collection and allowing those resources to be applied to other aspects of the research process" (p.54). Another added

advantage is that secondary data are often longitudinal, allowing the researcher to track themes and trends over time (Nicoll & Beyea, 1999).

There has been recent renewed and increased interest in secondary data analysis in nursing research (Magee, et al., 2006; Pollack, 1999). One reason for this increased interest is the availability of an unprecedented amount of data resulting from the recent increases in digital and electronic capabilities that allow for the capture, storage and access to an enormous amount of data from a variety of disciplines that may be of interest to nurse researchers (Magee, et al., 2006). The ability to electronically capture and store enormous amounts of data has provided nurse researchers with an exceptional amount of qualitative data from a variety of sources (that may or may not have been collected for research purposes) that can be used for secondary data analysis. Examples include U.S. Census Bureau data, minutes of meetings, patient satisfaction surveys and information from patient medical records. The advent of software to aid in the coding, retrieval and analysis of qualitative data is another development which has facilitated the use of secondary data analysis in research (Heaton, 1998).

There are unique conceptual and methodological considerations associated with secondary data analysis. These issues should be well understood and managed before embarking on a secondary data analysis. Conceptual and methodological issues associated with secondary data analyses include the selection of an appropriate theoretical framework, a “fit” between the original data and the new research question(s), the identification of a suitable database or data source, the reliability and validity of the original data, and the issue of missing or deficient data (Magee, et al., 2006; Pollack, 1999).

The “fit” between the available data and the new research question(s) is perhaps the most important issue to resolve (Szabo & Strang, 1997). A conceptual match between the original data collection and the research question(s) will increase generalizability, minimize error and guard against threats to reliability and validity (Magee et al., 2006; Pollack, 1999). In regards to identifying a suitable database or data source, while it is true that qualitative data sources may not be as abundant or readily available as quantitative data, there are still numerous suitable sources from which to obtain data for a qualitative secondary data analysis.

Secondary analysis of qualitative data is not without disadvantages and limitations; however, the effects of these potential limitations can be reduced or overcome if identified and addressed early on in the process of the study. Limitations of secondary data analysis include lack of control in generating the data set for the secondary study, difficulty in finding a suitable database, the inability to strictly follow the guidelines of the chosen data analysis method, missing or deficient data, and the inability to achieve complete theoretic saturation in some cases (Fain, 2004; Polit & Beck, 2008; Szabo & Strang, 1997).

#### Source of Data

The Libby CAG held meetings that were open to the public from early 2000 until February 2009. Meetings were initially held twice monthly until mid-2002, then were held on a monthly basis. The agenda for the meetings was set by the facilitator between meetings with consultation and input from the EPA. The facilitator also attempted to

include requests from CAG members as to what they wanted to see on the agenda (G. Mueller, personal communication, January 29, 2010).

The facilitator also transcribed the meeting summaries stating that the meeting summaries are “what happened at the meeting, filtered by me” and that he attempted to “capture the content of what happened, including questions and comments.” It was emphasized that these are meeting “summaries” and not meeting “minutes” (G. Mueller, personal communication, January 29, 2010).

Handwritten notes taken by the facilitator during the meeting were used to construct a meeting summary draft that was sent to the EPA representatives and any presenters for review and comment. After making any needed corrections, the summary was finalized and sent out via e-mail to individuals expressing interest in receiving them (i.e. CAG members). The number of individuals that meeting summaries were sent to was “over a hundred.” Occasionally during CAG meetings individuals would note inaccuracies in meeting summaries from the previous meeting. On these occasions, this was noted by the facilitator/transcriber, but revisions were not made to previous CAG summaries (G. Mueller, personal communication, January 29, 2010).

Meeting summaries from recent and past CAG meetings (January 2004 through February 2009) are available to the public from the EPA website. Meeting summaries from earlier years (August 2000 through December 2003) are available from the EPA Field Office in Libby.

For this study, CAG meeting summaries for the years 2001, 2003, 2006 and 2008 were analyzed. This sample of meeting summaries represent seminal events that occurred in both the CAG history and the history of the Libby community related to the ongoing

environmental disaster. The year 2001 represents the first complete year that the CAG was in place and regular meeting were held. This year also represents a seminal event in the community, which was the completion of the ATSDR medical screening study. The year 2003 represents the period of time shortly after Libby was added to the EPA's National Priorities List, which occurred October, 2002, as well as the year that the ATSDR study was published. The year 2006 represents continued cleanup efforts, and is representative of an "ongoing year" for the CAG. Finally, the year 2008 represents the time leading up to the CAG dissolution and the period of time shortly before the federal public health emergency was declared in Libby, which occurred in June, 2009.

#### Ethical Approval

Ethical approval was sought prior the collection of data. The study was granted approval from the Institutional Review Board (IRB) at Montana State University. The IRB determined that this study was exempt since the study involved a secondary data analysis of existing documents and no identifying information was used.

#### Procedure/Data Collection and Analysis

Meeting summaries for the years 2001 and 2003 were obtained via e-mail from the EPA Field Office in Libby. Minutes for the years 2006 and 2008 were obtained online from the EPA website, [www.epa.gov](http://www.epa.gov). The documents were stored on the investigator's personal computer. Documents that were in PDF format were converted to Rich Text Format. Continuous line numbering was used to facilitate identification of each line in the summary. Each meeting summary was printed and named using the year, month and day

of the meeting. Hard copies of meeting summaries were stored in file folders in the investigators personal home office.

The meeting summaries were read once to gain an overview of the information and to identify general patterns in the data. The meeting summaries were then carefully examined and analyzed for themes related to the five research questions. Other themes found during the analysis were also identified and examined. As specific patterns and themes emerged, all analyzed meeting summaries were re-read to verify the presence or absence of these patterns and themes. Broad categories were first identified. As the data analysis continued, the categories became more defined. Each topic of discussion in the meeting summaries was coded with the corresponding category that it fit and noted in the margins of the document (i.e. “research,” “healthcare,” “cleanup”). Some topics of discussion fit into more than one category. A binder divided into the identified categories was used to manage the data. The location (year, month, day and line number) was recorded under the relevant category for each instance the category was identified. In some instances, a brief description of the topic of discussion was included to help with theme identification within the categories. Care was taken to avoid using any identifiable information during data analysis. Repeated readings, analyses, and tracking of the themes were continued until data saturation had been achieved and no new themes emerged. To verify the coding and topic headings used in the analysis of the CAG minutes, a member of the thesis committee, who was blinded to the first coding, independently coded one meeting summary (six pages, 286 lines). A comparison of the codes revealed minor variations in terms used for the codes, e.g. government agency involvement versus

government agency personnel, and indicated 100% agreement on the meaning of the codes used for these pages.

## CHAPTER FOUR

## FINDINGS

The purpose of this study was to use existing documents (CAG meeting summaries) to identify concerns, perceptions and communication preferences of rural Libby residents related to research and other issues critical to the community's health and well-being. A retrospective, qualitative analysis of CAG minutes was conducted to identify themes that could lead to a better understanding of critical communication issues between community members and health service providers, policymakers, researchers and agencies involved with the health and environmental investigation and cleanup of the Libby area. The research questions answered were:

1. What are the primary information exchange topics among participants of the Libby CAG?
2. What are the communication characteristics among participants of the Libby CAG?
3. What are the primary themes related to community awareness, concerns, perceptions, preferences, knowledge, acceptance and resistance to healthcare, cleanup and biomedical and behavioral research?
4. What characteristics of rural people are evident among participants of the Libby CAG?
5. Is there evidence of Covello's Seven Cardinal Rules of Risk Communication in the CAG meeting summaries?

A total of 53 CAG meeting summaries from 2001, 2003, 2006 and 2008 were analyzed. The meeting summaries were a very rich source of data. There were many discussions among CAG members, audience members and presenters regarding topics important to the health and well-being of the community. The information contained in these meeting summaries allowed for a glimpse into the concerns and preferences of this unique community. Table 1 contains a breakdown of the meeting summaries analyzed.

Table 1. CAG Meeting Summaries Reviewed

<b>Year</b>	<b>Number of Meeting Summaries</b>	<b>Average Length (number/lines)</b>	<b>Average CAG Member Attendees</b>	<b>Seminal Events</b>
2001	18	333	19	<ul style="list-style-type: none"> <li>• First complete year of CAG</li> <li>• ATSDR medical screening</li> </ul>
2003	12	316	16	<ul style="list-style-type: none"> <li>• Post Libby NPL</li> <li>• ATSDR study published</li> </ul>
2006	11	299	11	<ul style="list-style-type: none"> <li>• Ongoing and continued EPA cleanup</li> </ul>
2008	12	369	10	<ul style="list-style-type: none"> <li>• Period leading up to public health emergency declaration and CAG dissolution</li> </ul>

#### Primary Information Exchange Topics

The first research question of this study was, “What are the primary information exchange topics among participants of the Libby CAG?” Eleven topics were identified in the CAG meeting summaries as primary information exchange topics: CAG purpose and

process, cleanup activities, economy, funding and finances, government agency involvement, health, litigation and legislation, Public Health Emergency declaration, research, schools and children, and Superfund designation. Table 2 summarizes the frequency by meeting summary of how often each primary information exchange topic was discussed.

Table 2. Frequency of Primary Information Exchange Topics

<b>Primary Information Exchange Topic</b>	<b>Number of Meeting Summaries Cited</b>	<b>Percentage of Meeting Summaries Cited</b>
CAG Purpose and Process	24	45%
Cleanup Activities	51	96%
Economy	23	43%
Funding and Finances	48	91%
Government Agency Involvement	50	94%
Health	43	81%
Litigation and Legislation	25	47%
Public Health Emergency Designation	19	36%
Research	40	75%
Schools and Children	33	62%
Superfund Designation	11	21%

### CAG Purpose and Processes

The purpose and processes of the CAG group were identified as a topic of discussion in 24 of the 53 CAG meeting summaries that were analyzed (45%). Discussions about the CAG centered on its purpose, procedures, problems and dynamics of the group. The CAG was a topic of discussion more so in 2006 and 2008 than in 2001 and 2003.

Conversations reflected differing views of the CAG participants. Some participants spoke of the CAG in positive terms, describing it as “well known and respected in the community.” The CAG was also recognized as a group having power that influenced decisions in the community and that could be used to address important issues. One audience member stated, “The CAG has made huge accomplishments for Libby. It continues to be needed and I hope it continues.” However, the tone of comments and discussions about the CAG became increasingly more negative as time went on. Some participants expressed frustration and anger toward the EPA, and at times this anger and frustration seemed to overshadow the problems solving efforts of the group. Some participants believed that the anger and frustration felt toward the EPA accurately reflected how the community felt. Others believed that too much time was spent during the meetings “complaining about the EPA.”

The CAG participants seemed to become increasingly divided and dysfunctional toward the latter years, with more participants expressing dissatisfaction with the CAG. Some believed that the CAG should make a greater effort to hear the concerns of the public. Concerns were also expressed that EPA presentations and resulting discussion dominated meetings. As one CAG member stated, “Loading up the agenda stifles public

comment. EPA dominates the meetings most of the time. We should ensure that one-third of the meeting is reserved for public comment.” Dissatisfaction was expressed by some participants, who believed that they were not treated with respect during the meetings. Some spoke of concerns that the CAG was not representative of the community. Others felt that CAG meetings had become dominated by a few individuals. As one CAG member put it, “There are about four people who dominate the meetings and are rude.”

CAG meeting attendance also dropped in 2006 and 2008 compared to attendance in earlier years (see Table 1). Concerns were voiced over the lack of attendance and participation of community members in CAG meetings. Some members agreed that the increasingly negative tone of complaints at meetings decreased CAG attendance. One audience member believed that “apathy” was the source of the problem. Difficulty in getting people together with “strong views” was cited as another reason. One member believed that the lack of attendance was because people were “trusting others to take care of business.” In a 2006 meeting, an EPA representative also voiced concerns related to the CAG, stating,

Since returning to Libby two months ago, I have seen a change in the CAG compared to my earlier years here. Participation in the CAG and the audience has dropped. Representatives of many interests, including the business community no longer attend.

In general, participants commented that the CAG meetings needed to be more orderly and effective in its work, and focus more on issues important to the community. These feelings were reflected in one CAG member’s comment: “We need to get the CAG back on a more positive and substantive track, identifying and helping to solve problems important to our community.” While some community members believed that the CAG

had “outlived its purpose,” many agreed with one CAG member, who stated, “The CAG does fulfill a useful purpose and should continue.”

### Cleanup Activities

Cleanup activities referred to the investigation and cleanup of asbestos contamination in the community. Cleanup was one of the predominant topics of discussion among CAG participants, and was a topic of discussion in 51 of the 53 CAG meeting summaries analyzed (96%). Generally each meeting included an EPA report on the current status of cleanup activities. It was evident by the discussions that occurred during the meetings that cleanup was a primary focus and of the utmost importance to community members. One participant stated, “In spite of our health needs, Libby’s number one priority should be cleanup.” Meeting summaries contained many questions and comments related to current cleanup activities.

Investigation activities included sampling of air and soil, and items found in residences, businesses, schools and other public areas (such as parks and creeks). Participants often had questions as to results of sampling activities. These discussions seemed to be more prevalent in 2001 and 2003, when sampling activities were prevalent (e.g. Phase II of residential sampling that occurred in 2001). However, discussions about sampling and sampling methods were ongoing.

Cleanup was a topic of discussion that included the removal of asbestos contamination from homes, businesses, schools and other public areas. Participants discussed inside (insulation) and outside (yards, playgrounds, parks, etc.) contamination removal. These discussions included many questions to the EPA representatives about

current cleanup activities, as well as comments and concerns on the topic. A topic that was particularly important to community members was the removal of asbestos contaminated insulation. During the time when EPA was deciding whether or not they were going to remove insulation (2001), many community members expressed concerns and frustrations. In a 2001 meeting, one audience member expressed their frustration with the following comment: “We are still living with asbestos-contaminated insulation in our homes. We need them cleaned up.” Another audience member voiced concerns over children’s safety related to the contaminated insulation, stating, “EPA is willing to clean up the school running tracks, but we are sending children home to contaminated houses. We need to get the vermiculite insulation removed now.” The decision was made by EPA to remove insulation, but not all of it. There was disappointment expressed by some participants that all of the insulation would not be removed.

As cleanup went from more of an “emergency phase” to a “remedial” or “maintenance phase” discussion also included more questions and comments related to future investigation and cleanup activities. Participants wanted a long-term plan for cleanup activities. Participants expressed the need for ongoing monitoring and cleanup for many years to come.

### Economy

The economic effects of the environmental disaster were hard felt by Libby community members. The economy and economic impact of the community-wide asbestos contamination was a topic of discussion in 23 of the 53 meeting summaries analyzed (43%). Community-wide contamination and the stigma attached to being the

site of an environmental disaster and Superfund site caused many to fear detrimental economic effects. Asbestos contamination not only affected the health of Libby community members, but also the health of the economy. The economy was viewed as an important aspect of the community, and just as the health effects of asbestos exposure needed to be addressed, participants believed that the health of the economy should be addressed as well. However, there did seem to be a division between businesses and those more interested in economic issues than asbestos related issues. In one meeting, an EPA representative shared his concerns: “I have found the division in Libby among people interested in the asbestos issues and economic development to be troubling.” Some members of the business community expressed concern that if they shared their views at CAG meetings that their businesses would suffer. One audience member shared the following comment related to the economy and this division:

Some business people are afraid to participate in the CAG. They are afraid that if they voice concerns or contrary views that there will be a backlash to their business. As business people, we care about both the health of our families and of our economy.

Participants had questions and concerns related to contamination of business properties. Business owners feared the economic effects of having to shut down their businesses for cleanup. One audience member voiced concerns related to the effects on employees, stating “It is not just the business owners who lose money during the cleanup. Employees also lose wages.” The designation as a Superfund site and the “nation-wide stigma for asbestos contamination” translated into actual or feared economic repercussions for the business community.

Participants also expressed concerns that property owners would be billed for cleanup activities, something that they just could not afford. While home and business owners did not have to directly pay for most cleanup activities, some costs were still incurred. Examples include having to pay for special filters for vacuums and for the extra costs associated with watering new sod that was laid as part of a cleanup. Mortgage issues and the ability to sell homes with contaminated insulation were also discussed. Participants expressed concerns and fears that they would not be able to sell their homes or obtain mortgages if their homes were contaminated.

Economic re-development was identified by CAG participants as an area of importance to the community. Community members showed interest in activities such as economic redevelopment workshops and seminars. One workshop held in 2003, and another seminar held in 2006, were both described as successful, as measured by attendance and attendee satisfaction. Funding for economic re-development was also a topic of discussion at meetings. In 2008, eight million dollars in federal funds was provided to the city to support community economic development and infrastructure. There were individuals who felt that some or all of this money should have been spent on healthcare. As one audience member commented, "A healthy community is needed for economic vitality." Other participants express that that economic development was the best use for these funds, and would not only provide important assets to Libby businesses, but would also help mitigate some of the stigma associated with Libby's designation as a Superfund site.

In a surprising turn of events, the disaster actually provided the community with various relatively high-paying jobs that related to investigation and cleanup of asbestos

contamination. Buying and hiring locally was important to community members. For example, one audience member asked the EPA representative if insulation was being bought locally. The answer was “yes.” In another meeting, a CAG member asked the EPA representative “How many local people are on the EPA payroll?” The answer by the EPA representative was that 40 out of 45 employees of one clean-up company were “local hires” and that “70-75% of the people doing the excavation and trucking were hired locally.”

### Funding and Finances

Funding and financial topics were discussed at 48 of the 53 CAG meetings analyzed (91%). Participants discussed funding of healthcare, cleanup, research and other activities and organizations involved in the community. Along with a forum for agencies to report on funding issues and community members to add questions and comments to the topic, CAG meetings were often used to brainstorm ways to obtain and ask for funding for various projects important to the community.

The discussions of participants reflected a community with many concerns and frustrations with relation to funding of cleanup and healthcare activities. Community members wanted Libby to be cleaned as quickly as possible, but unfortunately funding issues seemed to significantly affect the pace at which the cleanup could be completed. This was illustrated by the following two comments by one participant and an EPA representative: “The faster we can get cleanup in Libby the better.” “The issue is funding the cleanup.”

Prior to the designation of Libby as a Superfund site, the source of cleanup funding was not entirely clear to many members of the community. Many worried that they would be billed for cleanup activities if the EPA could not recoup cleanup costs from W.R. Grace. Some members of the community appeared to agree that this need for funding was one reason to seek Superfund designation. Community members were frustrated that even with the historical nature of the environmental disaster, contamination and resulting illness and death from asbestos exposure, Libby was not receiving the funding that it should. As one CAG member commented in a meeting prior to the Superfund designation: “The lack of funding for the cleanup is killing people today. This can’t go on.”

Some cleanup funding concerns were alleviated after Libby was declared a Superfund site, allowing for federal money from the EPA for cleanup, but concerns were still present. Participant’s questioned who would pay for cleanup if contamination was found on properties that were already cleaned. Community members voiced concerns that the EPA’s budget for the Libby cleanup was inadequate, and would result in contamination being left behind. These concerns were summed up by one participant:

The decisions about which cleanups and investigations occur now are all about money. They should be about eliminating risk. Cleanup decisions based on budget limitations are in effect decisions about who should get the next dose of risk of asbestos-related disease.

Funding for healthcare was one of the most contentious issues discussed by participants of the CAG meetings. Many desired more funding for healthcare, and felt that the funding available was inadequate. Community members desired and frequently asked for funding for some type of “medical trust” or “medical plan” to pay for

healthcare needs of asbestos victims. Some participants spoke about the W.R. Grace medical plan that some of them had. Many voiced that it was inadequate. Some believed that W.R. Grace should pay for the community's medical needs, and others believed that it should be the federal government that should provide the funding. Some participants felt that the declaration of a public health emergency was needed in order address the community's health needs. Community members shared personal stories of their own experiences with asbestos-related disease in attempts to garner support for additional funding for the people of Libby.

#### Government Agency Involvement

This topic referred to various government agencies involved in the healthcare and cleanup efforts in Libby. Government agency involvement was cited in 50 of the meetings analyzed (94%). Although not "agencies" per say, references to and discussions involving city, county, state and federal officials were also included under this topic. Most meetings included presentations by representatives from various government agencies, including the ATSDR, Department of Health and Human Services, EPA, Lincoln County, Montana Department of Environmental Quality, and Montana Department of Transportation. Several governors, senators and congressmen also attended meetings or communicated regularly with the CAG (usually via letter). The CAG sought assistance from governors, senators and congressmen on a variety of issues, including funding for healthcare and cleanup, Superfund designation and public health emergency declaration.

CAG participants expressed mixed emotions toward the various government agencies and officials involved in the investigation and cleanup of Libby. For example, the EPA received both positive and negative remarks. Some participants described the EPA as “very professional and open” and appreciated their efforts in Libby. Others expressed distrust and dissatisfaction toward the agency. As for another example, comments made about the ATSDR were generally positive. Participants expressed their appreciation for the ATSDR’s efforts in the community. In one last example, Senator Max Baucus’s efforts to help the Libby community were specifically mentioned during several meetings, and CAG participants generally had a very positive view of this particular politician.

### Health

Health issues, including healthcare, was another predominant topic of discussion among CAG participants. Health issues were discussed in 43 of the CAG meeting summaries that were analyzed (81%).

Participants discussed the health effects of asbestos exposure and shared questions and concerns related to possible or actual exposures in the community. Exposure pathways seemed to be everywhere, from swimming in local creeks to cutting firewood. The fact that the community had been exposed to asbestos for so long on a community wide level that they could not afford any more exposure was of concern to the participants.

Screening and treatment for asbestos related disease was also discussed. The medical community in Libby seemed to pull together to provide much needed healthcare

to area residents. This was illustrated by one CAG member, who stated, “In 30 years of working in healthcare, I have never seen a community come together more than we have in Libby... The medical community in Libby will continue to work to provide needed health care.” Three non-profit organizations- St. John’s Lutheran Hospital, the Center for Asbestos Related Disease (CARD), and the Community Health Center (CHC) - worked together in addressing the community’s healthcare needs. CAG meetings often had presentations from one or more of these organizations, which allowed participants to ask questions and make comments related to health issues.

Healthcare coverage and funding was a common sub-topic of health issues that were discussed. Participants discussed and gave personal stories related to the financial toll of asbestos-related health effects. Community members expressed frustration over the lack of healthcare coverage for asbestos victims and spoke of obstacles that made it difficult for them to meet their healthcare needs. They recognized that local medical organizations, such as the CARD clinic and St. John’s Lutheran Hospital, were doing what they could, but they too needed funding. CAG meetings were used to discuss and plan how to best pursue healthcare funding. Some believed that W.R. Grace should pay all healthcare costs for asbestos victims, and other believed it should be the federal government who should pay.

### Litigation and Legislation

Litigation and legislation related to the Libby environmental disaster was cited in 25 of the meeting summaries that were analyzed (47%). During W.R. Grace’s bankruptcy, community members questioned how it would affect the cleanup activities in

Libby. Participants requested a criminal investigation, and spoke of their desire to see that criminal charges were filed against the company. One CAG member stated, “It must be our goal to see that what happened in Libby never happens again. If we need new criminal laws, then they should be passed.” In 2008, a settlement agreement was reached with W.R. Grace, prompting questions from the community as to how it would affect cleanup and healthcare. Meetings were also used to discuss current federal asbestos and healthcare legislation.

#### Public Health Emergency Declaration

Discussion related to a public health emergency declaration was present in 19 of the meeting summaries analyzed (36%). The topic was discussed in every year analyzed, but discussions seemed to become more extensive in 2008, the year prior to the 2009 EPA declaration. Participants discussed whether or not a declaration should be sought, what the implications would be if the declaration was made, and the process for seeking such a declaration. The CAG sent several letters to the EPA and other government officials requesting a public health emergency be declared in Libby. Because such a declaration had never been made, the community faced many obstacles in their quest to obtain the declaration. One such obstacle was identified by an EPA representative who noted that information on the declaration of a public health emergency from CERCLA was “outdated and doesn’t apply” and had never been updated because the EPA had never declared one.

Not everyone was convinced that a public health emergency was warranted or should be sought. In one 2001 meeting, a participant made the comment: “I’m not sure

that a public health emergency is needed.” Some participants had questions and concerns about the economic impact of the declaration. This was seen more so in the earlier years (2001 and 2003), and as time went on there seemed to be more of a consensus that the declaration was appropriate and needed. Participants discussed the unique nature of the environmental disaster in Libby and the widespread contamination, which they felt made Libby a prime candidate for the first such declaration in history. As one CAG member stated: “I suggest that our situation here in Libby is the definition of a public health emergency.” Another CAG member shared their view on the subject: “We have special circumstances in Libby that argues in favor of the emergency health declaration.” Community members grew frustrated by the lack of a public health emergency declaration and many felt that their government had failed them by not making the declaration. In one 2008 meeting, an audience member pointed out, “We’ve been pursuing a declaration of a public health emergency for Libby for years.” After the 2008 elections, some participants felt that the change in administration might open the door to finally making the declaration that Libby had been seeking for eight years.

### Research

Research was a topic of discussion in 40 of the 53 meeting summaries analyzed (75%). Specific studies cited in the meetings addressed health, behavioral and economic issues. CAG meetings often contained presentations from researchers, such as researchers from the ATSDR and University of Montana. Local research, such as that conducted by the CARD clinic, was also discussed. In 2001, when the large ATSDR medical screening study was underway, researchers presented the CAG with frequent status updates.

Meeting summaries also included discussions related current and planned research efforts. For example, several meeting summaries in 2008 contained discussion related to the Libby Amphibole Health Risk Initiative, which was designed to allow the local healthcare community to partner with top universities to conduct research. Meetings were used to inform the community of upcoming studies and sometimes even included information how to participate in those studies. Researchers often used CAG meetings to disseminate research findings as well.

Involvement of researchers at CAG meetings spurred questions and comments by participants related to research. Research was generally well supported by the community. Participants expressed interest in research and most shared the belief that research was needed in order to best address the needs of the community.

### Schools and Children

Children and schools were a topic of discussion in 33 of the meeting summaries analyzed (62%). Asbestos contamination was not only found in family's homes, but it was also found in Libby and Troy schools, running tracks, ice rinks and playgrounds. Discussions focused on investigation and cleanup activities at schools and other areas where children played. Participants also shared questions, concerns and comments related exposure and healthcare concerns related to community children.

Asbestos exposure was an every-day fear for parents of children in the Libby community. Children could potentially be exposed at school, home or during recreational activities. An example is the comment made by one audience member: "The people of Libby are living in fear because of the vermiculite insulation. Every time a mother

changes a light bulb, the insulation falls and may endanger her baby.” The concern for children was also reflected in this audience member’s passionate comment:

I am concerned about the next generation and their children. I am sorry and ask forgiveness for what I am leaving you. We should continue to be concerned about unborn children exposed through their mothers, about babies exposed to dust today, and children and adults who were exposed in the past by playing in contaminated material or by their family members who brought home contamination on their clothes.

The participant’s discussions regarding sampling and cleanup at Libby and Troy schools reflected the importance that they placed on their children and schools.

Community members placed “extreme emphasis” on the safety of their schools, and when it came to their children, they felt that “low exposure” was not good enough.

Community members also felt that exposure at schools “shouldn’t just be reduced- it should be eliminated.”

In 2008, meeting summaries reflected that concerns were raised that school contamination was still present, and that the EPA had not done the best job in handling contamination at the schools. Some felt that the EPA had not prioritized schools, and felt that there was a “lack of EPA response to school contamination.” One participant called the EPA’s handling of contamination at one elementary school “irresponsible.” However, one CAG member disagreed with this assessment, stating, “I do not agree that the EPA has not prioritized schools.”

### Superfund Designation

Superfund designation was discussed in 11 of the 53 meetings analyzed (21%). These discussions occurred in 2001- the year leading up to Libby’s designation as a

Superfund site. Participants had comments and questions related to the implications, advantages and disadvantages of a designation. Participants had some concerns related to the designation, including concerns related to potential economic impacts of being labeled a Superfund site. Some participants supported the designation, some opposed it, and some wanted to wait. At one CAG meeting, at the invitation of the CAG representatives of four Montana communities and organizations shared their experiences with Superfund designations. As the year went on, more participants seemed to support a designation and the CAG eventually sent a letter to the Governor in October requesting she use her authority to make the designation.

### Communication

The second research question of this study was “What are the communication characteristics among participants of the Libby CAG?” CAG meeting summaries revealed methods of communication and information exchange that were used, preferred or suggested by participants. Given the nature and complexity of the environmental disaster in Libby, open and frequent communication among stakeholders including community members, health care providers, researchers, educators, and local, state, and federal health officials played, and will continue to play, a crucial role in addressing the cleanup and health needs of the community. CAG participants utilized and recommended a variety of communication and information exchange methods associated with seeking solutions for addressing the many needs of the community. These methods are each presented in more detail and include: CAG meetings, letters, newspapers and printed media, “press reports” or “the media,” public meetings or face-to-face interactions (other

than CAG), radio, telephone, television and websites or e-mail. Table 3 presents the communication methods identified. Because of the implications for research, communication and information exchange related to research was placed into its own sub-topic.

Table 3. Communication Methods Cited in CAG Meeting Summaries

<b>Communication Method</b>	<b>Number of CAG Meeting Summaries Used/Cited</b>	<b>Percentage of CAG Meeting Summaries Used/Cited</b>
CAG	53	100%
E-mail and Websites	10	19%
Letters	36	68%
Newspapers and Other Printed Media	20	38%
“Press Reports” and “Media Reports”	9	17%
Public Meetings and Face-to-Face Interactions (excluding CAG)	10	19%
Telephone	4	8%
Television	4	8%

### The CAG

The first method of communication and information exchange that was identified was the CAG. In all CAG meeting summaries analyzed (53 meeting summaries or 100%), some form of communication took place between and amongst community members and individuals and organizations involved with the community. The CAG was utilized by community members as a way to get important information from agencies

involved in the cleanup and health-care efforts of Libby. The meetings also allowed participants to ask questions and share comments with their fellow community members and with the various agencies involved. The CAG served an important role in providing an avenue of communication among community members and those involved with addressing the environmental disaster, but toward the last couple of years as attendance decreased and the group became more dysfunctional, its purpose as a conduit for communication and information exchange seemed to be at times overshadowed by its problems. None-the-less, a lot of important information was shared at these meetings, and the CAG provided a venue for community members to get together and share questions and concerns related the cleanup and healthcare efforts in the community.

### Letters

Letters were one of the predominant methods of communication referenced in the meeting summaries, and were cited in 36 (68%) of the meeting summaries analyzed. Letters were used to communicate the community's problems, concerns, and requests. The CAG, acting on behalf of the community, sent letters to local, state and federal officials and organizations to seek support and funding for cleanup and healthcare. Personalizing letters with pictures and real-life stories was something that participants recommended to make this method of communication and information exchange "more powerful." One participant recommended mailing information including information about the proper handling and disposal of vermiculite "to every community mailbox." This participant went on to suggest "Perhaps it could be included with utility bills, such as Flathead Electric Co-Op."

### Newspapers and Print Media

Newspapers and printed forms of communication (such as brochures) were referenced in 20 (38%) meeting summaries as a preferred or utilized communication method. Names of some specific newspapers were given by participants, including the two local Libby papers, “The Western News” and “The Montanian.” The Kalispell newspaper “The Daily Interlake” the Missoula newspaper “The Missoulian” were also referenced by participants. “The Spokesman Review” is a larger, more national newspaper that was also referenced. Participants commented on information that they had read in the newspapers, and made suggestions that newspapers be used to communicate issues important to the community, such as upcoming meetings.

Other printed forms of communication, such as newsletters and brochures, were also utilized or recommended by CAG participants. Examples include EPA brochures that were referenced by participants during meetings. Another example is the suggestion of one audience member, who recommended putting “posters in stores” in order to recruit letters from community letters to present to the EPA.

### Public Meetings and Face-to-Face Interactions

The actual or suggested use of public meetings (other than the CAG) or face-to-face interactions as a communication method was cited in 10 (19%) meeting summaries. Participants voiced their preference that politicians and representatives from organizations (such as the EPA) visit the community and interact with community members “face to face.” In a 2001 meeting, a Montana governor sent a representative from her office to read a letter to the CAG. One audience member expressed their desire

to see the governor come to Libby in person, stating, “Words are not enough. The Governor should come to Libby and talk with us.” In another meeting later that year, the CAG prepared for the upcoming visit of this same governor referenced in the previous quote. The CAG again recommended that the governor attend a “town meeting during which she could listen to people from the Libby community.” Participants who preferred public meetings and face to face interactions seemed to feel that it was important to allow community members to really share their stories with others.

#### Television, Radio and Press and Media Reports

Television as a communication method was cited in four meeting summaries (8%). Radio was cited in five meetings (9%). The use of radio as a communication method was illustrated by one audience member, who commented: “My wife and I were not aware of the CAG, but we heard it advertised on the radio, so we came tonight out of curiosity.” Some methods of communication were referenced as simply “press report” or “media” (in 9 meeting summaries, 17%). Participants generally utilized or recommended this form of communication to try to inform others about the situation of the Libby community or gain support for the community. For example, in one meeting participants were discussing the need to request funding for healthcare from the governor. One audience member made the suggestion, “The CAG or someone should issue a press release about the need to ask to governor to support this funding.”

#### Websites and E-Mail

Websites and e-mail were another method of communication utilized by CAG participants. These methods were mentioned in 10 of the meeting summaries analyzed

(19%). The CAG used email to send information to its participants (and those on the group's e-mail list). For example, the CAG facilitator used email to circulate a draft of a letter generated by the CAG.

### Telephone

Communication via telephone was cited in four meeting summaries (8%). Community members called individuals and organizations involved in the cleanup and healthcare of Libby with questions, concerns and comments. In one meeting, a representative from the CARD clinic gave a report on the status of the clinic. She stated, "It (the CARD clinic) has received about 3,000 telephone calls from people seeking information about asbestos-related disease." This comment is one example of the utilization of phone calls as a method of information exchange.

### Research Communication

As stated earlier, because of the implications for research, communication and information exchange related to research was placed into its own subtopic. Research communication included communication and information exchange between researchers and community members related to: the current status of research studies, plans for upcoming research, opportunities to participate in studies and research results. Comments from meeting summaries reflected that participants believed research communication was important and beneficial to the health and welfare of the community. Table 4 presents research communication methods cited in the CAG meeting summaries.

Table 4. Research Communication Methods

<b>Research Communication Method Cited</b>	<b>Number of CAG Meeting Summaries Cited</b>	<b>Percentage of CAG Meeting Summaries Cited</b>
CAG and Public Meeting	40	75%
Letters and Mail (including electronic mail)	12	23%
Local Offices	5	9%
“Media” Including Radio, Newspaper and Television	10	19%
-Newspaper	5	9%
- Radio	4	8%
- Television	5	9%
Telephone	5	9%

Note: More than one method may have been referenced in a meeting summary

### CAG and Public Meetings

One venue utilized for research communication was the CAG and other public meetings, which were cited as a research communication method in 40 of the 53 meetings analyzed (75%). These meetings acted as a two-way communication avenue between researchers and community members. Researchers from the ATSDR, Karmanos Cancer Institute, Montana State University College of Nursing, University of Montana and other institutions provided presentations at CAG and other public meetings, keeping the community informed of the status of research studies and providing them with results. Participants were able to share their comments, concerns and questions related to research studies during these meetings. CAG participants were often presented with

handouts and copies of research reports from researchers. For example, in one 2003 meeting, the ATSDR presented CAG participants with pre-publication copies of their large medical screening study. CAG meetings were also used to share research opportunities with participants. One example is at a 2006 CAG meeting, where presenters from the CARD clinic informed meeting participants that they were “actively recruiting volunteers” to participate in focus groups that were going to be held by Karmanos Cancer Center researchers. Requirements to participate date of the meetings and compensation was also discussed.

#### Letters and Mailings

Letters and mailings, including electronic mailings, were cited in twelve meeting summaries (23%) as a method used to communicate research results and opportunities to participate in research. For example, the ATSDR mailed medical results screening letters to the individuals that participated in their large medical screening study. In another example, at the suggestion of CAG participants at a previous meeting, researchers sent letters to Libby High School graduates of the class of 1961 (who had an upcoming high school reunion in town), informing them that the research group had arranged to make medical screening available to them during their class reunion. One CAG member suggested utilizing e-mail to recruit research participants: “Recruitment can be made by email message. Each person who receives the message can be asked to send it to ten others.”

### Local Offices

Local offices were referenced in five of the 53 CAG meeting analyzed (9%) as a means of research communication and information exchange. Researchers utilized local offices, such as the EPA Information Center and the local ATSDR office to provide copies of research material. Researchers from the ATSDR provided the community with pre-publication copies of a study that was made available at the EPA Information Center in one example.

### Media

Media, such as radio, television and newspaper, was referenced in 10 of the 53 meeting summaries analyzed (19%) as a research communication method. Of these, five meeting summaries specifically cited newspapers (9%), five cited television (9%), and four (8%) cited radio as communication and information exchange methods related to research (some meeting summaries cited more than one example of research communication methods). One CAG participant made the following recommendation related to communicating research, indicating a preference for communication via television: “The medical screening toll-free telephone number should be put on cable TV channel 10.” Another suggested using the newspaper to communicate information related to a medical screening study, stating, “EPA should publish a reminder of this fact in the newspaper questions and answers.”

### Telephone

Research communication via telephone was referenced in five of the 53 meeting summaries. The ATSDR utilized a toll-free number during their time conducting a large

medical screening study. The number was used for individuals to call with questions related to the study and to obtain information on how to qualify and participate in the study. CAG participants suggested the researchers advertise this number both locally and nationally.

Community Awareness, Knowledge, Concerns, Perceptions,  
Preferences, Acceptance and Resistance to Cleanup and Healthcare

The CAG meeting summaries reflected several themes related to community awareness, knowledge, concerns, preferences, acceptance and resistance to cleanup and healthcare efforts (Research Question 3). In general, Libby community members perceived their experience as truly “unique.” The level and length of community wide exposure coupled with the toxicity of the specific asbestos fiber involved were factors that community members believed played into this uniqueness. This perception was reflected in the following CAG member comment: “The situation in Libby is unique. We are learning as we go.” Another statement made was, “We should make the point that our situation in Libby is unique because of our history of asbestos exposure.” The special circumstances involved in the Libby disaster were spoke of by participants in relation to both cleanup and healthcare. Ultimately, it was the goal of the community to achieve a complete cleanup of asbestos contamination in and around the community and to ensure the health needs of those exposed asbestos were met. In addition, as one participant stated, “It must be our goal to make sure what happened here never happens anywhere again.”

## Cleanup

Cleanup was viewed as the community's primary priority. Community members believed that a "complete cleanup" was necessary to eliminate ongoing exposure and was important to the economic recovery of the community. As one participant stated, "In spite of our health needs Libby's number one priority should be cleanup." Another shared their view on the subject, stating, "Every day that goes by someone else may be exposed." The economic implications of completing the cleanup was illustrated by this participant, who stated, "Libby has a nation-wide stigma for contamination. Without a complete cleanup reported by the media, this stigma will remain." Community members wanted cleanup completed as quickly and thoroughly as possible. One CAG participant shared their feelings on the subject, stating, "The faster we can get Libby cleaned up, the better." Another stated, "As a result of our historical exposure, Libby people cannot afford the risk of one more asbestos exposure."

CAG participants discussed cleanup activities currently being conducted, and shared their perceptions and experiences related to cleanup activities. Discussions suggested that some community members seemed to be fairly aware and knowledgeable on the topic, but discussions also reflected confusion related to cleanup procedures and activities. Community members did utilize CAG meetings to increase their knowledge and awareness on cleanup activities.

In general, community members seemed to be accepting and willing to have their businesses, residences and properties cleaned. In one 2001 meeting summary, a CAG member asked an EPA representative "What if someone with piles of vermiculite on their property refuses EPA access to remove them?" The EPA representative answered, "No

home-owner has denied access yet.” In a 2006 meeting summary, a discussion of soil sampling took place. One audience member asked if the EPA had received access for screening from 100% of property owners. The EPA representative responded with this comment, “No. Out of 4,000 total properties in the Libby area, we were denied access 352 times.” In the same meeting, one audience member asked what the access rate for cleanup was. The response was “This year we have cleaned 216 properties, and 7 people opted not to have cleanups.”

Participants shared mixed reviews on the cleanup activities. As one CAG member commented: “Some people support and some people oppose EPA’s action here.” Another CAG participant, a local politician, stated, “I hear from people who are both satisfied and dissatisfied by the cleanup of their property.”

Some expressed support of and satisfaction with cleanup activities and shared positive comments and experiences. For example, one CAG member shared their experience with cleanup of their home: “EPA has cleaned our house, and they did a good job inside and out.” Another CAG member shared this comment: “Thank you to EPA for your extra effort to make the high school safe.” Another audience member expressed their satisfaction with this comment: “We notified EPA of contamination on a Monday, and it was removed on the following Wednesday. We appreciate the prompt removal action.”

Discussions also reflected concern, dissatisfaction and frustration related to cleanup efforts. Community members believed that the cleanup was taking too long and had concerns related to the need for repeat cleanups in some instances. Participants were concerned that cleanups were not being conducted right the first time around. One

audience member shared their experience: “My property has been cleaned, but in spite of repeated visits by EPA, I am not satisfied. We need the cleanups to be cleaned right the first time.” Community members also seemed to share the belief that they initially wanted the EPA to come in and do the cleanups and leave, and most had no idea that the EPA would be involved for over a decade.

Some community members shared concerns related to the EPA’s priorities and procedures for sampling and cleanup. One participant shared their views on the subject: “I am concerned about EPA’s priorities for sampling and cleanup activities. Workers who had the highest exposures, homes with contaminated vermiculite insulation and schools should have the highest priority for cleanup.” Discussions reflected concerns related to a lack of consistency in cleanups as well: “For each residential cleanup, EPA reaches a different agreement with the homeowner about cleanup. There is no consistency about how clean is clean.” Another audience member stated, “It is very important to take a unified approach to the cleanups. All of them should be reviewed under the same criteria and given equal treatment.” One CAG member believed that the different approaches to cleanup were based on money and politics, stating, “I see different responses for different properties depending on cost and political connections.”

In addition to taking longer than they thought or believed it should, some CAG participants voiced concerns that cleanup was not happening as in-depth as they believed it should. For example, one of the biggest concerns was related to asbestos contaminated insulation. Before the decision was made by the EPA to address asbestos-contaminated insulation in 2003, many community members expressed the desire to see that the contaminated insulation was removed. In a 2001 meeting, one audience member

commented, “We are still living with asbestos-contaminated insulation in our homes. We need them cleaned up.” In the same meeting, another audience member stated, “Libby will not be clean until all of its homes are clean.” After EPA’s decision to address contaminated insulation, some community members still expressed concerns because they believed the EPA should remove all contaminated insulation, not just “contain” it. One CAG member believed that the problem originated not in the EPA, but higher up in laws and policies governing environmental disaster cleanup:

Several months ago, I was critical of the EPA cleanup. I was told that they are doing everything that they can. In my mind the cleanup is still unacceptable. EPA is deliberately leaving asbestos behind. I agree, however, that the problem is not EPA, but the laws and policies under which they are working. We need to work on changing the laws and policies so that we can get the cleanup right.”

Community members also raised concerns related to “flawed science” and the lack of a risk assessment. In statements made in 2008 meeting summaries, participants seemed to be quite concerned that a risk assessment had not been completed yet. One audience member stated, “Why do we have to wait until 2011-2012 for completion of a risk assessment to know how clean is clean?” Others shared concerns that the lack of a risk assessment would result in the EPA having to re-visit homes already cleaned.

Budget and finance concerns related to cleanup were also a topic of discussion at CAG meetings. In general, discussions reflected a community that believed that a complete cleanup should be cleanup, “whatever the cost” and that the government should provide enough money to adequately fund a complete cleanup that would satisfy the community. Participants expressed worry that cleanup decisions were “all about the money now” and that decisions based on budget limitations put the community at risk.

As cleanups progressed, community members began to find contamination at sites that were already cleaned. Discussions reflected the community's concerns related to post-cleanup contamination. For example, one audience member stated, "My concern is that you are leaving this town with problems." Participants expressed the need to have a program in place to address contamination found on properties that had already been cleaned and a program for long-term maintenance in the community.

It was evident from the meeting summaries that the community faced a long and difficult road to cleanup. While discussions often reflected frustrations and negativity, they also reflected a community that seemed to use pulling together and focusing on the positive as a way to cope with the challenges they faced. As one participant stated, "It is important for us not to dwell on the negative." One CAG member shared this comment: "We should remember that the EPA and ATSDR are helping us. The job, however, is hard and takes longer than any of us would like." Another stated: "Our community has banded together to work on issues stemming from the asbestos contamination." Another CAG member shared their view on the cleanup progress, stating, "As frustrating as things are, we should recognize how far we have come." This CAG member further added, "We need to continue working hard and persistently with the tools available to us."

### Healthcare

The frequency, depth and content of discussions related to healthcare reflected that the community believed that addressing the present and future healthcare needs of those exposed to asbestos was a top priority, equaled only by the community's for cleanup. As one CAG member commented, "Our focus should be on what health care is

needed in Libby and how that care might be provided.” Community members desired healthcare that was affordable, accessible and that addressed unique healthcare needs associated with exposure to Libby asbestos.

Discussions reflected that many in the community believed that their healthcare needs were not being adequately addressed. This was reflected in one participant's comment: “People don't have the healthcare we need.” An un-met healthcare need was a persistent theme throughout all years of meeting summaries analyzed (2001, 2003, 2006 and 2008), but 2008 meeting summaries seemed to reflect years of pent up frustrations related to the topic. One participant stated, “Our need for healthcare is falling through the cracks.” Another made the comment: “Everyone exposed here should be given a medical card so they can get the treatment they need for the next 80 years.” Long-term health care needs were a priority, given the latency period of asbestos-related disease.

Discussions reflected the financial and economic toll of asbestos-related health effects and related healthcare. The impact was illustrated by one participant, who stated, “A healthy community is necessary for economic vitality. Some asbestos victims are only one bill away from disaster.” One audience member spoke of her husband's asbestos-related cancer: “My husband had cancer and his treatment cost over \$250 thousand in six weeks.” As one participant stated, community members needed “... somewhere to go for treatment that won't end up costing us our homes.” Another shared their feelings: “Those of us afflicted with asbestos disease hope to go into the ground without too much debt.”

The need for funding for quality healthcare was expressed by one participant, who stated, “This community needs funding for asbestos disease-related healthcare.”

Discussions reflected that some believed that W.R. Grace should be held responsible for

funding the communities healthcare needs. Others believed that it should be the federal government who should provide for their healthcare. Some community members believed that the federal government had failed them, first by not protecting them from exposure, then by failing to address their healthcare needs. The need for healthcare prompted most community members to support and seek a Public Health Emergency declaration. In one 2008 meeting summary, a CAG member shared their view on the topic: “We need to put pressure on our local officials and Congressional delegation to provide funding for healthcare. We have not been successful yet, but we need to try harder.” In the same meeting, another CAG member disagreed, stating, “W.R. Grace is the appropriate source to fund a trust fund (for healthcare).” Some community members had W.R. Grace’s medical plan, but spoke of obstacles associated with the plan. One participant stated that “Being subject to the requirements of the W.R. Grace medical plan is insulting, and I have opted not to do so.”

Participants also believed that the need for healthcare was not just limited to the Libby community. This was reflected in this audience member comment: “People forced to leave Libby because of our economic conditions also need healthcare.” Another participant stated, “We need a medical card from the federal government that would pay for our present and future medical needs as well as those suffering from the adverse effects of other vermiculite exfoliation plants across America.”

Perceptions of local healthcare efforts were generally positive, such as this CAG member comment: “St. John’s Hospital and CARD have been doing a good job.” Community members seemed to be grateful for local healthcare agencies, including the CARD, St. John’s Lutheran Hospital and Community Health Center, and these agencies

seemed to work together to try to meet the healthcare needs of the Libby community as much as they could. This was illustrated by one CAG member, a local physician: “In 30 years of working in healthcare, I have never seen a community come together more than we have in Libby... The medical community will continue to work to provide needed healthcare.”

Community Awareness, Concerns, Perceptions, Preferences,  
Knowledge, Acceptance and Resistance to Biomedical and Behavioral Research

Part of the third research question asked what the primary themes related to community awareness, concerns, perceptions, knowledge, acceptance and resistance to biomedical and behavioral research. Discussions reflected a community that was generally quite interested in and supportive of research efforts in the community. Research presentations were generally met with many questions and comments to the researchers. As put by one CAG member, research gave the community “our first ray of hope.” A letter sent on behalf of the CAG to a University of Montana researcher (included in a CAG meeting summary) thanked her for her presentation and participation at the CAG meeting, and stated that the presentation provided “hope and insight for our community.” The letter further went on to say that the CAG supported the researchers efforts related to asbestos-related disease within the community and “pledge our full cooperation.” The community’s support and acceptance of research could also be seen in the large number of individuals that participated in the ATSDR’s medical screening study. In an April, 2003 meeting summary, a presentation by ATSDR researchers stated that over 7,000 current and former community members that were potentially exposed to

Libby asbestos were screened for lung abnormalities. In one meeting summary, a CAG member and local physician from the CARD clinic recommended that people can help their children by participating in research. Participants also felt that research should receive more funding. One participant shared this comment: “We should focus on getting money from our political leaders for research related to our children.”

Some community members believed that Libby was the perfect site to set up a research center to look at asbestos-related disease. As one participant stated, “Libby has the population exposed to asbestos. We need a research center here to look closely at ARD and treatment for both Libby and the nation.” In one meeting summary, representatives from the CARD clinic stated that the CARD had developed a data base , in partnership with the Karmanos Cancer Institute to support asbestos-related research.

Community members and members of the local healthcare community took actions to support research. For example, one participant drafted a letter that was signed on the CAG’s behalf in support of research on asbestos-related disease being conducted by the University of Montana. The letter was given to the researchers to assist them in applying for grants. In another example, the CARD clinic held a blood drawing event to collect blood samples to contribute to research. In one meeting summary, a local physician involved with the CARD clinic stated that “there continues to be great interest in the research community about Libby” and he was continuing to build relationships with researchers that will help the community.

Receiving accurate and prompt communication from researchers and keeping the community informed was important to community members. One participant asked researchers presenting at a CAG meeting, “Please keep us in the loop about the results of

this research.” In one meeting, participants stated that screening results letters from the ATSDR “should be more prompt” and that a delay in receiving the letters was “causing paranoia in the community.” In other meetings, participants thanked researchers for presentations and their commitments to keep Libby informed of research efforts in the community.

Collaboration with the community and local agencies was also important to community members. The CARD clinic was seen as a leader and facilitator of asbestos-related research on behalf of the Libby community. One CAG member commented:

People in Libby have trust and confidence in the CARD clinic and are willing to provide information to it. They may not be as willing to share their information with an outside university. CARD should continue to lead the research effort and to collect patient data and share it with the community.

In a 2008 meeting summary, researchers from the ATSDR provided the CAG with an update of the Libby Amphibole Epidemiology Research Program. Researchers stated that the ATSDR had conducted two listening sessions with community groups, including the CAG and members of the medical community. Suggestions were made at these listening sessions, including the initiative should be “a partnership between the grant awardee and agencies in Libby” and that “Libby groups need to have input into the research activities.”

There were some concerns and confusions related to research. Some participants spoke of some misperceptions in the community related to screening that was conducted for research purposes. The confusion was that some community members equated screening with healthcare, which was not the case. Another example is a concern that was

brought up was regarding a survey conducted by the ATSDR for research purposes. Some participants stated that they did not understand the questions on the survey.

Not everyone was supportive of research in the community. The main concern was that community members felt that medical care was more important than research and that research in the absence of medical care would essentially be worthless. The following statement illustrates this: “We need healthcare and quality medical insurance or the research will be useless.” Another participant commented, “We have been studied repeatedly. We need a program for treatment.” Some participants also expressed the desire for outsiders to get out of their community. In a 2008 meeting, the EPA gave a report on the status of epidemiological studies. One participant commented, “You mentioned a December 2009 timeline for completing the studies. We told EPA eight years ago that we wanted you to get the cleanup done and be gone.”

#### Rural Traits and Characteristics

The fourth research question asked, “What characteristics of rural people are evident among participants of the Libby CAG?” Several rural traits and characteristics were evident among the participants of the Libby CAG. Rural traits and characteristics that were identified were: independence, self-reliance, hardiness/resilience, distance/isolation, and insider/outsider.

The Libby community demonstrated independence and a desire to help itself. This independence was reflected in one comment by a representative from the Libby Community Health Center. An audience member asked if people in Libby were not seeking care because of cost. The answer was, “Barriers include cost as well as people’s

values, including a reluctance to ask for help.” Members of the community also seemed to pull together to try to help itself to the best of their ability. A local physician shared this comment: “I have never seen a community come together more than we have in Libby.” The CAG, made up of local community members, also worked hard in trying to promote the health and well-being of the community by communicating the needs of the community and seeking funding, healthcare and additional cleanup efforts. The following CAG member comment further illustrates self-sufficiency: “We need to continue working hard and persistently with the tools available to us. The heavens are not going to open and rain money on us.”

Hardiness and resilience was reflected in the sheer nature of the environmental disaster and resulting cleanup, research and healthcare efforts that the community endured. Although meeting summaries could sometimes contain a lot of negativity and frustration, some community members appeared to try to stay positive. One CAG member stated, “As frustrating as things are, we should recognize how far we have come.” Another stated, “It is important not to dwell on the negative.” Most community members appeared to believe that while the cleanup was longer and more difficult than anyone had anticipated, the community needed to continue work hard to ensure the health and wellbeing of the community.

Distance and isolation was reflected in the community’s isolation from specialty healthcare services. Participants spoke of having only one pulmonologist that worked with the community, and worried what they would do when he retired.

The concept of insider/outsider was also seen in the meeting summaries. Hiring and buying locally was important to the community, and community members seemed to

prefer having members of their community to conduct cleanups, provide healthcare and other activities, as compared to “outsiders” from other agencies. This trust and preference to deal with “insiders” was reflected in the following comment: “People in Libby have trust and confidence in the CARD clinic and are willing to provide information to it. They may not be as willing to share their information with an outside university.” In a 2001 meeting summary, CAG members also expressed their belief that an EPA representative should live in Libby. A reluctance to accept care from “outsiders” was reflected in some of the discussions. Some participants expressed feelings of distrust toward government agencies, namely the EPA. Spending time in the community equated with increased trust and acceptance from community members. Participants expressed the desire to see politicians and government agency officials in person and have them actually visit the community and listen to their personal stories and experiences. Those “outsiders” that actually spent time in the community appeared to become more trusted and accepted than those that did not.

#### Covello’s Seven Cardinal Rules of Risk Communication

The fifth research question was, “Is there evidence of Covello’s Seven Cardinal Rules of Risk Communication in the CAG meeting summaries?” There was evidence of these risk communication rules in the meeting summaries. However, there was also evidence to suggest that the rules were not fully met.

The first cardinal rule of risk communication is to “accept and involve the public as a legitimate partner (Covello & Allen, 1988).” Involvement of the community and clarification about risk was evident in meeting summaries. The Libby CAG was put in

place shortly after EPA first arrived to the community and began sampling activities. The EPA utilized the CAG and the EPA Information Center to communicate risk information. The EPA provided copies of documents, such as a schedule of cleanup activities, investigation reports and documents and studies summarizing risk information, at the EPA Information Center. Each CAG meeting generally had a presentation by the EPA that included current investigation and cleanup activities being conducted, as well plans for future investigation and cleanup activities. Clarifications of decisions related to risk were also referenced.

The second cardinal rule is to “listen to the audience (Covello & Allen, 1988).” The development, use and EPA involvement with the CAG as a two-way forum for communication is evidence of this risk communication rule. The CAG provided a venue in which community members shared questions and comments with the EPA, and provided a way for the EPA to find out what the community was thinking. When concerns were brought up in meetings, EPA officials generally replied that they would further investigate or follow-up on the concerns, and there was evidence as to these follow-up actions.

The third cardinal rule is to “be honest, frank, and open (Covello & Allen, 1988).” The foundation of risk communication principles is to establish and maintain trust and credibility. Evidence of this rule can be seen in the following comment from the CAG: “The EPA coordinator and his staff have been very professional and open to Libby residents.” In another example, an EPA representative shared an honest appraisal of the cleanup, stating that “mistakes have been made” and that the EPA cleanup was “behind

schedule.” The EPA representative also explained that the EPA was “still learning” due to the unprecedented nature of the environmental disaster in Libby.

The fourth cardinal rule is to “coordinate and collaborate with other credible sources (Covello & Allen, 1988).” The EPA coordinated and collaborated with researchers from ATSDR and University of Montana to study the toxicity of the asbestos fibers found in Libby vermiculite. In 2001, the EPA coordinated with personnel from the National Institute of Safety and Health (NIOSH) to conduct health hazard evaluations of work on homes that may disturb vermiculite insulation. In the same year, EPA, “in coordination with Libby community inter-agencies” brought a national second hand smoke campaign to Libby.

The fifth cardinal rule is to “meet the needs of the media (Covello & Allen, 1988).” Evidence for this rule was seen in a meeting summary from 2001, in which the EPA Administrator had planned to come to Libby. The Administrator had scheduled time during her visit to hold a “news conference.” The EPA also published a “question and answer” section in the local newspaper every two weeks. An example where the community perhaps thought that the EPA had not met the needs of the media, a CAG member commented: “EPA should do more to publicize that the ambient air in Libby is free from asbestos fibers. Driving through the town will not result in exposure.” The response: “EPA is making an effort to report this result, but the press doesn’t always report it.”

The sixth cardinal rule is to “speak clearly and with compassion (Covello & Allen, 1988).” Each meeting contained a presentation by EPA that reviewed current actions being taken, or should be taken. Examples were cited in which EPA

representatives spoke with compassion and validated community members concerns. In one meeting summary, an EPA official replied to a community member, “You have the right to be concerned.” In another example, an EPA representative stated, “I hear your disappointment and we need to address these concerns.” Representatives promised to follow through with concerns.

Speaking clearly and using a variety of methods to clarify risk communication information was evidenced in the meeting summaries. Meeting summaries contained discussions related to EPA risk communication, education and outreach efforts in the community. In 2001, the EPA provided funding for several community members to attend a conference on the health effects of exposure organized by the EPA. In another meeting, an EPA representative stated, “Because of public concerns about the ongoing cleanup activities, EPA is developing additional outreach materials.” These outreach materials included a video showing the entire cleanup process, a “detailed fact sheet” on the residential property cleanups and an update to the EPA website, adding more information. In response to a CAG participant’s questions regarding how to address children’s asbestos exposure, an EPA representative stated that EPA will prepare a “fact sheet” addressing this topic.

The seventh cardinal rule is to “plan carefully and evaluate performance (Covello & Allen, 1988.” Performance evaluation was evidenced in one 2001 meeting summary, in which EPA conducted a CAG evaluation. In another meeting summary, the EPA had held an economic development conference, and stated that it was a success, “as measured by attendee satisfaction.”

There was also evidence to suggest that some of the cardinal rules were not always followed. At times, there seemed to be some lack of communication related to risk information. One participant shared their feelings with this comment: “EPA has kept this community in the dark.” Another stated that information from the EPA was “slow in coming.” In another example, one meeting summary contained a discussion related to EPA’s decision about how they were going to address asbestos contaminated insulation. A CAG member commented, “Why did I read about this decision in the Daily Interlake rather than at a CAG meeting?” The response from the EPA representative was, “EPA should have brought up this issue sooner.” In another example, community members had concerns related to what they should do if they found asbestos-contaminated insulation (a topic which apparently had not yet been addressed or communicated adequately). The community member asked the EPA if they could mail a brochure with information on the topic to “every community mailbox.” These issues were summed up by one participant, who stated, “EPA needs to do a better job of reaching out to homeowners.” Other participants expressed confusion as to the cleanup process for their homes and properties. The lack of a risk assessment after eight years was also an area of risk communication concerns, as community members believed that this risk information should have been provided to the community years ago.

Trust and credibility were another area related to the risk communication rules that seemed to be an issue at times. As one CAG participant stated, “We need to develop the trust with EPA that our concerns will be satisfied.” There were community members that expressed distrust of the EPA, and one participant even accused the EPA and a local politician of “corruption.” References were also made that the EPA was “misleading” the

community and that it made “false statements.” Distrust of EPA was expressed more in 2006 and 2008 than 2001 or 2003.

## CHAPTER FIVE

## DISCUSSION

Summary

The rural community of Libby, Montana continues to be affected by what has been called the worst environmental disaster in U.S. history (EPA, 2007; Carr & Hawes-Davis, 2004). Investigation, cleanup, healthcare and research efforts are ongoing in the community. Effective communication is an essential component to the success of community-based activities. Although the Libby CAG was developed as a forum for two way communication and information exchange between the community and agencies involved in the clean-up effort (Lux, 2003), little is known about preferred modes of communication and the community's acceptance and resistance to biomedical and behavioral research.

The purpose of this study was to use existing documents (CAG meeting summaries) to identify concerns, perceptions and preferences of rural Libby residents related to communication pertaining to research and other issues critical to the population's health and well-being. A retrospective, qualitative analysis of CAG meeting summaries was conducted to identify themes that could lead to a better understanding of critical communication issues among stakeholders in the community, including community members, health service providers, policymakers, researchers and other local, state and federal agencies involved with the investigation, cleanup, healthcare and research efforts in the Libby area. Two theoretical models, Covello's Risk

Communication Model (Covello & Allen, 1988) and Lee and Winters (2010) Rural Nursing Concepts, were used to help frame this study. A review of the main conclusions from the data analysis will be provided.

### Limitations

The analysis of meeting summaries was limited to four years of summaries that represented seminal events in the community (2001, 2003, 2005, 2008). It is possible that analysis of additional years would have yielded additional themes or information pertinent to the study. The study was also a secondary data analysis, so there was no opportunity to clarify information with participants or explore topics further in depth.

### Conclusions

The CAG meeting summaries were a very rich source of data and contained revealing discussions among CAG members, audience members, presenters, government agencies and other presenters regarding topics of importance to the community and to this research study. This research provides important insights into the concerns, perceptions and preferences of rural Libby residents related to communication pertaining to research and other issues critical to the population's health and well-being.

### Primary Information Exchange Topics

The eleven primary information exchange topics that were identified were: CAG purpose and process, cleanup activities, economy, funding and finances, government agency involvement, health and healthcare, litigation and legislation, Public Health

Emergency declaration, research, schools and children and Superfund designation.

Additional research is needed to determine if these topics match primary information exchange topics from other communities affected by environmental disaster cleanup.

The primary topics of discussion that were identified reflect topics of importance to the Libby community. Understanding the unique characteristics of a community, including information about the community's primary concerns, is necessary for effective risk communication and interaction with community (Covello, McCallum & Pavlova, 1989). The more that is known about those with whom you are communicating, the greater the likelihood that communication efforts will be successful (Landesman, 2005). Therefore, understanding what the primary topics of discussion among members of the Libby CAG has implications for nursing research and involvement in the community.

### Libby is Unique

Primary themes related to healthcare, cleanup and research were also identified. Libby was viewed as "unique" not only by community members, but also by researchers, local healthcare providers and EPA officials. The situation in Libby is unique because of the length and extent of their exposure and the rural context in which this exposure occurred. The site has human health concerns unrivaled by other U.S. environmental disasters in history. The uniqueness of rural communities in general and specifically of this rural community must be understood and taken into consideration to effectively interact with the community. This is consistent with previous literature (Kuntz, et al., 2009).

### Cleanup

In general, cleanup was the community's primary priority and community members wanted cleanup conducted as quickly, completely and efficiently as possible. At times, frustrations were expressed because the cleanup was taking longer and was harder than the community first anticipated. Community members believed that given their history of asbestos exposure, they could not afford additional exposure. A complete cleanup was viewed as essential to addressing the physiological and economic health of the community. Concerns and frustrations were raised when contamination was found post-cleanup. The experiences of the Libby community could be used to guide cleanup of other Superfund sites more efficiently.

### Health and Healthcare

Addressing the health and healthcare needs of the community was of primary importance to CAG participants. Participants believed that a plan to address their current and long-term health needs was needed. Participants also seemed to focus more on their children when it came to health-related issues. More concern was expressed for potential exposure of children than actual exposure of adults. This finding supports findings by Bales (2010) that rural dwellers (women of childbearing age, specifically) put "children first" and sought care earlier for their children than they did for themselves. Despite the high priority given health related issues and healthcare, most participants seemed to focus more on the financial implications of illness than the actual physical or emotional effects and consequences of ARD. The review of local healthcare efforts was quite positive. Community members seemed to trust their local providers, and seemed to be satisfied

with the care they were receiving locally. The need for rural communities to have a specialist available in the community, rather than having to travel long distances to one, is a theme also described by Lee and Winters, 2004. More research is needed that addresses the health concerns of the community post Public Health Emergency declaration.

### Research

In general, the Libby community was quite supportive and accepting of research. Keeping the community updated on the status of research studies and presentation of results were important to the community. This is consistent with findings and recommendations by Lightfoot, et al. (2008) that state that in research in rural communities it is important to keep the community updated and informed of results. Coordination and collaboration between researchers and local healthcare agencies was also important to the community. Community members expressed that they would be more likely to participate in research if their local healthcare provider was involved. This is consistent with existing literature, which states that research in rural communities is more likely to be successful if there is collaboration with the community (Lightfoot, et al., 2008). The establishment of a personal presence in the community and face-to-face interactions of individuals involved in research and cleanup in the community was important to and valued by community. This is consistent with previous literature on rural nursing research (Lightfoot, et al., 2008). More research is needed that addresses how to best implement research in a rural community.

### Communication

Preferred methods of communication pertaining to research and other topics important to the community were identified. Several methods of communication were referenced, including via the CAG or other public meeting, letters, newspapers, radio, and television. In a study of rural community leaders' perceptions of environmental health risks conducted by Larsson, et al. (2006), participants emphasized that environmental health messages “needs to get out in a lot of different ways (p. 109).” Participants also emphasized that communication and interventions must be compatible with and sensitive to the rural culture and regional identity. Although not specifically identified in this study, according to Larsson, et al. (2006), word of mouth communication is strength of rural communities, and should be utilized as a culturally appropriate and effective communication medium.

Communication preferences specific to research were also identified. Many members of the community obtained information related to research from CAG and other public meetings. Mailings, including e-mails, were also referenced. Local television, radio and newspapers were also utilized or recommended to communicate research information. This information can be used to design, implement and evaluate strategies for communicating research opportunities and results to Libby community members.

### Rural

Rural characteristics and traits were also evident in the CAG meeting summaries, which supports previous rural nursing literature. Libby community members placed value and trust in keeping things “local.” Buying and hiring locally was important. Community

members also placed trust in their local healthcare providers, and indicated that they would be more willing to share information with healthcare providers that they knew at the CARD clinic than researchers from outside universities. This concept of local preference could be correlated to the rural nursing concept of “insider and outsider.” The preference of Libby community members to seek care locally with persons with whom they were familiar is consistent with research conducted by Long and Weinert (1989).

More trust and acceptance was placed in those who spent time in the community. This could correlate to an “outsider” becoming more of an “insider.” Community members placed value in face-to-face interactions and involvement in the community. This validates previous literature related to research in rural communities. According to Lightfoot, et al. (2008), spending time in the community and with key community leaders helps to build interest, support and rapport. Research by Long and Weinert (1989) emphasizes that nurses who enter the rural community must allow for extended periods prior to acceptance. Involvement in diverse community activities may help the nurse in being known and acceptance. This could include the Libby CAG.

Many Libby community members, including members of the local healthcare community, described the community as “coming together” to address the needs of the community. Community support is a rural concept described by Winters, Bales and Lee (2010). This community support will continue to be needed as the community faces challenges related to this environmental disaster for many years to come.

### Risk Communication

There was evidence of Covello's seven cardinal rules of risk communication in the CAG meeting summaries. Trust and credibility are the foundation of these rules. While there was evidence that supported appropriate risk communication activities, there was also evidence to suggest that the EPA's credibility and the community's trust in the organization had been compromised. Additional research is needed to determine if these rules are appropriate and effective in rural communities, and if additional "rules" should be added when addressing risk communication in rural communities.

### Implications

The findings of this study have implications for nursing practice and research in rural areas affected by environmental disaster, and specifically in the rural community of Libby, Montana. Additionally, findings have specific implications for the Libby Partnership Initiative related to improving communication and interaction between researchers and the Libby community. Findings can be used to guide research efforts in this unique rural community.

The future of Libby as a research center for the study of long-term asbestos-exposure on a rural community appears quite positive. Findings of this study help to illustrate the research milieu of the community, and indicate Libby community members are generally accepting and supportive of research efforts. The Libby community provides a rich source of data and a unique opportunity to bring together researchers from across a wide range of disciplines to study asbestos and the impacts of asbestos exposure

and an ongoing environmental disaster. Findings from this study support earlier findings by Pfau, et al. (2006, p.28), who stated,

It is a unique population with both occupational and environmental exposures, excellent ongoing monitoring and demographic data, enthusiasm for participation in these studies and sufficient numbers of exposed individuals...for statistical analyses of many parameters (p.28).

Findings from this study can also be used to help create strategies for communicating research opportunities and results to Libby community members. Community members utilized a variety of communication methods to seek and receive information related to research, including CAG meetings, mailings, television, radio, and newspapers. This study also found that community members often made valuable suggestions as to how to best communicate research results and opportunities with community members (such as the suggestion to utilize a mailing list for an upcoming class reunion). Soliciting such suggestions from community members would be a worthwhile effort. These suggestions could be solicited at public meetings or through collaboration with local healthcare agencies (such as the CARD clinic). Additionally, community members expressed the importance of keeping the community informed of research efforts and results. In order to keep a positive image of research in the community, researchers must take care to always keep the community “in the loop” related to research activities and results.

The rural and community traits and characteristics identified are relevant in terms of acceptance of nurses, healthcare providers and researchers involved with the Libby community presently and in the future. It will be important for researchers to collaborate and coordinate research efforts with community members and the local healthcare

community, including the CARD Clinic. Nurses working with local healthcare agencies could have an important role in facilitating research efforts. Research efforts should be a partnership between the researchers and the community (CBPR would be a good “fit” with this community). In order to gain trust and acceptance in the community, researchers should also spend time in the community and participate in community activities. Participation in future CAG meetings may be an option. Having an “insider” partner in the community would be valuable in terms of introducing researchers to community members and agencies, educating researchers on local culture and providing insights into potential research topics of interest to the community.

Future research studies could further explore the communication preferences of the Libby community in a more direct manner (e.g. interviews, surveys). Participation rates of Libby community members in research studies and factors that influence the decision to participate or not participate should also be explored. Additional research aimed at examining and encouraging partnerships and collaboration between rural healthcare providers and academic researchers (such as Montana State University) should also be pursued. The division between the local business community, who were generally more focused on economic and financial issues, and the rest of the community, who were generally more focused on healthcare and cleanup, is an interesting finding that should further be explored as potentially having implications to rural nursing concepts and/or risk communication concepts.

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