

METHICILLIN RESISTANT *STAPHYLOCOCCUS*  
*AUREUS* (MRSA): KNOWLEDGE, LEARNING AND ADAPTATION

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METHICILLIN RESISTANT *STAPHYLOCOCCUS*  
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2010

## **DEDICATION**

I dedicate this dissertation to my family. My wife, Bonnie, who has encouraged me, offered support, and listened to all of my hardships and victories during this journey. You make me a better man, son, husband, and father. I thank God every minute that he placed you in my life. To my children, Haley and Landry, for putting up with my absences during school events, sporting events, and just plain Daddy time when I was doing homework, research, or writing this dissertation. You both make me so proud and I hope that you continue to pursue your dreams in education and elsewhere and remember to always, do it the right way and outwork everyone. To my parents, David and Nelda Rohde, for instilling in me the values of being a Christian, hard work ethic, and the belief that anything is possible with effort. I can never repay you for what you have provided to me. I hope you know that my accomplishments are always in humble appreciation for the many sacrifices you have made to get me here. Thank you for everything. I would also like to think that all of my grandparents, Alvin and Irene Rohde and Edward “Doc” and Nell Brinkley, are looking down on me and this accomplishment. I miss you. Thanks also to Bonnie’s parents and family. All of you have been so very supportive in ways you may not even understand. I thank you for all of your love, insight and encouragement.

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## TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	v
LIST OF TABLES.....	xi
LIST OF FIGURES.....	xii
ABSTRACT.....	xiii
CHAPTER ONE: INTRODUCTION TO THE STUDY.....	1
Statement and Significance of Problem.....	1
Purpose of the Study.....	6
Research Questions.....	7
Assumptions.....	8
Definition of Key Terms.....	10
Limitations.....	11
Summary.....	12
CHAPTER TWO: REVIEW OF THE LITERATURE.....	14
MRSA Knowledge and Awareness – Healthcare.....	15
MRSA Knowledge: U.S. Healthcare Environment.....	16
MRSA Knowledge: Healthcare Environment outside the US.....	17
MRSA Knowledge and Awareness – General Public.....	19
MRSA Knowledge: U.S. General Public.....	19
MRSA Knowledge: General Population outside the US.....	22
Theoretical Influences.....	23
Adult Learning Theory.....	23
<i>Self-directed learning</i> .....	23
<i>Transformational learning</i> .....	26
Ecological Perspective.....	28
Social Representation Theory.....	29
Summary.....	31

CHAPTER THREE: METHODOLOGY .....	33
Research Paradigm – Approach.....	33
Qualitative Research .....	35
Constructivism and Grounded Theory.....	36
Participant Criteria .....	37
Recruitment.....	38
Sample Description.....	39
Data Collection .....	39
Data Analysis .....	40
Role of the Researcher .....	42
Validity and Reliability Issues .....	44
<i>Credibility</i> .....	44
<i>Transferability</i> .....	45
<i>Dependability</i> .....	45
<i>Confirmability</i> .....	46
<i>Triangulation</i> .....	46
Ethical Concerns .....	47
Summary.....	48
CHAPTER FOUR: FINDINGS OF THE STUDY.....	50
Profiles of the Participants .....	51
Personal Stories of the Participants.....	52
Aaron.....	52
Dora.....	54
Trene .....	56
Alvin .....	58
Irene .....	60
Edward .....	61
Becky .....	64
Erin.....	65
Nell.....	67
Mary .....	69

Emergent Themes .....	71
Part I: Learning – “I guess everything changes when it happens to you”	72
<i>Experiences with MRSA,</i> .....	73
<i>What was learned?</i> .....	80
<i>General MRSA Information</i> .....	80
<i>MRSA care and prevention</i> .....	83
<i>Antibiotic resistance</i> .....	86
<i>How did learning occur?</i> .....	87
<i>People</i> .....	88
<i>Media.</i> .....	93
Part II: Adaptation – “People make the difference” .....	96
<i>Self-reliance</i> .....	97
<i>Reliance on others</i> .....	104
<i>Reflections on the MRSA journey</i> .....	107
Summary of Findings.....	116
CHAPTER FIVE: DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS	118
Summary.....	118
Literature Review.....	119
Methodology.....	126
Key Findings.....	127
Discussion and Conclusions .....	128
Pre-diagnosis.....	130
Diagnosis.....	131
Post-diagnosis and Learning.....	135
Adaptation.....	151
Conclusions.....	157
Implications.....	159
Practice.....	160
Research and Theory.....	162
Recommendations.....	163
Practice.....	164

Research .....	165
Final Thoughts .....	167
APPENDIX A – RECRUITMENT AND SCHEDULING FLIER .....	170
APPENDIX B – LETTER OF INTRODUCTION / CONSENT FORM.....	171
APPENDIX C – INTERVIEW GUIDE .....	174
APPENDIX D – CROSS REFERENCE MATRIX .....	176
REFERENCES .....	177

## LIST OF TABLES

Table 1 The Ecological Perspective: Levels of Influence .....	29
Table 2 Participant Profiles: Demographics .....	51
Table 3 Themes and Subthemes: MRSA Diagnosis .....	72

## LIST OF FIGURES

Figure 1 MRSA Model of Learning and Adaptation .....	129
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## **ABSTRACT**

METHICILLIN RESISTANT *STAPHYLOCOCCUS*

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The purpose of this study was to investigate how people in the community who have MRSA develop their understanding and knowledge about antibiotic resistance. The research design was conducted within a constructivist theoretical framework that allowed their experiences and stories to unfold and be understood. The overall questions that guided the study were, “How do individuals in the general public construct knowledge about MRSA?” and “How do they adapt to their condition?” Purposeful sampling was essential to the recruitment and selection of ten, unique participants. A semi-structured interview-guide ensured collection of information in the same general areas from each interviewee during the one to two hour interviews. The interviews were digitally recorded, transcribed, and coded, and themes were developed.

The findings revealed two main themes with six subthemes. The first main theme, *Learning*, revealed the participants experiences with learning about MRSA. Three subthemes were uncovered within this theme: *Experiences with MRSA*, *What was learned?* and *How did learning occur?* The second main theme, *Adaptation*, had to do with how individuals handled their condition. Three subthemes also surfaced within this theme: *Self-reliance*, *Reliance on others*, and *Reflections on the MRSA journey*.

Several conclusions were drawn from the analysis of this study. First, there appears to be a common model of MRSA learning and adaptation. Second, the nature of adult learning was primarily self-directed, and for some, transformational. Third, the major content learned was general MRSA information, care and prevention, and antibiotic resistance issues. Fourth, the nature of adaptation was interconnected with self and others. Fifth, a consistent message with a step by step plan of how to deal with MRSA from healthcare is important upon diagnosis. The implications for practice and research indicate a need to address issues of how the general public discovers, learns, and adapts to antibiotic resistant infections, especially MRSA. Likewise, this study emphasized the critical importance of informing healthcare professionals and health educators (schools, universities, etc.) about the need for better programs of patient education and continuing education surrounding the pre and post diagnosis of MRSA infections.

## **CHAPTER ONE**

### **INTRODUCTION TO THE STUDY**

#### Statement and Significance of Problem

*Staphylococcus aureus* is a member of the staphylococci, a broad group of bacterial organisms that are associated with infections in humans and are colonizers of various skin and mucosal surfaces. The term *colonization* means that you carry the organism but are not infected; however, you have the potential to transmit the organism to someone else or to yourself. The colonization state is common among the human population and infections are frequently acquired when the colonizing bacteria gains entrance to a typically sterile site as a result of trauma or abrasion to the skin or mucosal surface. However, the traumatic event that allows entry of the organism often may be so minor that it goes unrecognized (Forbes, Sahn, & Weissfeld, 2007). For instance, a person may use gym equipment or share a towel that could cause a minor abrasion that allows the organism to enter the body.

The staphylococci are also transmitted from person to person. Once transmission has occurred, the bacteria may establish itself as part of the recipient's normal flora and later be introduced to sterile sites by trauma or an invasive procedure. Normal flora is bacteria that humans (and other living hosts) are colonized with throughout their lives and usually do not cause harm unless an opportunity allows the bacteria to gain entrance

to sterile body sites. Alternatively, the organism may be directly introduced into normally sterile sites, such as by a surgeon or nurse during surgery. Person-to-person transmission of staphylococci, especially those that have gained antimicrobial resistance, most often has been documented in hospitals and presents substantial infection control problems. However, more recently serious *S. aureus* infections have been encountered in the community setting as well (Forbes, et al., 2007).

*S. aureus* has been established as the most virulent (disease causing) species of staphylococci encountered. A broad set of factors, not all of which are well understood, contribute to this bacterium's ability to cause infections and disease. A variety of enzymes and toxins augment with tissue invasion and survival at the site of infection. These factors are responsible for the various skin, wound, and deep tissue infections commonly caused by *S. aureus*. These infections can, and do, become rapidly life-threatening if not diagnosed and treated appropriately (Forbes, et al., 2007).

Localized skin infections usually affect multiple hair follicles (i.e., folliculitis) and spread deeper to cause boils (i.e., furuncles). If, these furuncles coalesce to form carbuncles, then more serious, deeper infections result. The commonly known *S. aureus* skin infection, impetigo, involves the epidermis and is characterized by the production of vesicles that rupture and crust over. Importantly, it does not matter where the initial infection occurs because the invasive ability of this organism always presents a threat for deeper tissue involvement, bacteremia, and eventual spread to one or multiple internal organs including the respiratory system (Forbes, et al., 2007). Infections caused by *S. aureus* are found in surgical sites and the skin (most frequent in the United States [US]), the bloodstream, the lower respiratory tract, vascular catheters (second most frequent in

the US), and the urinary tract (National Nosocomial Infections Surveillance System, 2001). Furthermore, these serious infections have emerged more frequently among non-hospitalized patients and are associated with strains that produce an extremely problematic toxin called Pantone-Valentine leukocidin (PVL). Finally, it is worrisome that these dangerous community-associated infections are frequently caused by *S. aureus* that has become resistant to methicillin (Forbes, et al., 2007).

Methicillin-resistant *Staphylococcus aureus* (MRSA) is probably the best-known example of a resistant bacterium and has been the focus of intense scientific and political interest around the world (CDC, 2008; Darzi, 2007). Nasal colonization of *S. aureus* has been identified as a major risk factor for subsequent invasive infections and inter-patient transmission of strains, including MRSA strains. The emergence of MRSA infections adds to the overall number of *S. aureus* infections, thus increasing the total number of nosocomial (hospital associated) infections caused by this pathogen (Hartstein & Mulligan, 1996). The Centers for Disease Control (CDC) has reported a consistent range of 25-50% nasal colonization of *S. aureus* (30% average) in the general population, while MRSA colonization is typically 1-2% (2008). MRSA colonization rates can dramatically change for different populations (i.e., healthy family versus jail inmates). MRSA infection, much like *S. aureus*, is spread predominantly by person-to-person contact, although it also may be transmitted by contaminated surfaces and objects. In addition to a history of MRSA infection or colonization, high community prevalence, recurrent skin disease, and recent or frequent antibiotic use, risk factors for infection include the five Cs: Contact, Crowding, Contaminated surfaces, lack of Cleanliness, and Contaminated skin (Weiner, 2008).

MRSA was initially reported in the 1960s and it quickly became known for its ability to cause large hospital outbreaks and become endemic. Since then, MRSA has become progressively more common. As a result, MRSA infections are often the source of a great deal of concern in institutions. Most strains of MRSA are sporadic, but a few strains have the ability to spread very rapidly throughout an institution and reach epidemic levels. In 1999, the proportion of MRSA among *S. aureus* hospital associated infections in the US was estimated at 50% with large local variations (CDC, 2008).

MRSA has also evolved in the community and is unrelated to the evolution of healthcare-associated MRSA (HA-MRSA) in hospitals. These community-associated strains, known as community-associated MRSA (CA-MRSA), have been isolated from people without the commonly known risk factors. CA-MRSA infections are commonly reported in miscellaneous groups: patients with cystic fibrosis, children attending day-care centers, athletic teams, and prisoners (Estrada, 2001; Felkner, Rohde, Valle-Rivera, Baldwin, & Newsome, 2007). Both HA-MRSA and CA-MRSA infections have significant mortality and morbidity rates ranging from 8% to 49%, respectively (Austin, Austin, & Coleman, 2003; Hartstein & Mulligan, 1996; John & Barg, 1996; Talon, Woronoff-Lemsi & Limat, 2002). HA-MRSA and CA-MRSA cannot be truly differentiated without laboratory testing that distinguishes genetic differences between the two types. Thus, one should not assume that one type of MRSA is acquired over the other in a particular environment. The reasons for the emergence of MRSA are multifaceted, with the most common reasons being host factors, infection control practices, and antimicrobial pressures.

Despite the growing amount of research on HA-MRSA there has not been a parallel increase in research on CA-MRSA, though it too is rising in prevalence (Bryl, Lojko & Giersz, 1995; Dunkelberg, 1976; Kingdom, Joyce & Bradley, 1983; Kunz, 1993; Stubbs, Pegler & Vickery, 1994). Bischoff, Wallis, Tucker, Reboussin and Sherertz (2004) reported 29% prevalence of *S. aureus* in a college community. Variables identified in the study as significant predictors ( $p < 0.05$ ) of carrier status in univariate analysis were age (mean = 23.15 +/- 6.86), male gender, and use of antibiotics in the past month. Based on the results of a stepwise logistic regression, an optimal model was identified that included the variables older age, male gender, and chronic sinusitis as risk factors. Additionally, antibiotic use (< 4 weeks) and allergy therapy were identified as being protective (2004).

While MRSA prevalence and risk factor analysis is beginning to be conducted within various groups of the general population such as the Bischoff et al. study (2004), the critical issue of health education for these groups (pre and post infection) is not being fully addressed. In particular, the underlying need to educate adults about the characteristics, risk factors, and consequences of MRSA needs to be addressed.

Recent data show that Americans visit the doctor approximately 12 million times each year to get checked for suspected staphylococci or MRSA skin infections (CDC, 2008). Health education and literacy is critical for addressing the increasing prevalence of MRSA. Its aim is to develop in people a sense of responsibility for health conditions for themselves as individuals, as members of families, and as communities. In communicable disease control, health education commonly includes an appraisal of what is known by a population about a disease, an assessment of habits and attitudes of the people as they

relate to spread and frequency of the disease, and the presentation of specific means to remedy observed deficiencies.

### Purpose of the Study

Although there are high levels of awareness and concern about MRSA among healthcare personnel and hospital patients, there has been little research focused on the general public. To help address this lack of research in the general public, I have conducted an investigation of the prevalence and characterization of MRSA in a Texas correctional facility (Felkner, Rohde, Valle-Rivera, Baldwin, & Newsome, 2007) and in a university population (Rohde, Denham, & Brannon, 2009). I am also a member of a statewide committee that oversees issues of MRSA in the community and healthcare environment and that tries to identify community needs.

In the correctional facility investigation and university pilot study, we identified nasal colonization of *S. aureus* and MRSA and risk factors that were associated in becoming carriers of MRSA. In particular, the university pilot study (Rohde, et al., 2009) identified that 29.6% of our study population (60/203) was colonized with *S. aureus*. Of the 29.6% *S. aureus* carriers, 7.4% were colonized with MRSA. Thus MRSA prevalence found in the pilot study population is greater than the 1-2% found in the general community (CDC, 2008). This is an important finding from the standpoint of developing university guidelines and health education programs and policy for the general public. My involvement in this research has illuminated a critical need for this important public health education concern because of the implications for major university outbreaks of MRSA mortality and morbidity.

The purpose of this study is to investigate how people in the community who have MRSA develop their understanding and knowledge about antibiotic resistance. The intention is to explore how members of the general public who have a need to know discover, learn, and adapt to MRSA. It is clearly known that hospital patients are educated about MRSA from their physicians and other healthcare providers (CDC, 2008). However, the general public is poorly informed about antibiotic resistance health issues such as that seen with MRSA. The investigator's level of expertise in MRSA provides an opportunity to further explore the phenomenon of *what do I do now* with respect to how the general public deals with this rapidly growing health threat.

Through the use of semi-structured interviewing, a better understanding of the contextual, social, and clinical factors that influence an individual's awareness and knowledge about MRSA was sought. An attempt to discover what members of the adult population know or understand about antibiotic resistance and how they adapt to such a dangerous health issue was conducted. A clarification of learning needs for this population was also sought.

### Research Questions

The following research questions guided this qualitative inquiry:

1. How do individuals in the general public who have MRSA construct knowledge about MRSA?
  - a. How do participants describe their experiences with learning about MRSA?
  - b. How do participants acquire their knowledge about MRSA?
  - c. What understandings do participants have of MRSA and antibiotic resistance?
2. How do people with MRSA adapt to their condition?

- a. What strategies for living with MRSA are apparent among those who have a diagnosis of this condition?
- b. What factors enhance or detract one's ability to adapt to this disease?

### Assumptions

As a researcher, I have several assumptions that influenced the conceptual framework, design of the study, sample selection, data collection, and other aspects of the study. My assumptions originate from my professional experience as a public health microbiologist, educator, and researcher of MRSA and other infectious disease over the past 15 years. Additionally, my continuous, extensive review of the literature on MRSA issues influenced my assumptions.

The first assumption was that the general public is poorly educated on issues of antibiotic resistance, particularly with MRSA. This assumption comes, in part, from my own experiences as a practicing microbiologist within the academic and clinical healthcare arena. I have observed that within the healthcare environment patients are given many opportunities to become aware and knowledgeable about the health issues involved with antibiotic resistance. However, in my research experience with populations in the general public, individuals were sorely lacking basic awareness and knowledge surrounding antibiotic resistance including MRSA (Falkner, et al., 2007; Rohde, et al., 2009). Several studies have documented the failure of public health campaigns to curb antibiotic resistance because there is a lack of understanding public attitudes (Brinsley-Rainisch, Cochran, Bush-Knapp, & Pearson, 2006; Cespedes & Larson, 2006; Hawkings, Wood, & Butler, 2007; McLaughlin, et al., 2008; McNulty, Boyle, Nichols, Clappison, &

Davey, 2007; Washer & Joffe, 2006). The general public often becomes disillusioned over what to do or where to go for proper health education.

A second assumption was that many individuals acquire their information to make critical health decisions from the mass media. In my experience with MRSA and the general public, people often become self-directed in their quest for knowledge via the internet search engines or other forms of media. Washer and Joffe described a study that examines the meanings of MRSA circulating in Britain by analyzing newspaper coverage of the disease over the 10-year period from 1995–2005 (2006). In this study, the mass media's portrayal of the so-called *hospital superbug* MRSA acts as a bridge between medical and public understandings of the phenomenon. In this and other newly emerging infectious diseases (EIDS) the media plays a vital, if under-studied role, in transforming medical findings into public knowledge. This form of knowledge gathering by someone in the general public can often be accompanied by misinformation and incorrect data which leads to poor choices and decision making in regards to MRSA management and control.

A third assumption was that people in the general public who have MRSA are desperate to know if they are making the correct decisions about their situation. I have fielded numerous phone calls and emails from individuals who simply have been transferred from one place to the next in regards to *what to do* about MRSA. People are extremely frustrated because they only want to do *what's right* to alleviate the suffering by themselves or their friends and loved ones. They are tired of being neglected.

A final assumption was that I bring my own personal bias to the research experience. My own personal perceptions of what my senses tell me, as well as how

those perceptions may affect the data analysis, have the potential to ultimately affect the research outcomes. I was constantly aware of these biases using the research design process and evaluative rigor to minimize its affects. As Patton suggests, the qualitative researcher should always emphasize the importance of self-awareness, political/cultural consciousness, and ownership of one's perspective (2002, p. 64).

#### Definition of Key Terms

1. Antibiotic resistance – Antibiotic resistance is defined as the ability of bacteria and other microorganisms to withstand an antibiotic to which they were once sensitive (and were once stalled or killed outright). Also called drug resistance (Forbes, et al., 2007).
2. Community associated methicillin resistant *Staphylococcus aureus* (CA-MRSA) – CA-MRSA are those strains (genetic types) of staphylococci that are resistant to certain antibiotics and originate from the community at large. These antibiotics include methicillin and other more common antibiotics such as oxacillin, penicillin and amoxicillin (CDC, 2008).
3. Healthcare associated MRSA (HA-MRSA) – HA-MRSA are those strains (genetic types) of staphylococci that are resistant to certain antibiotics and originate most frequently among persons in hospitals and healthcare facilities (such as nursing homes and dialysis centers) who have weakened immune systems. These antibiotics include methicillin and other more common antibiotics such as oxacillin, penicillin and amoxicillin (CDC, 2008).
4. Staphylococci - A broad group of bacterial organisms that are associated with infections in humans and are colonizers of various skin and mucosal surfaces.

*Staphylococcus aureus* is the most virulent species in this group of bacteria (Forbes, et al., 2007).

5. MRSA awareness – MRSA awareness is described as an individual's perceptions about the risk factors and dangers associated with this antibiotic resistance problem.
6. MRSA knowledge – MRSA knowledge is described as an individual's cognitive level of understanding about antibiotic resistance in general and MRSA in particular.

#### Limitations

Limitations to this study can be linked to the memory of the participants with respect to their ability to reproduce valid stories of the experiences. The age of the participants may be seen as a limitation because two distinct age groups emerged as the sampling process continued – a young adult group and an older retired or approaching retirement group. This lack of heterogeneity in mid-life of the population limits depth of knowledge garnered about specific age ranges at the time of participation. The small number of participants interviewed was a limitation to breadth. However, this could lend strength to the study because the small sample allowed for a certain depth of understanding. The lack of ethnic diversity also could be seen as a limitation, making questionable the transferability of the study's conclusions to a more ethnically diverse population. It was also the case that a majority of the participants had a family member or friend that was a member of the healthcare environment. This too could be seen as a limitation because participants may be seen as having greater access to help than other members of the public without this characteristic. This would also make the transferability of the conclusions an issue. Also, time may be seen as creating certain limitations. Each participant was required to reduce their MRSA experiences into one

interview of one to one and a half hours each. Time also may have acted as a limitation in regards to not following participants over time. For instance, a longevity study that observed participants dealing with reoccurrences of MRSA. Finally, the participants all had some college education, with a majority of them having earned at least an undergraduate degree. Thus, the experiences of adults without any college education or limited education were not investigated and this may be viewed as a limitation to the study.

### Summary

Chapter one introduced the characteristics of *Staphylococcus aureus*, a member of the staphylococci bacterial organisms that are associated with infections in humans and are colonizers of various skin and mucosal surfaces. It also introduced the growing healthcare and community associated morbidity and mortality caused by Methicillin-resistant *Staphylococcus aureus* (MRSA). MRSA is spread predominantly by person-to-person contact, although it may also be transmitted by contaminated surfaces and objects. Questions arose from the literature about the lack of research concerning community-associated MRSA as compared to healthcare-associated MRSA. Specifically, how do members of the general public learn and adapt to this growing healthcare threat? This chapter also presented the purpose of the study, research questions, and definition of terms, assumptions, and limitations.

It is anticipated that by acquiring a deeper level of understanding about how individuals explore their decisions about MRSA, healthcare professionals and health educators will be able to gain valuable insight into how people make complex choices about their own health and the health of others. This research will contribute to the fields

of health education, public health, health social science, infectious disease, and epidemiology. By understanding individual perspectives on MRSA, it may translate personal health knowledge construction to public health personnel and policymakers. Thus, the findings in this study may lead to better planned and more successful public health campaigns against antibiotic resistance in general, and MRSA in particular.

## CHAPTER TWO

### REVIEW OF THE LITERATURE

The typical patient with HA-MRSA is a nursing home resident, one who has undergone prolonged hospitalization, one who has been admitted into an intensive care unit, or a person with diabetes mellitus or renal disease receiving dialysis. In contrast, those most often infected with CA-MRSA are athletes, prisoners, college residents, and other like settings (Wiener, 2008). Worldwide, an estimated two billion people carry some form of *S. aureus*; of these, up to 53 million (2.7% of carriers) are thought to carry MRSA. In the US, 95 million carry *S. aureus* in their noses; of these, two and a half million (2.6% of carriers) carry MRSA (Graham, Lin, & Larson, 2006). A population review conducted in three U.S. communities showed the annual incidence of CA-MRSA during 2001–2002 to be 18–25.7/100,000; most CA-MRSA isolates were associated with clinically relevant infections, and 23% of patients required hospitalization (Jernigan, et al., 2006).

Public settings, especially those settings that bring socially active groups into small living areas, are environments rich for CA-MRSA to become epidemic. For example, the investigator has shown in a pilot study of a large university that 29% of students sampled were colonized with *S. aureus*; of these, almost 8% carried MRSA. This prevalence rate of a subset in the general population is four fold higher than the general

population as reported previously (Rohde et al., 2009). The study identified college students as being unaware and lacking knowledge about MRSA. The literature review for this study focuses on three main areas. First, literature on MRSA in the healthcare environment is examined for information on MRSA knowledge and awareness. This part of the review establishes a foundation for MRSA issues with respect to its origin and eventual transition into the general public. Presented next is a review of the literature associated with MRSA knowledge and awareness in the general public. This part of the review documents the critical need for building research on this population re issues of MRSA. Third, the literature associated with theoretical influences which relates to bridging gaps in MRSA knowledge, learning needs, and adaptation to the condition is presented. Specifically, an examination of learning theory (self-directed and transformational), the ecological perspective of health, and social representation theory will be presented.

#### MRSA Knowledge and Awareness – Healthcare

The first methicillin-resistant *Staphylococcus aureus* (MRSA) case was reported in the United Kingdom in 1961, shortly after methicillin was introduced into clinical practice (Jevons, 1961). Seven years later, after the resistant strain had become widespread in Japan, Europe, and Australia, the first case of MRSA in the US was reported in 1968 at a Boston hospital (Barrett, McGehee, & Finland, 1968).

A current literature review of knowledge, sources of information, and perceptions about healthcare-associated infection (HCAI), particularly MRSA, provides an excellent foundation to the general trends associated in patients and the public (Gould, Drey, Millar, Wilks, & Chamney, 2009). The authors found 16 studies that met their healthcare

inclusion criteria for studies of MRSA in the healthcare environment. With respect to patients, the overall findings for the healthcare arena demonstrated that fear of acquiring HCAI, especially MRSA, is the single greatest worry of individuals contemplating hospital care. Importantly, the review reports that in all accounts, people expressed anxiety about the risks and consequences of HCAI. The most frequently reported source of information was the media. Individuals often do not appear to access credible sources, and if they do, do not appear to understand them well (Gould et al., 2009). More than half the studies in the Gould et al. literature review took place in the U.K. (including Bellamy, 2004; Brooks, Shaw, Sharp, & Hay, 2008; Criddle & Potter, 2006; Duncan & Dealey, 2007; Gill, Kumar, Todd, & Wiskin, 2006; Hamour, O'Bichere, Peters, & McDonald, 2003; Jolley, 2008; Kennedy & Hamilton, 1997; Madeo, Shields, & Owen, 2008; Merle, Van Rossem, & Tavolacci, 2005; Newton, Constable, & Senior, 2001; Tarzi, Kennedy, & Stone, 2001; Washer, Joffe, & Solberg, 2008) with the remainder in the US (including Guinan, Fu, O'Neill, Tsang, & McGuckin, 2005; McGuckin, Waterman, & Shubin, 2006; Miller & Farr, 1989), France (Merle et al., 2005), Italy (Abbate, Giuseppe, Marinelli, & Angelillo, 2008), Germany (including Mattner, Mattner, & Zhang, 2006; Vonsberg, Sander, & Gastermeier, 2008), Australia (Donaldson, Jalaludin, & Chan, 2007) and the Irish Republic (McLaughlin, Canavan, Adams, McDonagh, Breet, Fitzpatrick, et al., 2008).

*MRSA Knowledge: U.S. Healthcare Environment*

Miller and Farr (1989) surveyed recently discharged patients to determine knowledge of HCAI. Sixty two percent were dissatisfied with the information they had received and 69% claimed that the risks had not been explained prior to admission.

Guinan et al. (2005) and McGuckin et al. (2006) similarly evaluated knowledge about HCAI and found opposite results – 17% versus 85% considered that it was important to know about infection rates in the hospital, respectively. Each study demonstrated that the respondents knew about HCAI (85% and 94%, respectively). Unfortunately, studies in the US have focused primarily on the prevalence and genetic relatedness of HCAI, particularly MRSA (as documented in the introductory chapter of this document), while only recently investigating perceptions, knowledge, or awareness.

*MRSA Knowledge: Healthcare Environment outside the US*

However, if one looks abroad there is considerably more literature about MRSA knowledge in the healthcare arena. Brooks, Shaw, Sharp, and Hay (2008) have shown that many primary care patients in the United Kingdom (U.K.) are unaware of what antibiotic resistance is and how it arises. The authors' qualitative study concluded that the causes of, and responsibility for, antibiotic resistance like MRSA are usually attributed to external rather than personal factors and patients perceive that its solutions are outside of their control. Like Brooks et al., Newton, Constable, and Senior (2001) report in a qualitative study of 19 patients in the U.K. that the majority of participants did not appear to have a clear understanding of MRSA infection nor did they fully comprehend the reasons for source isolation. Abbate, Giuseppe, Marinelli, and Angelillo (2008) document patient's acquisition of knowledge, understanding, attitudes, and experiences of HA-MRSA in Italy. Importantly, 69% reported receiving information about HCAI albeit mostly from the media and to a lesser extent (15%) from health professionals. Criddle and Potter (2006), in a phenomenological study conducted in Britain, found that increased prevalence of MRSA does not appear to result in improved knowledge and

understanding among staff and patients; however, staff knowledge has clearly been a factor in some patient's experiences. In contrast, Gill, Kumar, Todd, and Wiskin report a high awareness of MRSA from U. K. patients and healthcare workers (94% & 100%, respectively); although for patients the most common source of information was the media (2006). Similarly, an English study found high awareness and that the media is at least equal in prevalence to health care professionals with respect to information dissemination (Hamour, et al., 2003). Practically, all of the remaining studies report similar findings with respect to patients being aware of MRSA but not understanding the critical aspects of transmission, infection control, and prevention (Lugg & Ahmed, 2008; Madeo, et al., 2008; McNulty, Boyle, Nichols, Clappison, & Davey, 2007; Trigg, Timmons, & Pynegar, 2008).

Gould et al. (2009) report that there is no shortage of information about the risks of HCAI, how it is transmitted or prevented from the statutory bodies and National Health Service trusts. Likewise, the investigator in this study has also found that the US and other countries have many credible sources about MRSA, primarily governmental resources (e.g. CDC) and other peer-reviewed medical sources, both print and web-related. However, the literature appears to document poor understanding and knowledge about risk factors associated with MRSA and similar infections. The main source of information among patients is the media which has been linked to exaggerated claims or incorrect information. In the investigator's association with healthcare environments for the past 15 years, it appears that even with all of the misunderstanding and low levels of knowledge about this organism, that at least there is an opportunity for patients to cross paths with correct knowledge about MRSA – that is not always true in the general public.

## MRSA Knowledge and Awareness – General Public

While research, especially outside the US, has begun to document levels of awareness and knowledge of MRSA within the healthcare arena, little research has been conducted on the awareness and knowledge of MRSA within the general public. Gould et al. (2009) reviewed six studies that examined MRSA and HCAI awareness and knowledge in the public. They categorized the studies of the public as “those that set out to explore the knowledge and perceptions of people who had not undergone recent healthcare interventions and were not about to use the health services” (p. 3).

### *MRSA Knowledge: U.S. General Public*

McGuckin et al. (2006) reported that members of the public generally knew about HCAIs and MRSA but did not understand the importance of infection rates within the hospital or simply did not care because they felt they could not do anything about the problem. The current review uncovered four other studies conducted in the US that did not meet the criteria for the Gould et al. review paper. Brinsley-Rainisch et al. conducted eight focus groups, two each in New Orleans, Louisiana; Atlanta, Georgia; Houston, Texas; and Phoenix, Arizona, in July 2005. A convenience sample of parents or legal guardians of at least one child under the age of 12 residing within each of the metropolitan areas was used with the variables of age, ethnicity, gender, and income. Individuals were excluded if they or their relatives worked in the medical field. Ninety percent of participants had heard of staph; only 22% and 8% had heard of MRSA or CA-MRSA respectively. The participants reported hearing about this issue from person(s) with staph or MRSA (27%), a health care provider (22%), a lay person (20%), media (18%), a class or work-related training (8%), and/or personal experience (4%).

Respondents gave diverse (and often incorrect) answers with respect to what they knew about this issue (~~–~~“flesh eating”, ~~–~~“impetigo”, ~~–~~“heart disease”, etc.) and they often did not understand how it was transmitted. In another study among Latinos, the investigators found that ultimately the most important factors associated with this growing problem include (a) traditional barriers for access to care (inadequate knowledge about health, healthcare, and antibiotic uses) and (b) behaviors and cultural beliefs held by immigrants from countries in which antibiotics are easily obtained and used by self-directed methods (Cespedes & Larson, 2006).

In the most comprehensive study located to date, researchers used interviews to explore the attitudes of members of the public to bacterial resistance. The authors wanted to explore lay perceptions because they felt that for behavioral change to occur, individuals need to perceive the issue as important to them and feel able to make a valuable contribution, otherwise public campaigns for MRSA education will continue to fail. A purposive maximum variation sample included 32 (70%) women and 14 (30%) men with an age range from 18 – 89, from areas of high, average, and low income levels. Interviewees were confused or uncertain about what bacterial resistance meant and their understandings were not consistent with current medical concepts. Threat perception and perceived importance of the topic were low. As with other studies mentioned, the media was found to be a main source of information. Very few understood they could help the resistance problem by expecting antibiotic prescriptions less often, or taking them according to prescription instructions and even fewer understood the importance of frequent hand washing. A majority of participants felt like MRSA was a *hospital problem* and not a community problem (Hawkings et al., 2007). This is a critical problem with all

antibiotic resistance –blaming healthcare and not taking personal responsibility in the issue.

Finally, McBrien, Felizardo, Orr and Raymond (2008) report on a comprehensive study about the work of an interdisciplinary professional work group using focus groups to revise an educational booklet for people living with MRSA as patients, family members, and caregivers. This guide contained discussion questions covering four key areas of inquiry, including (a) types of information needed at the time of MRSA diagnosis and at present, (b) motivation for seeking information about MRSA, (c) adequacy of key information as presented in the interim revision of the booklet, and (d) suggestions for booklet revision. The main findings during the focus group sessions centered around transmission of MRSA to family members (especially children), duration of infection, MRSA affecting daily living, clarification about knowledge (e.g. MRSA lifecycle, colonization versus infection), and how to deal with recurrent infections.

The rapid increase in the number of studies investigating lay perceptions about the risks associated with MRSA and other like infections reflects the growing importance of this public health threat to patients and the public. While these studies document awareness and perceptions fairly well, they lack in other analyses of how the individual with MRSA is impacted, what they need to know, and how they take efforts to learn and adapt to the illness. These are the questions that will be addressed in this study. The literature also suggests that the media (print and electronic) heavily influences lay knowledge and attitudes toward risk instead of more credible sources of information about MRSA. This finding differs from previous findings about the behavior of people with chronic illnesses for whom newspapers and television are not the choice of

information and an explanation for this difference is unclear (Coulter, Ellins & Swain, 2006). Coulter et al. (2006) found that for individuals with a variety of chronic diseases or other health-related concerns, doctors and other health professionals are the most frequently used resource.

*MRSA Knowledge: General Population outside the US*

Mattner, Mattner, and Zhang (2006) explored knowledge and perceptions about MRSA on the premise that knowledge is a precondition for prevention spread. The investigators interviewed 224 Germans in a metro station in Hanover and found 70% of commuters claimed to have heard about HCAI and 60% knew about multiple resistant bacteria. However, very few identified infection as a problem with hospital admission. Likewise, Guinan et al. (2005) evaluated public knowledge of HCAI as part of a larger enquiry exploring the most important factors when choosing a U.S. hospital. Only 17% considered it important to know about infection rates before admission even though 85% knew about HCAs. Two other studies of the public (Vonsberg et al., 2008; McLaughlin et al., 2008) found similar results in which German and Irish Republic individuals, respectively, knew about HCAs and MRSA but didn't appear to comprehend the importance of infection rates within the hospital. Finally, Washer et al. (2008) interviewed 60 people described as demographically diverse living in Greater London to explore perceptions of HCAs. Most participants attributed risk of MRSA to poor environmental conditions in hospitals arising through mismanagement, thus reflecting media accounts. Awareness of the role of antibiotic over-prescription and misuse in the origin of resistant bacterial strains was not reflected in responses. The investigators

differentiated ‘lay beliefs’ of MRSA as being media derived and ‘scientific beliefs’ of MRSA as being medical-biological derived.

### Theoretical Influences

A number of theoretical frameworks have been identified which may provide possible lenses through which to interpret data that are collected as part of this study. One might consider these frameworks – learning theory, ecological perspective, and social representation theory – as sensitizing concepts of this study. Sensitizing concepts are viewed as interpretive devices that can be used as a starting point for a qualitative study (Patton, 2002). These concepts may offer ways of seeing, organizing, and understanding the experiences of those impacted by MRSA.

#### *Adult Learning Theory*

*Self-directed learning.* In self-directed learning (SDL), the individual takes the initiative and assumes responsibility for what occurs. Individuals choose, manage, and evaluate their own learning activities, which can be pursued anywhere, anytime, anyplace, through any means, at any age. SDL has been described as the ability of individuals to initiate, either alone or with the help of others, the diagnosis of their learning needs, formulation of their learning goals, identification of resources for learning, selection and implementation of learning strategies, and evaluation of learning outcomes (Knowles, 1975). An estimated 70 percent of adult learning is self-directed in nature (Candy, 1991; Cross, 1981).

In Merriam, Caffarella, and Baumgartner’s (2007) review of SDL, they grouped the work that they reviewed into three broad categories focusing on: goals, processes and applications, and personal attributes of learners. They maintain that the three main goals

of SDL are as follows: (a) to strengthen the ability of the adult learner to be self-directed in their learning, (b) to foster transformational learning as critical to SDL, and (c) to advocate emancipatory learning and social action as an integral part of SDL. Likewise, the processes and applications of SDL have been discussed in the literature with three types of models: linear, interactive, and instructional. Finally, autonomy of the learner has received the most attention in the realm of personal attributes and assessing self-directedness (p. 129). It is not the intent of this current review to examine every facet of SDL. Rather, the intent is to introduce SDL theory as a potential lens to view how individuals diagnosed with MRSA learn and create knowledge to manage their illness and adapt to the situation.

While most research focuses on self-directed learning growing out of formal learning settings or the workplace, our everyday lives hold major challenges that require SDL as well. For instance, Guglielmino (2008) mentions a few of those examples as being parenting, pursuing interests and leisure activity, seeking meaning, and managing health care and health emergencies. It is of critical interest to this research to examine more closely the instance of managing health care. There are many examples of SDL for personal use that have been documented and I will address three that align with this current study.

A diagnosis of a disease or life-threatening condition often initiates a deep desire for SDL for the individual and for family members and close friends. Caffarella (Merriam & Caffarella, 1999) discusses her own experience with SDL after being told she had a serious illness. She was in a constant learning mode with respect to treatment regimens and new medications. Holland (1992) reports on the SDL learning efforts of individuals

dealing with multiple sclerosis (MS) in her dissertation. MS is an unpredictable disease in regards to how it progresses and the number of treatment types. The findings showed that reading and questioning healthcare professionals were the most popular and satisfactory modes of learning. MS individuals consistently pursued topics such as symptoms and therapies, the disease process, and coping. The themes that emerged in this study were the frequent use of experiential learning as a mode for SDL about MS, the view of the physician as the leader of the MS care team, and resistance to the use of lectures and group support modalities by some individuals with MS because of the desire to avoid others more disabled. Hollingsworth and Scott (2008) detail the learning of a multiple kidney transplant recipient attempting to balance the effects of the disease and the treatment and maintain her role as wife and mother. Her personal losses emerged as five sub-themes in this study: emotional consequences, effects on the family, financial burden, social withdrawal, and physical effects, addressed by an overarching theme: lifelong learning challenges. The informal learning focused on fully understanding kidney disease, with the calculated ability to decipher side effects, the need to stay aware of constant medication restrictions, and the desire to understand complicated and diverse medical terms. Her self-directed learning experience involved change and adjustment, in non-routine conditions. Her informal self-directed learning was a mix of proactivity, creativity, and critical reflection.

The three studies discussed above fall within the interactive model of SDL in which the learning is not viewed as being highly planned or linear in nature. This type of SDL process has been reported in similar studies of specific populations or topics, such as health care management or health emergencies. The SDL in these types of

environments often include a catalyst around a diagnosis such as an individual being told of a MRSA diagnosis.

*Transformational learning.* Transformational or transformative learning is about change. The change may be sudden or occur over an extended time period. Whatever the time may be though, the change prompts a major shift in the way individuals see themselves or the world. Transformational learning theory has typically been approached from two perspectives based on the locus of learning – individual versus sociocultural (Merriam, Caffarella, & Baumgartner, 2007). There is an exhaustive amount of research detailing the differences between the two perspectives but that is not the focus of this research study. The focus for this study will remain on the individual locus of learning, specifically Jack Mezirow's psychocritical approach, because it appears to fit with the experience one might encounter with a diagnosis of MRSA.

Mezirow's transformative learning theory (1981) describes four main parts of the transformative learning process: experience, critical reflection, reflective discourse, and action. The experience is often set in motion by a disorienting dilemma such as a life threatening illness or death of a loved one. A MRSA diagnosis appears to have the characteristics of a disorienting dilemma. These events cause one to critically self-examine the assumptions and beliefs that surround the experience. In doing so, one revises specific assumptions about themselves to the point of transformation of the structural make-up of assumptions. The new meaning that is created by a transformation is then subject to reflective discourse. This might be in the form of seeking out expert opinions in a variety of settings – groups, one-to-one, and formal educational settings. Action is the final component of the transformative learning experience. The action may

be immediate or delayed. Action might be viewed as simply a small step like a decision or a more dramatic step such as changing careers.

Two studies applying transformative learning theory were identified that inform the current study on MRSA. In a study of healthy lifestyle change after a cardiovascular disease diagnosis, Montoya (2008) reported that transformative learning was a critical aspect of lifestyle change. Participants who were able to maintain healthy changes described empowering interactions with both health care professionals and others that enabled them to clarify the meaning of their experience and enact positive and lasting changes. Participants who failed to maintain healthy lifestyle changes described anxious and disempowering interactions that impeded the development of trusting, collaborative relationships. Their subsequent actions were poorly developed and based on inaccurate understandings of their condition.

Baumgartner (2002) conducted a study of the same 11 participants in 1995, 1998, and 1999. The study sought to understand how individuals with HIV/AIDS continued to make meaning of their chronic illness. Four major findings emerged including (a) transformational learning occurred, (b) meaning changes were acted upon, (c) new meaning structures were a higher appreciation for the human condition and an enlarged view of intimacy, and (d) interaction (socially) was crucial to the learning process.

Each of these investigations has important implications for how adults integrate new meaning over time in such a way that it changes the very foundation of their beliefs about themselves or the world. It will be critical to examine how MRSA intersects with the constructs of Mezirow's transformational learning theory.

### *Ecological Perspective*

Health issues, such as public knowledge of MRSA, can be examined from a global lens with respect to the ecological perspective created by McLeroy and colleagues in 1988. The *ecological perspective* emphasizes the interaction between, and interdependence of, factors within and across all levels of a health problem. It highlights people's interactions with their physical and sociocultural environments. Two key concepts of the ecological perspective help to identify intervention points for promoting health: first, behavior both affects, and is affected by, *multiple levels of influence*; second, individual behavior both shapes, and is shaped by, the social environment (*reciprocal causation*). The first key concept, multiple levels of influence, is composed of five levels of influence for health related behaviors and conditions: (a) intrapersonal or individual factors; (b) interpersonal factors; (c) institutional or organizational factors; (d) community factors; and (e) public policy factors (Table 1). The second key concept of an ecological perspective, reciprocal causation, suggests that people both influence, and are influenced by, those around them.

The ecological perspective includes a network of interrelated theories which can be examined in light of knowledge, learning strategies, and adaptation to antibiotic resistance issues, particularly MRSA. The individual level is composed of four key theories: (a) health belief model; (b) stages of change model; (c) theory of planned behavior; and (d) precaution adoption process model. The interpersonal level is composed of one primary theory, social cognitive theory. It is important to mention that the ecological perspective focuses on social cognitive theory at this level because the authors felt that it was the most encompassing theory. The community level is composed

of three key theories: (a) community organization; (b) diffusion of innovations; and (c) communication theory (McLeroy, Bibeau, Steckler & Glanz, 1988). Each of these theories may play a part in understanding how people build knowledge and how they learn about and adapt to MRSA.

Table 1

*The Ecological Perspective: Levels of Influence*

<b>Concept</b>	<b>Definition</b>
<b>Intrapersonal Level</b>	Individual characteristics that influence behavior, such as knowledge, attitudes, beliefs, and personality traits
<b>Interpersonal Level</b>	Interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support, and role definition
<b>Community Level</b>	
Institutional Factors	Rules, regulations, policies, and informal structures, which may constrain or promote recommended behaviors
Community Factors	Social networks and norms, or standards, which exist as formal or informal among individuals, groups, and organizations
Public Policy	Local, state, and federal policies that regulate or support healthy actions and practices for disease prevention, early detection, control, and management

Note. From *Theory at a Glance: A Guide for Health Promotion Practice* (p. 11), by K. Glanz, B. K. Rimer, and S. M. Su., 2005, New York, NY: Department of Health and Human Services, National Institutes of Health (NIH Publication No. 05-3896), United States National Cancer Institute. Copyright 2005 by United States National Cancer Institute. Reprinted with permission.

*Social Representation Theory*

Another important theory, social representation theory, which is not part of the ecological perspective, although it appears to fit at the community level within the ecological perspective, may be an important piece of the puzzle in a possible explanation of MRSA knowledge and adaptation. Social representation theory allows one to study the

passage of knowledge from scientific thinking, via the mass media, to lay thinking. One of its major concerns is the way in which new threats to a society are constructed, with the media being a key player in the evolution of public thinking (Moscovici, 1984). Two key tenets of this theory are anchoring and objectification.

Anchoring simply means how people make sense of the unknown by using anchors to make the unfamiliar seem familiar. For example, in the case of the coverage of severe acute respiratory syndrome (SARS), the (alarmist) anchors used to describe the new disease were the Spanish influenza epidemic of 1918 and the Black Death (Washer, 2004). In the case of ‘mad cow disease’ the early anchors were salmonella and the sheep disease scrapie, and later, AIDS (Washer, 2006). Anchors can play a role in raising one’s fears if they are attached to high mortality (alarmist and sensationalist media) to lowering one’s concern if they are not attributed to being serious or not affecting humans (Moscovici, 1984).

The second tenet of social representation theory is objectification. Objectification coats an unfamiliar thing with more familiar images, symbols and metaphors that are easier to grasp (Moscovici, 1984). The process of objectification overlaps with that of symbolism (Joffe, 2003). A fundamental function of a symbol is to provide people with a means to experience abstract content. Symbols provide a sense of understanding at just a brief glance; complex messages are encapsulated in a simple and vivid manner. Symbols also contain an emotional factor, helping to create and maintain certain feelings.

Washer and Joffe (2006) examined MRSA in Britain over the 10-year period by analyzing newspaper coverage of the disease from 1995-2005. The study utilized social representations theory and embedded MRSA within the framework of other emerging

infectious diseases (EIDs). Key findings were that MRSA is the new ‘superbug’ and its rise has marked the failure of the golden age of medicine conquering disease. The study also found that MRSA is built around an *it could be you or me* set of assumptions played out in the media. Finally, the blame for MRSA is laid at the doorstep of *why it spreads* instead of its origins (antibiotic misuse). Ultimately, the blame is placed on poor hygiene of the hospitals and mismanagement, a form of ‘othering’ that is inherent in social representation theory. This is seen as having a close fit with the current investigation.

### Summary

The present limitations in the literature suggest that more information is needed to better understand the ways in which individuals make meaning from the information they receive about a MRSA diagnosis, how they construct knowledge from those meanings, and what learning strategies they use to adapt to their condition. Although there are high levels of awareness and concern about MRSA among hospital personnel, patients, and the general healthcare profession, there has been limited research focused on the general public. The growing number of studies investigating lay perceptions about the risks associated with MRSA and other like infections reflects the growing importance of this public health threat to patients and the public. The literature also suggests that the media can influence people, positively or negatively, in the ways they are transferring knowledge from the scientific-biomedical environment into the lay knowledge of the general public.

While these studies document awareness and perceptions fairly well, they lack in other analyses of how the individual with MRSA is impacted, what they need to know, and how they take efforts to learn and adapt to the illness. Despite the present challenges

that come with a MRSA diagnosis, it is anticipated that by framing the MRSA experience in this investigation through the lenses of adult learning, ecological perspective, and social representation, that one will begin to better understand these events at the interpersonal, intrapersonal, and community level. Health educators and those involved in prevention and control efforts will benefit from further investigation into the learning and adaptation strategies utilized by the individuals that are affected by MRSA. By gaining insight into this internal process, the findings from this study will facilitate the self-management of the sometimes chronic and stigmatized condition that often comes with a MRSA infection.

## **CHAPTER THREE**

### **METHODOLOGY**

The purpose of this study was to better understand the experiences that an individual goes through when they are dealing with MRSA in terms of how they construct knowledge from the meaning they make about the condition and what learning strategies they use to adapt to their illness. With this goal in mind, it was best to use a qualitative methodology to explore the core understanding of human action and relationships (Patton, 2002). There is little evidence of research conducted in which individuals in the community have been asked how MRSA has impacted them. This was the aim of this dissertation; to have a better understanding of the impact and the consequences of a MRSA infection on an individual in the general public. In doing this, I planned to make accessible to those who read my research (both who have experienced MRSA and those who have not) the common significance of a real-life experience of each of the people in my study. Further, by understanding the real-life experience of people, I hoped to influence health education, policy and prevention efforts with this growing public health threat.

#### **Research Paradigm – Approach**

Paradigms are often defined by purists in extreme, opposite end approaches. On one end of the spectrum are the positivists (and post-positivists) whose reality can be objectively explained, and thus causal linkages may be defined. At the other end of the

spectrum are the constructivists or interpretivists whose reality is socially constructed and only knowable from multiple and subjective points of view. The former view employs deductive reasoning and quantitative methods of research while the present view employs inductive logic and qualitative methods. While each of these purists often disagree over which paradigm is the most accurate, they both agree that each view explains the world and truth in such a fundamentally different way that they should not be mixed (Rocco, et al., 2003).

As a clinical scientist, I have been trained as a classical post-positivist and I have explained findings from primarily a deductive viewpoint. It is from this stance that I have conducted research using quantitative methods to identify risk factors associated with MRSA colonization in a Texas prison (Folkner et al., 2007) and a university pilot study (Rohde et al., 2009). However, as a current student in Adult Professional Community Education I have evolved from this stance of a post-positivist worldview within a scientific culture of inquiry. I have come to appreciate the stance that scientific phenomena are not always explicitly explained by this view.

I believe that I have come to understand the strengths and weaknesses of both the qualitative and quantitative paradigm. I initially set out to conduct a mixed method for this study so that I might be able to examine a large population (university students) for MRSA knowledge and awareness. What I ultimately arrived at, however, after immersing myself in the literature and in my encounters with individuals who were experiencing MRSA was that I would not be able to get to the root understanding of *how* or *why* people learn about MRSA relying on a post-positivist view.

## Qualitative Research

In this section, I have summarized the basic tenets and themes of a typical qualitative study and how they align with my proposed research. I am aware and understand that qualitative research is accepted in the arena of education and the social sciences. However, I also intend for many individuals in my professional field, clinical laboratory science and public health, to utilize the findings of this study. In these laboratory-based professions, quantitative research still dominates the literature. Thus, I wanted to share the foundations upon which a qualitative study is built to bridge the different viewpoints of the professionals that will be reading this dissertation.

Qualitative research often starts with a *how* or *what* question so that initial forays into the topic describe what is going on (Creswell, 1998, p. 17). This objective of qualitative research made it the best fit for this study. It looked at *how* individuals with MRSA are impacted, what they need to know, and how they make efforts to learn. Fully exploring and understanding the effect from the subject's point of view is the goal of qualitative research. This is different from quantitative research which seeks to measure the effect rather than understand *what* the effect is. Qualitative and quantitative research also differs in that quantitative researchers rely on many cases and fewer variables, whereas qualitative researchers rely on a few cases and many variables (Patton, 2002). By choosing to use a qualitative approach and a smaller sample, this study explored in-depth all the variables that individuals brought to their experiences with MRSA. Qualitative research allowed for the attention to detail that this study required.

Patton (2002) describes qualitative research as reflecting some portion of each of the following three themes to some degree: (a) design strategies (naturalistic inquiry,

emergent design flexibility, and purposeful sampling), (b) data collection and fieldwork strategies (qualitative data, personal experience and engagement, empathic neutrality and mindfulness, and dynamic systems) and (c) analysis strategies (unique case orientation, inductive analysis and creative synthesis, holistic perspective, context sensitivity, and voice-perspective-reflexivity (p. 40-41). This study embodies each of these themes to some degree.

### *Constructivism and Grounded Theory*

This section will briefly discuss my approach to the study. A detailed explanation will follow in the coming sections where appropriate. The study will be conducted within a constructivist theoretical framework. The classic qualitative study opens up a world, usually unknown by the reader, through rich, detailed, and concrete descriptions of people and places – known as thick description (Creswell, 1998; Denzin & Lincoln, 2005; Maxwell, 2004; Patton, 2002; Strauss & Corbin, 1998). The study used interviews of participants with MRSA to discover their experiences with construction of knowledge about MRSA, what learning strategies they used, and how they adapted to a MRSA diagnosis. These interviews were transcribed into raw data that were analyzed for patterns through open coding. Open coding produced distinct categories or themes that were organized into a typology for explanation of the *MRSA experience* (Creswell, 1998; Denzin and Lincoln, 2005; Patton, 2002; Strauss and Corbin, 1998).

I hoped also to develop theory or a model that explains the *MRSA experience* by integration of the coded categories into a possible explanation of this phenomenon. Glaser and Strauss (1967) discovered and appropriately labeled this method as grounded theory – becoming grounded in the data. Briefly, open coding of themes or categories are

established which is followed by axial coding. Axial coding involves selecting one open category and using it as the central cog to relate all the other categories to it. Finally, selective coding is performed in which a theory is developed based on the interrelationship of the categories from axial coding (Creswell, 1998). Grounded theorizing, then, involves “both inductive (deriving concepts and properties of categories) and deductive processes (hypothesizing about the relationships between concepts)” (Strauss & Corbin, 1998, p. 22).

### *Participant Criteria*

Participants were chosen for inclusion in this study if they met the following criteria;

1. The individual (male or female) was from the general public (non-healthcare environment and not a patient) and has been diagnosed with MRSA.
2. The individual had been diagnosed with MRSA at least one month prior to the time of the interview and within the last year.
3. The individual was 18 years or older.

To the degree possible, an effort was made to select a sample that was diverse in ethnicity, gender, and age. These criteria were set so that each individual participating should have firsthand experience to describe in regards to the impact that MRSA has had on them. Additionally, it was expected that these criteria will create a sample of maximum variation that will increase the robustness of the conclusions and enhance the likelihood of transferability of this research study.

This population was chosen for several reasons: (a) there is a critical need to study individuals in the general public as identified by the literature review; (b) the investigator has had experience with the public's lack of knowledge and understanding about MRSA during consultation with members of the community; and (c) it offers a way to understand how individuals construct knowledge, utilize learning strategies, and adapt to a diagnosis of MRSA.

### *Recruitment*

Participants were recruited through three different mechanisms – prior contact, referrals from the university health center, and snowballing. Due to the investigator's prior research and publication in the field of MRSA, a number of inquiries (phone and email) were made from members of the general public about MRSA. These inquiries were typically concerned with a number of factors about MRSA including transmission, treatment, prevention, and infection control. I relayed an interest to interview these individuals for my dissertation. Several participants were successfully recruited through this means. The university health center physicians and other staff were contacted and asked to provide information about participation in the study to individuals who met criteria. A Recruitment and Scheduling Flier (Appendix A) was placed in the university health center and in the investigator's place of employment. The flier briefly discussed the study with a request to contact the investigator by phone or email. I subsequently screened the participants that made contact by a return brief email or phone call. The screen consisted of a request for information on age, gender, and ethnicity, time of MRSA diagnosis, and a preferred contact time and information. Lastly, existing study participants were encouraged to identify potential participants from among their

acquaintances, a process known as snowballing. Willing participants from all three sources were provided with my contact information as well as an invitation letter which briefly described the study and parameters of participation.

### *Sample Description*

The purposive sampling strategy employed resulted in a sample consisting of ten individuals who met the criteria described previously. All participation was voluntary, and participants first authorized consent documents (see Appendix B). Ten participants (four male and six female) who ranged in age from 21 to 73 were selected. Nine identified themselves as Caucasian – White and one as Vietnamese – French Canadian. Two subgroups emerged – a young adult group (four) and a retired or approaching retirement group (six). Most participants had college degrees with several having advanced degrees (Table 2).

### *Data Collection*

After coming forward as willing participants, the individuals received a request for an interview by phone or email and the letter of informed consent was delivered through the mail or by email. In the first contact, I confirmed that the participant met the criteria in order to participate in the study. The participants were then scheduled for an interview time. The interviews took place under private and confidential circumstances at mutually agreeable sites. At the time of the interview, I again discussed the letter of informed consent.

Due to the personal medical nature of the interviews, I began the interview by sharing my background in public health. The interview began with informal introductions, the purpose of the study, and the desired results and impact on the greater

community dealing with this emerging infectious disease. The interview consisted of open-ended questions which encouraged participants to share their opinions and experiences with me. The intent was to encourage an open and honest exchange by beginning with a social conversation aimed at creating a comfortable environment (Denzin & Lincoln, 2005; Patton, 2002; Strauss & Corbin, 1998). Questions for the interview were guided by the investigator's background in MRSA research and by the literature review as it relates to the research questions of this study. The interviews were semi-structured and nondirective in order to obtain as much information about the phenomenon as possible. The predetermined interview questions (see Appendix C) were a guideline to follow, not a rigid structure. The interview guide was piloted with two individuals who did not meet the inclusion criteria but had had a similar *close encounter* with MRSA (e.g. the sibling of someone who died of MRSA). The in-depth interview provided an open environment for participants to control the flow of the conversation, for example to bring in any details which, for them, held some meaning. There was time and space for clarifying and probing questions. The participants were encouraged to use their own words to describe their experiences. Individuals are experts on their own experience. Evidence from constructivist research is derived from first-person reports of life experiences (Creswell, 1998; Denzin & Lincoln, 2005; Patton, 2002; Strauss & Corbin, 1998).

### *Data Analysis*

Upon completion of the interviews, the recordings were transcribed and labeled with a pseudonym for confidentiality. Data analysis of transcripts was continuous beginning with the first interview (Patton, 2002). Most interviews were transcribed

previous to the subsequent interview taking place. This allowed me to make adjustments to the questions used in subsequent interviews as well as track data saturation.

Clarification of transcript meanings was conducted by phone or email with the earlier interviewees. Concomitantly, analytic memos were used throughout the research study to facilitate reflection and analytic insight which provided a logical, systematic, and coherent process for carrying out the analysis and synthesis needed to arrive at essential descriptions of experience (Creswell, 1998). First, the transcripts were coded for commonalities as they emerged during the reading and transcribing of interviews. A cross-reference matrix (Appendix D) based on the interview guide was used to screen for these commonalities. Second, when all of the interviews were completed and transcribed, they were read and reread from a more global stance using the sensitizing concepts (lenses) previously described to identify and index categories and themes: it was anticipated that these might develop around particular phrases, incidents, or types of behaviors (Patton, 2002; Strauss & Corbin, 1998). As mentioned previously, a qualitative study attempts to explain the why and how of a process or interaction. The central aim of this research was to explain how individuals learn about their MRSA condition: how they construct knowledge, what learning strategies they undertake, and how they adapt after the diagnosis.

Because data analysis was inductive and ongoing, data saturation was used to determine the point at which no further interviews needed to take place. Data saturation is the point at which no new information is being received from the participants. Unlike quantitative researchers who wait until the end of the study to analyze their data, qualitative researchers analyze their data throughout their study (Patton, 2002; Strauss &

Corbin, 1998). The interviews and any other data collected in this study were analyzed during the research process. Because of the goal for saturation, there was no formula to decide in advance the precise number of interviews that would be conducted.

Guest (2006) studied 60 interviews to determine the degree of data saturation and variability over the course of thematic analysis (p. 59). Based on the data set, they found that saturation occurred within the first 12 interviews, although basic elements for metathemes were present as early as six interviews (2006, p.59). Access to individuals with the MRSA experience did not influence the final number of individuals interviewed in the current study. Ultimately, the participants were chosen on a first come, first served basis while adhering to the previously discussed criteria for this study. Data saturation occurred at approximately the eighth interview. Two additional interviews were conducted to ensure no additional themes might emerge.

The circumstances surrounding the research process and the analysis of the data permitted the development of a learning and adaptation model that may inform public health and policy around campaigns to augment the reduction of antibiotic resistance, particularly MRSA. To achieve the generation of this model, the researcher bridged himself to the data in such a way that all the embedded meanings and relationships could emerge. Glaser and Strauss (1967) discovered and appropriately labeled this method as grounded theory – becoming grounded in the data.

#### *Role of the Researcher*

Patton (2002) details the role of the researcher as the *instrument* in qualitative inquiry (p. 566). Because of this, qualitative reports should contain information about the researcher. The investigator's interest in this study was multifaceted. I have conducted

research and published reports (Folkner et al., 2007; Rohde et al., 2009) about risk factors and awareness surrounding MRSA in a Texas prison and university. I have been contacted numerous times by individuals in the general public who have MRSA or who have known someone close diagnosed with MRSA. These consultations typically are about issues of understanding exactly what MRSA is and what to do next with respect to treatment and preventing transmission to their family. Additionally, these individuals express their feelings of being lost and neglected – not knowing where to turn for credible information or how to adapt to the infection. It is from this perspective that I entered the research environment with my participants.

I utilized a process known as bracketing during this research study. Bracketing is a technique used in qualitative research for confirmability, the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher (Siegle, 2006, p. 3). My personal experience was only used as a resource for me to access during my interviews; a way for me to join with the participant. I attempted to enter the interview as a researcher setting aside my own definitions and meanings. The information was derived from the interviews with the participants. Each question that was asked was presented in a way to elicit their lived experience without bias or presupposition in the question. This separation goes beyond the interview; it is essential to do one's utmost to separate the interviewer's own perceptions, experiences and biases from the interview and analytical process (Creswell, 1998; Denzin & Lincoln, 2005; Patton, 2002; Strauss & Corbin, 1998).

There are steps to take as the researcher to minimize the influence of my personal biases during the research inquiry. While interviewing the participants and transcribing

and coding each interview before the next interview takes place, a journal was maintained and notes were made in the margins of the transcripts. This helped to track and separate my responses against the responses of my participants (Patton, 2002). My role as a researcher in this study was one of a curious scholar with an interest in this emerging public health threat. I aimed to improve the understanding of how people in the general public construct knowledge and cope with MRSA with the aim of creating new ways and programs to reach those that feel neglected without anywhere to turn for help.

### *Validity and Reliability Issues*

Qualitative research is different than quantitative in ways that rigor is sought and established. –Social construction, constructivist, and interpretivist perspectives have each generated new language and concepts to distinguish quality in qualitative research” (Patton, 2002, p. 546). Lincoln and Guba (1986) substitute reliability and validity with the parallel concept of trustworthiness, containing four aspects: credibility, transferability, dependability, and confirmability. Rather than use the terms reliability and validity, qualitative research use the terms credibility, transferability, and dependability (Lincoln & Guba, 1986). Confirmability is also used to check validity and reliability. These four criteria are used for judging the soundness of qualitative research and are offered as an alternative to more traditional quantitatively-oriented criteria.

*Credibility.* Credibility is the qualitative term equivalent to internal validity (Lincoln & Guba, 1986). It asks if the research is accurate. The goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described. There are several ways to insure this. Prolonged engagement and member checks were used in this study to maintain credibility. The

interviews continued until data saturation had been reached. Also, each participant received a transcript of the interview to confirm the accuracy of the information. In this way, the participants were not only asked for verification of the information, but also for clarification. This form of member checking is highly credible because it is only the participants who can confirm that the results derived from their experiences were accurate.

*Transferability.* Transferability is the qualitative term equivalent to external validity (Lincoln & Guba, 1986). It inquires whether the research can be applied to other groups experiencing the same situation. Is the information obtained in this study relevant and representative of other individuals in the general public who have MRSA? Judgments of transferability are made by the reader based on thick description allowing them to ascertain similarities between their own setting and the participant. Thick description is a rich and extensive set of details concerning participants, methodology, and context provided in a research report (Patton, 2002). Through the in-depth interview and use of loosely structured questions, there was an opportunity to obtain detailed information or thick description from the study participants.

*Dependability.* Dependability is the qualitative term analogous to reliability (Lincoln & Guba, 1986). Dependability is monitored by both internal and external auditors. The main ways in which qualitative researchers ensure the retest reliability of their analyses is in maintaining meticulous records of interviews, observations, and document analysis and by documenting the process of analysis in detail (Patton, 2002). This can be thought of as an example of an internal audit. An external audit might include working with a person not participating in the study to verify process, analysis, and logic

used in interpreting the data (Lincoln & Guba, 1986). In certain ways, the dissertation committee served as external auditors. In this study, both an internal and external auditor was used for dependability.

*Confirmability.* Confirmability is the qualitative term for objectivity (Lincoln & Guba, 1986). It is the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher (Siegle, 2006, p. 3). Bracketing, as discussed previously, is one way to do this. Qualitative investigators must be responsive and adaptable to changing circumstances, holistic, having professional immediacy, sensitivity, and ability for clarification and summarization (Lincoln & Guba, 1986). The combination of my skills and of my understanding of the qualitative standards credibility, transferability and dependability as outlined by Lincoln and Guba (1986) and Patton (2002) guided me in maintaining trustworthiness in my research.

*Triangulation.* Patton (2002) describes several ways to use triangulation to overcome the intrinsic bias that comes from single-methods/single observer and single theory studies (p. 555). For this study, I utilized triangulation of sources – checking of consistency of different data sources within the same method. This type of triangulation technique involves comparing and cross-checking the consistency of information derived at different times and by different means (Creswell, 1998; Denzin & Lincoln, 2005; Patton, 2002; Strauss & Corbin, 1998). This was accomplished by checking for the consistency of what the participants say about the same thing over time and by using multiple participants. Additionally, my dissertation chair reviewed charts of data with me to verify coding of transcripts and development of themes.

*Ethical Concerns*

The research proposed in this qualitative study was approved by the Texas State University-San Marcos Institutional Review Board (2009z4233). I completed all training on human subject research and understand the full implications of informed consent and confidentiality. I have also conducted research within both the human and animal environment for 16 years as a public health researcher and academic researcher. In accordance with the requirements of the IRB, the participants were informed of their rights and asked to read and sign an informed consent form. They were advised they could stop the interview at any time and could drop out of the project at any time. None chose to drop out. No participant indicated that they felt uncomfortable when being asked about their experiences during their MRSA infections, and all expressed their willingness to tell their stories. Participants were assigned their own pseudonym to be used in this document and any subsequent reports and publications. All recordings, computer files, transcripts, and paperwork were identified only by the participant's pseudonym and were kept in a locked file cabinet to which only the researcher has access. Likewise, the researcher's computers used during this study for file storage and analysis had secure passwords and were locked in an office to which only the researcher has access. The participants were advised that their information was confidential, and through the use of their assigned pseudonyms, their identities would be protected. This study was supported financially by a grant the researcher received from the American Society of Clinical Laboratory Science (July 2009). The participants were compensated \$100.00 for their time (\$50.00 after the first interview and \$50.00 after any subsequent follow-up).

### *Summary*

This qualitative study, framed within a constructivist epistemology and using grounded theory methods, was designed with the purpose of gaining a better understanding of the impact and the consequences of a MRSA infection on an individual in the general public. A constructivist design was chosen to help uncover and understand the learning and adaptation experiences of the participants as revealed by them during their interviews. This interpretive study relied on the experiences and perceptions of the participants. An open-ended, semi-standardized interview guide allowed for the gathering of information, and an exploratory design aided in identifying themes. Participants were recruited through three different mechanisms – prior contact, referrals made from the university health center, and snowballing. Potential participants received e-mails or personal phone calls. This recruitment produced ten information rich participants and composed a purposeful sample. After a potential participant was identified, they were sent an invitation letter with information about the study. Once they agreed to participate, a meeting was set during which they signed a consent form, were assigned a pseudonym to protect their identity, and were interviewed for one to two hours. Clarification of interview transcripts was conducted by a follow-up phone call or email. The interview guide was piloted with two individuals who did not meet the inclusion criteria but had a *close encounter* with MRSA (e.g. the sibling of someone who died of MRSA). The interviews were digitally recorded, ensuring that the data were accurately recorded for analysis, and transcriptions. The transcripts were coded, and themes emerged from the data.

To establish its trustworthiness, the research was conducted with rigor. A major criterion of trustworthiness is credibility, which was established through member checking. A second criterion is transferability, accomplished through the use of questions soliciting rich, thick descriptions, thus enabling readers to reach conclusions about the transferability of the data. Third is dependability. A semi structured interview-guide was utilized, allowing the interviewees' thoughts to flow. In addition, triangulation and member checking established dependability. Fourth, confirmability was established through the audit trail comprised of field notes, the interviewer's reflective journal with analytic memos, and the transcripts.

## CHAPTER FOUR

### FINDINGS OF THE STUDY

The purpose of this study was to investigate how people in the community who have had MRSA develop their understanding and knowledge about the condition. The intention was to explore how members of the general public who have a *need to know* discover, learn about, and adapt to MRSA. The two main questions guiding this study were –“How do individuals in the general public construct knowledge about MRSA?” and –“How do people adapt to their condition?” It was hoped the analysis of these findings would contribute to this study by (a) adding to the knowledge base and potential development of theory surrounding the acquisition of knowledge about MRSA within the general population, (b) the identification of learning strategies and mechanisms that can be shared with other individuals who find themselves impacted by MRSA, and (c) the identification of potential strengths and weaknesses in publicly available information about MRSA. It was anticipated that the findings would help facilitate better communication about adaptation to MRSA between the healthcare-medical environment and the general community. From the analysis a story emerges of these individuals’ diverse experiences at the point of their MRSA diagnosis and the subsequent unfolding events.

## Profiles of the Participants

The information obtained from the personal interviews and notes from my personal journal served as the basis for construction of profiles of the ten participants (four male and six female), as revealed by them. An overview is presented on Table 2 – Participant Profiles: Demographics.

Table 2

### *Participant Profiles: Demographics*

Participant	Age at Interview	Gender	Ethnicity (self-identified)	Education	Work Status at Interview
Aaron	21	Male	Caucasian	B.S.	Unemployed
Dora	52	Female	Caucasian	Assoc. LVN	Retired
Trene	21	Female	Vietnamese	B.S.W.	Unemployed
Alvin	62	Male	Caucasian	M.B.A.	Retired
Irene	65	Female	Caucasian	B.A.	Retired
Edward	73	Male	Caucasian	Some college	Retired
Becky	21	Female	Caucasian	B.A.	Part-time
Erin	22	Female	Caucasian	Some college	Part-time
Nell	62	Female	Caucasian	M.S., M.Ed.	Full-time
Mary	51	Female	Caucasian	Some college	Part-time

Bachelor of Science – B.S.

Associates – Assoc.

Licensed Vocational Nurse – LVN

Bachelor of Social Work – B.S.W.

Master of Business Administration – M.B.A.

Bachelor of Arts – B.A.

Master of Science – M.S.

Master of Education – M.Ed.

The participants were assigned pseudonyms for confidentiality. The names were Aaron, Dora, Trene, Alvin, Irene, Edward, Becky, Erin, Nell, and Mary. They ranged in age from 21 to 73 at the time of the interviews. Nine identified themselves as Caucasian – White and one as Vietnamese – French Canadian.

There were several commonalities among the participants. Based on age, two subgroups emerged – a young adult group (four) and a retired or approaching retirement group (six). Three of the four young adult participants had earned undergraduate degrees and one had some college work; two were not employed and two worked part-time. In the older age group, two of the participants had earned undergraduate and graduate degrees (Master's), one had earned an undergraduate degree, and one had earned an associate degree (LVN), with the remaining two having some college work. Two of the older age participants were still employed either part-time or full-time and four participants were fully retired.

#### Personal Stories of the Participants

During the interviews the participants offered a snapshot of their experiences with a diagnosis of MRSA and how that had impacted their lives. It was an honor to have conversations with these diverse individuals and learn about their walk with MRSA, their fears and triumphs, and their insights about the world of emerging antibiotic resistant infections. Their stories were a combination of pain, *aha moments*, and an inner search about the strategies that they used to learn and adapt to this growing public health problem. Each story, in some way, helped describe the impact MRSA had on their construction of knowledge about the microbe and the subsequent adaptation to the infection. All of the participants seemed very forthcoming with their stories and happy to have the opportunity to share what they had learned in their personal journey.

#### *Aaron*

Aaron lives in a different state so his interview was conducted by phone with some follow-up emails for clarification. He became a participant for this study because

his mother had been referred via a friend who had participated in a pilot interview. Aaron is a young adult male who especially enjoys working out at the gym. For him, the diagnosis of MRSA was not immediate. He first noticed a ‘bug bite’ on his elbow that was swollen but the next day he had two more on the forearm, one on the chest, and a couple on the thighs which caused some worry. He states, “I didn’t know what it was so I went to the urgent care type of thing and the doctor there thought it was shingles.” Unfortunately, he was just given Valtrex which is an antiviral medication for herpes viruses like shingles and sent home. Over the next few days his condition worsened until the pain became unbearable and he was taken to the family doctor who took an actual culture and it was diagnosed as MRSA. Aaron experienced frustration with his slow diagnosis.

Aaron was aware of MRSA because he had seen some articles about it in a men’s fitness magazine but his knowledge was relatively poor at the onset. Interestingly, it appeared that his diagnosis didn’t prompt him to be very proactive in his understanding of his condition. “I didn’t really, I guess look into it much. Just from what the doctors were telling me I kind of got information about it and stuff like that.” His mother, a registered nurse, did most of the research for him. He states about his mother’s involvement in learning about MRSA,

That’s how my mom is. She’s a registered nurse so whenever she hears about some kind of medical condition that she doesn’t know that much about, she will always research it and print out pages and pages of information to give to me to read. She’s persistent that we see the same doctor every time because if we start going to other doctors, trying to treat this, they’re not going to know what the

other one is doing. So she is adamant about going to the same, exact doctor. And, telling them that we need the blood test. Not waiting or asking. Without her to help me, surely it would have been a lot harder and probably could have been a lot worse too.

Aaron learned what he had to learn to manage the condition. He was thankful for his mom and family's help during his episode(s) with MRSA but his story suggests he was at times disengaged or apathetic. At the end of his interview when I asked him to reflect on what he found helpful during his condition, he stated almost boringly, "More so, I was that guy, that just really wanted to figure out what I could do, what I couldn't do, what were the risk factors. But I'm going to do what I want to do anyway, even if it's going to make me sick."

#### *Dora*

Dora is a 52 year old widow who lives alone and has a myriad of health issues that has led to her being immunocompromised. We conducted her interview over the phone due to her health issues. She had a severe automobile accident which caused a closed head injury that resulted in vagal nerve seizures, and since that she has developed diabetes, hypertension, post-traumatic stress syndrome and constant migraine headaches. Compounding her health issues, Dora lives alone but has family close by to check in on her. An interesting facet to her story is that before her head injury, Dora was a nurse. That career has given her professional insight and strong opinions about the healthcare environment, including her experience as a patient. The head injury caused memory lapses which created frustration with not being able to nail down an important fact or

component about her during the interview. In the midst of all her health issues, Dora appeared to be a pleasant person with a great outlook on life.

In August of 2009, Dora woke up in the middle of the night because she thought something “stung” her. The next morning she found a big red hole on her stomach so she went to the clinic. A diagnosis was made and she was sent home with antibiotics. After the wound continued to get worse, she returned and they performed an incision and drainage (I & D), and she was hospitalized for a week. She described the experience as “extremely painful, scary, and lonely.” Dora gained most of her knowledge about MRSA from a home health nurse that visited her for several weeks after being released from the hospital. When I asked her about doing any research herself to learn about MRSA, her reply was “No sir. I didn’t have any way to do that. I didn’t have a computer or a way to go to the library. I have to depend on people to take me places.”

Due to her former career as a nurse, Dora had a fair understanding of infection control and universal precautions to prevent the spread of disease. However, her knowledge about MRSA was poor. She wasn’t even sure that it was a bacterial infection during the interview until I confirmed it for her. She was very inquisitive about everything connected to MRSA during our interview. The major impact of MRSA on Dora’s life that emerged during the interview was her concern about transmission of the bacteria to her family and friends. She states, “I was so scared my son would get it, and so scared any babies or anybody that would come over to see me would get it, you know, I was just really, really scared.”

The experience of being scared about transmission to others was intensified by her feelings of being stigmatized. When I asked Dora if she learned anything about

MRSA from someone besides the nurses and her doctors, she mentioned that “people would sit way across the room from me” and that it made her feel like “a little bitty ole ant that somebody wanted to smush.” This feeling of stigmatization was amplified by her family. She states,

You know, I’ve got a large, large, large family, and when they would come over, you know, I wouldn’t get a hug. You know, “come here and hug me,” “no, momma, I’ll get it,” “no, you’re not gonna get it, you don’t have any open sores,” “I don’t care momma,” you know, just like an outsider.”

Dora talked about how prayer was part of her method for dealing with everything.

### *Trene*

Trene is a 21 year old college student that has a history of being “involved with healthcare” because of a problem with allergies since childhood and because her mom (and family) have had a history with breast cancer. Due to this involvement, she stated many times during her in person interview that this had built a trust for most doctors and healthcare in general. However, she did experience frustration with her diagnosis of MRSA. Initially, Trene went to a student health center (SHC) because she noticed a very painful “big, pimple looking thing” under her arm with redness spreading throughout her right breast. The SHC did a skin culture, placed her on antibiotics, advised her to take bleach baths, and sent her home. The pain became so bad that she couldn’t get out of bed and her mother took her to the emergency room (ER). The ER was concerned about the breast cancer history so they did an ultrasound which was not helpful. Finally, after multiple visits to the ER and SHC, Trene’s mother took her to her breast cancer specialist. The specialist immediately knew that it was a MRSA infection and not

associated with breast cancer. The frustration with a slow diagnosis at the onset was very apparent in Trene's voice during the interview. Fortunately, once the infection was identified and the correct drug regimen was started, her condition improved over the next three weeks and the infection subsided.

Trene had a prior experience with a staph infection during high school but she didn't know the difference between a staph infection and a MRSA infection. In addition to learning about MRSA from her doctors, she used online sources. She states, "I Googled it and looked at all the Dr.net junk. What I got out of it was its resistant to certain antibiotics" and "the only thing I really learned that I didn't really know was what MRSA stands for." When I asked her what type of impact the MRSA diagnosis had on her, she said,

I don't go to public gyms, because there's grossness everywhere. Yes, they clean them, but they clean them at night and then people get on them during the day. They have the cleaning stuff, but who uses it? Nobody. So, I'm really cautious about that. I am a clean freak.

She also mentioned that even though she liked things clean, she hadn't been like that pre-MRSA. In her words, she "wasn't really impulsive or obsessive. Now, everything has to be clean." Trene was reflective about the seriousness of MRSA, availability of information, and the stigma associated with accessing information and/or being clean. When I asked her what she meant about the stigma of cleaning things she stated,

You don't see boys wiping down the weights before they use them. They're just like, look at myself and my muscles. They don't think anybody else uses them. And girls on the machines, they'll just go and touch the bars and get moving.

Even on the treadmills, they'll put their Ipad on it, their cell phone on it, their keys, and then they'll just pick them back up and leave. And I'm like; do you know how many other people's sweat has been on that? And I think a lot of people are just too afraid to go and get that spray bottle and look like a germaphobe' or whatever. You need to be doing that. And I think there's a big stigma on stuff like that.

*Alvin*

Alvin is 62 and retired. He and his wife love to travel and often spend their winters in the south and work part-time at state parks to avoid the severe weather in their home state. His first encounter with MRSA was in May of 2007 while returning home from a trip to Texas. At a stop for car repairs in Colorado, he noticed some large cysts on his scrotum with severe swelling and pus. He was put on antibiotics for presumed MRSA, but a culture for confirmation was not done at the ER he visited. Upon returning home, the infections seemed to clear but he started experiencing swelling on the right side of his neck. He was put through a fast-track biopsy by his family doctor and the diagnosis was non-Hodgkin's lymphoma. Since that time, Alvin has had multiple reoccurrences with MRSA, confirmed by his doctor, with the last one occurring in late March of 2009.

I came into contact with Alvin via his wife's research. She discovered my work with MRSA by way of several publications in the public realm. He agreed to do a phone interview with me when he learned of this study. Alvin was extremely reflective about his experience with MRSA, especially because of his immunocompromised state with cancer and the multiple bouts of MRSA. Alvin was very proactive about his health, both with the doctors and with the research he and his wife conducted elsewhere. He states,

Our family doctor, their office, they were very knowledgeable. They gave us a lot of information. Mostly it was verbal. Then, once we found out we were dealing with something different, I got on the internet. I hit the internet really hard. And then, after a few bouts with this, [his wife] found out you were heavily involved with it, so we contacted you and you sent us a ton of information. It was confirming what our doctors said. What you said and what the doctors said was almost a carbon copy.

Alvin's experience with MRSA affected him on many levels. He has been very involved with the education of others, including helping a friend who was hospitalized with a MRSA bloodstream infection and almost died. He and his wife are such advocates of educating others that they spend time with others in church or at a state park telling others their story and the lessons they have learned. He became very serious when I asked him what advice he would give to others, "make sure you know what you are dealing with...if they think it's MRSA, do the culture" because he had learned how critical it was to know which antibiotic(s) would work by way of a culture. He was also adamant about the need for better patient education, "you don't even know what questions to ask until you start learning about it."

MRSA has had a major impact on Alvin and his wife. It has affected their choices about work, travel, and other normal activities of life that you deal with on a daily basis. It has influenced their health behavior with respect to caution and hygiene. Even the treatment with hard line antibiotics and other medications has had an impact on his life. Alvin dealt with digestive issues, yeast infections, and photophobia. However, it appears that he did not feel a sense of stigma during his journey with MRSA. Instead he believes

that “I don’t really think we had people adapting to us, it was understanding why we pulled back the way we did. We had people questioning that. Oh, come on over, no, we’re not going to do that.” Overall, the MRSA journey for Alvin and his wife has been transformative with respect to their outlook on health.

### *Irene*

Irene has autoimmunity (condition where one’s own immune system attacks itself) problems and because of this has limited mobility due to an amputation. I learned of her MRSA encounter through a colleague and followed up with a phone call to Irene. She was a very pleasant lady who had retired several years before due to her medical condition. She was 65 at the time of the interview. Irene noticed that something “didn’t feel right” on the right side of her hip and asked her home health nurse to inspect it for her. She had a home health nurse to help her care for herself and her immobility. A small sore was on her hip, and it was eventually diagnosed as MRSA. Eventually, she was hospitalized and was treated there with antibiotics and constant cleaning. Later, she was sent home for rehab and the home health nurses and her daughter helped with the care.

Irene’s experience with MRSA was a positive one with respect to her interaction with healthcare. She had access to a daughter who was a healthcare professional, a close cousin who was a physician, and several good friends that were all physicians. She knew that it was an advantage in her medical care that she was surrounded by caring family and friends that were part of the healthcare system. She states, “It’s easy, you know, to have these people around you that you are close to that if you have a problem that you feel like you can discuss it with, whether it be [my daughter], whether it be a friend, or whether it

be a family member.” The people and the consistent message she received about her treatment instilled high confidence for her about her care.

Irene also had been a long time volunteer at a private hospital for years and had cared for older relatives in nursing homes so she had some basic information about infections that was useful. She talks about being ~~v~~ery cautious to see that I knew that they [older relatives] were being moved or that their positions were changed because of what I knew about staph infections.” However, she did not know the difference between a staph infection and MRSA.

Her experience with learning about MRSA was primarily through people, not any personal research. She relied on others, especially her daughter. The infection has impacted her mainly in her interaction with her family and friends with respect to transmission concerns. It was interesting to hear Irene talk about her outlook on MRSA. When I asked her if she had anything to tell me about what may have helped her live through the process, she stated in a matter of fact voice, ~~I~~was having to deal with so many other problems that this [MRSA], if you really want me to be completely honest, this was almost like having a common cold getting over it.”

### *Edward*

~~We~~‘ve got to put this box on your door because you have a staph infection. The guy said it was MRSA, and that was it. He just left.” This is how Edward learned that he had MRSA from a nurse at the hospital he was being seen at. He and his wife were scared to death. Edward is 73 and retired. When I interviewed him by phone, I thought of my grandfather. He comes across as a man’s man, but he was very soft and nurturing to his wife and family when you listened to him. His knee hadn’t really been bothering him but

he followed the advice of his doctor to have a knee replacement. Things had been going pretty well with physical therapy after the replacement, until he came home from church with a high fever and the infection had begun.

He and his wife felt like the way they were told of the diagnosis was —a very cold way of announcing it,” and Edward felt the initial interaction with the doctor or nurse or whoever told you about MRSA was critically important. In his words, —Well, in the way it is delivered can count for 95% of it. When you tell somebody something [MRSA], you need to get a certain amount of education to them.” Edward and his wife had not really heard of MRSA, at least anything specific about it. He —thought that [MRSA] was just some big, bad germ that lurked in the dark hollows of the hospital and you don’t get it.” This is a common misunderstanding with the public — that MRSA is only healthcare associated and not found in the community. His experience in the hospital helped influence this misconception. He states,

Well, people say it jokingly; you don’t want to go to the hospital if you’re sick because that place is full of germs. I don’t want to go through this again. I’m so tired of it. We really feel like I got the MRSA at the hospital. The reason we think that is because the way they clean hospitals. Hospitals are dirty. The floors are dirty. They’re not just dirty, they’re nasty. Bandages would be on the floor for days.

While Edward may believe his MRSA infection was acquired at the hospital, it is possible that it was via the community route at home or elsewhere after his knee surgery. At the very least, his infection route was unknown and for that reason the investigator believes Edward fits the criteria for participant inclusion.

Edward's experience with MRSA reiterates some of the other commonalities that have been mentioned previously. People were the main source of information for Edward and his wife during their ordeal with the infection. Edward mentioned that ~~w~~e've got several people that are in the medical profession. They're nurses and we talked to them. We did it word of mouth. We did not go to the internet and look up MRSA." Learning through others who had shared the same medical experience was also important to him as was a consistent message from healthcare.

MRSA was transformative for Edward and his wife. When I asked him how MRSA had changed his life, he said ~~i~~t made me realize that life is short and sweet. Don't take anything for granted." He admitted during the interview that he became depressed in the long treatments that he had to receive but that he ~~b~~egan praying more and more and more. I just said, no, don't let this get hold of you. I just kept fighting it, praying, and saying, no that's it." His wife was present during his interview and stated that ~~i~~t really scared her that she was going to lose him, and she shared that with him and we prayed and she cried in his room."

In hindsight, Edward along with his wife was reflective about how he may have been too passive in the early stages of learning about the diagnosis. He felt like they missed a chance to catch the problem early due to not speaking up and trusting too much in the non-medical or younger healthcare staff. He especially had strong opinions about the need for better pre-surgical education with respect to post-surgical care and warning signs of infections.

*Becky*

Becky was a 21 year old college student when she experienced her MRSA infection. Her overall interaction with healthcare was very positive. She primarily visited a SHC physician and their staff. However, her experience was one that she called “extremely painful” and she ranked the MRSA infection as being in the “top three” of the most serious medical issues she has dealt with in her life. She states that during an incision and drainage procedure she experienced “the worst pain I have ever felt in my entire life, like I was screaming like bloody murder.” She still experiences anxiety and concern over a reoccurrence due to the significant pain she endured during her treatment. In many ways, the pain and emotional journey she went through have created an appetite for self-directed learning and advocacy for educating others about the dangers of MRSA.

Becky had very positive things to share about how the personal interaction with a physician should occur when I conducted her in person interview. In fact, when I asked her about any advice she had for healthcare she said that [they] should follow her example. Briefly, the healthcare provider should give you options, be supportive, and offer a plan of what to do, and encourage people to do their own research to learn about the condition. She states, “I don’t know, I was just very shocked by how he [physician] knew what to do, like exactly what I think a doctor should do, he did. And he didn’t make me feel threatened, wasn’t after the money...he was all about me instead of like all about this piece of paper.” She was very impressed that he took the time to explain things clearly and make sure she understood them and what the next step would be even though he “was super busy with appointments and swamped.”

It also helpful that Becky had a bit of background education on staph infections from her high school swimming team and from a boyfriend that experienced MRSA. With respect to her learning, Becky used a combination of the healthcare “people” and other media in the print and online realm. After finding out about her diagnosis, she immediately used the internet to do research. She talked about using sources such as WebMD and other like sources, but not as an exhaustive search. She also read personal blogs of others who had experienced MRSA. She talks about her learning, “I’d like to see everyone’s opinion and then see the medical aspect from it, like the facts and opinions with real life and try to correlate them both, seeing which one makes the most sense like together with little emotion as possible into it.” Becky mentions that she asked a “million questions” and that was possible because of the comfortable and trusting environment her doctor created with her in discussions. This style of learning (comparing her findings with healthcare) was important for Becky because her knowledge about bacterial infections and resistance was poor prior to her condition.

The impact that MRSA has had on Becky is multidimensional. Her health behavior has changed dramatically in the way she takes care of her body. She has also become an advocate for telling everyone and she says her friends now “see her as the person to talk to about MRSA.” Becky is very reflective about her experience and has several suggestions for education opportunities in the healthcare and public environment.

### *Erin*

Erin told me during her in person interview that when she called her mom, a registered nurse, “she told me my leg was probably going to have to get cut off which really freaked me out, especially hearing it from a nurse.” Erin had several friends,

including her boyfriend and a sister, who had all had staph or MRSA infections over the past year. She is a 22 year old part-time college student who was diagnosed at a SHC. Similar to others in this study, Erin experienced significant pain when her knee became infected after falling and scraping it. She related that she had never had an infection like MRSA, “[It] hurt bad...keeping me up, I couldn’t sleep because it was super uncomfortable. Any move in the car and I’d start crying.” She talked about being very anxious and truly believing that her leg would need to be amputated because of what her mom and friends were telling her about MRSA. Her boyfriend who was a paramedic was “more logical” and helped ease some of her worry.

Beyond what she learned from people in her life, Erin liked to use the internet. She considers WebMD a trusted source because of the consistent messages she got from it and other medical sites. She did not find other forms of media, like newspapers or television, as filling a role for education about MRSA. However, she did mention that she had learned about a supermodel that had died from MRSA via her parents watching television. She believes that from that story and her mom she “learned it was a really an intense infection that could actually cause you to lose a limb or could kill you.” Erin’s knowledge about MRSA was poor. She talked about how she thought of an infection as being “random” and not necessarily with being “dirty” or risk factors. However, the experience had a major effect on changing her hygiene behavior and precautions with wounds and cuts.

As other participants have mentioned, Erin talked about how “embarrassing” the wounds could be in public. She states, “They were all looking at me like I was crazy. That was embarrassing. That was weird to deal with.” She said she tried not to let it affect

her and wanted people to know about MRSA, but ~~yeah~~, in the back of my mind I was wondering if people would think I was some dirty person.”

Erin discussed an interesting perspective about why people might not take MRSA, and even regular staph infections, seriously. She felt like college students especially get ~~lazy~~” in college with respect to ~~taking~~ care of themselves or self-learning” and that they don’t even consider it a possibility. Erin says,

Yea, I think it’s just the general; everybody has it in their minds that it is not going to happen to me, with like anything. So, you’re just like, whatever. You don’t want to wash your hands all the time because it’s annoying and you don’t want to have to go to the bathroom and wash your hands and whatever. You just forget about it at your house. You’re like; it’s my own house, why should I wash my hands – that kind of thing. So everyone’s like, I’m not going to worry about it, it hasn’t happened to me, hasn’t happened to my friends.

She suggests that because of this attitude, universities and colleges should have their student newspapers lead with headlines that ~~grab~~ your attention” like ~~Girl~~ loses leg to staph infection” and that a message should be conducted with repetition like they have done with ~~wine~~ flu.” She also suggested that texting and social networks should play a role in health education and precautions about MRSA.

### *Nell*

Nell was probably the most informed and knowledgeable participant with respect to antibiotic resistant organisms, infections, and other healthcare related concerns. At the time of her phone interview, she was 62 and still working full-time as a licensed speech language pathologist. She has a M.S. and M.Ed. and has past work experience in both the

hospital and long-term care setting. Due to her education and career, Nell has had formal and continuing education in the realm of universal precautions and other healthcare acquired infections like MRSA. Her insider perspective coupled with her actually experiencing MRSA offered a significant lens to view MRSA. Nell also had multiple sclerosis (MS) so she was immunocompromised.

Nell became a participant by way of a referral from another participant who had helped her realize the seriousness of MRSA at the time of initial diagnosis. Nell was first diagnosed with MRSA, in her words, “in the female area.” She initially was put on the wrong antibiotics to fight the infection and by several days later she was “making no sense at all” to her husband. From the point of arriving at the ER to awakening in the intensive care unit the next morning, she does not remember a thing. She came very close to death according to her doctors.

With respect to her learning, Nell realized that the internet was “not the greatest source of information” but she was very careful about what online sources she used by corroborating what she found with what she already knew about MRSA, her doctor’s information, and by other peers who had experienced MRSA. The main online source for Nell was WebMD and she branched off of that into other “medical related” sources like the Mayo Clinic. Nell doesn’t believe she ran into any obstacles when it came to her learning. Nell demonstrated a high level of knowledge about specific details surrounding MRSA – drugs, drug delivery, resistance, immunity, and misuse of antibiotics.

Nell’s journey with MRSA created a heightened sense of awareness about her health. She states, “I will tend to go see my doctor now if I am concerned about something, rather than hesitate. My days of a wait and see approach are far fewer than

they were.” While she believes she has always questioned others to learn about things, now she is very adamant and proactive in her interaction with others. Even with her MS, she knows that she’ll never forget how I felt that night” with the level of confusion and pain.

As a healthcare practitioner, Nell believes she was well educated by the healthcare professionals. Interestingly, she talked about “[her] MRSA being in such an unusual place, I became quite a teacher to a number of people. I was willing to let them take a look, because to me that education is important.” However, as a patient Nell had much to offer to her fellow colleagues – “if I had to recommend anything, it would be to speak in terms that lay people would understand.” She felt no stigma and in her experience, she thinks the public is actually aware of MRSA but probably not knowledgeable. Nell seems to have had a transformational experience with MRSA. She ranked her experience with MRSA as one of the most serious health matters she has dealt with in her lifetime. She states powerfully at the end of her interview, “I don’t believe I’m dying of multiple sclerosis, but I was dying of MRSA.”

### *Mary*

“I had already been semi-familiar with knowing about MRSA, but I had not begun research on it. I guess everything changes when it happens to you.” Mary related these words to me at the beginning of her phone interview. She was 51 years old, worked part-time and had few health issues prior to MRSA. She first noticed a small lump under her arm about “the size of a BB” that became painful over the course of several days. With the encouragement of a friend, she went to an InstaCare and had it lanced and sent out for a culture. She received antibiotics but followed up her care with her regular family

doctor and with an infectious disease specialist. Her experience with her regular doctor indicated she felt a little under informed, especially because she was proactive in her own research. It made her angry with the doctor's apathetic stance. Mary was probably the most self-directed learner in this study. She used books (in-depth, detailed medical sources), people, and the internet extensively to learn everything possible. She states,

I'm on computers all the time and I researched with Mayo Clinic and I think Johns Hopkins University, and any other source that I could read. I read down to microbiology reports, things that were way over my head that I didn't quite understand, but I also researched the testing process and what is the newest technology and, it seemed like the medical healthcare that we use here seemed to have some of the latest technology to confirm this diagnosis, which I felt good about. So I went very deep into all kinds of reading, and I kind of was obsessed with it.

Her research made her realize the seriousness of her condition and how uninformed the public was about MRSA.

Part of her extensive learning also created some mental worry and in her words, ~~an~~ "an emotional component going on." She was very concerned about exposing others to her MRSA. She details her anxiety over protecting others in her church family (communion, hand shaking, etc.), her husband who had had a heart attack recently, her teenage son, and her boss who was undergoing cancer treatment. In addition to her concern about transmission risk, Mary states, "I'm cognizant that it could come back at any time...But I will tell too, though, at the time that I was struggling with it, the feeling of being a leper, I mean, I was cognizant of every hand I shook..."

Mary had much to offer in her thoughts about MRSA and its impact on her and on other people. She reflected on the tension between individual responsibility and that of the broader society regarding potential transmission of infectious disease. For instance, she worried if all individuals take appropriate precautions to avoid transmission to others in public spaces. Her experience has made her question healthcare, “You know, I mean I used to think a hospital was a place you would go to get well, but now I worry that hospitals can also be a place where you contract secondary complications and infections.” She has become an advocate for educating others about all areas that are connected with pre and post MRSA situations. She believed that healthcare must offer compassion, accurate information, and a step-by-step plan that a lay person can follow. Having MRSA was and is a powerful, transformative event in Mary’s life.

Common elements can be heard in each of these stories – being diagnosed with MRSA is a painful, serious condition that sometimes causes anger, anxiety, and issues of trust with the healthcare system. Their accounts reveal numerous commonalities with respect to their experiences, their learning and construction of knowledge, and their adaptation to the impact that MRSA has had on them and their loved ones and friends. A more extensive and detailed analysis of themes emerging across interviews will be discussed next.

### Emergent Themes

This section of the chapter presents the emergent themes identified with the investigation surrounding a MRSA diagnosis. The two main themes were *Learning* and *Adaptation*. First, subthemes of learning about MRSA are discussed. The second part presents subthemes regarding the nature of adaptation to MRSA. Table 3 presents these

two themes and their respective subthemes. The interviews as text were analyzed using constant comparative method associated with grounded theory (Glaser & Strauss, 1967). Grounded theorizing involves “both inductive (deriving concepts and properties of categories) and deductive processes (hypothesizing about the relationships between concepts)” (Strauss & Corbin, 1998, p. 22).

Table 3

*Themes and Subthemes: MRSA Diagnosis*

<b>Theme</b>	<b>Subtheme</b>
I. Learning	A. Experiences with MRSA
	B. What was learned?
	C. How did learning occur?
II. Adaptation	A. Self-reliance
	B. Reliance on others
	C. Reflections on MRSA journey

*Part I: Learning – “I guess everything changes when it happens to you”*

The objective for doing the research was to understand the learning that occurred with individuals who experienced a diagnosis of MRSA. The interview questions offered opportunities for the participants to discuss openly the context of the role learning played in their journey. It was evident that every participant found learning to be critical in their production of knowledge during their walk with MRSA and how it played out later with adaptation to the health threat. Within the broader theme of *Learning*, three subthemes – *Experiences with MRSA*, *What was learned* (content), and *How did learning occur* (process and sources) – were identified after a comparison of findings across interviews.

*Experiences with MRSA.* The participants experienced several common threads with their MRSA journey. All of the participants expressed the physical “pain” associated prior to and after the diagnosis. The pain ranged from bad to severe. After Becky was diagnosed with MRSA, she said,

He [doctor] was like, this is a necessity, like this is important. So he fitted me in later that afternoon and they opened me up. The worst pain I have ever felt in my entire life, like I was screaming like bloody murder. I’m sure you probably heard me from there, like from here, like screaming hardcore, and they just like cut it open. I felt immediately when they cut it open, like I just felt like more pressure building, not like a release, like more. It felt like, it felt like it was like this big, but apparently it is like only this big, and then he opened it up and was like, yeah, it is, but he said that not that much stuff came out of it. My boyfriend was watching because I was like squeezing his hand half to death, I think I broke his finger from squeezing his hand so hard. And they gave me a shot before they opened it up, like into it, they said it might help the pain, but it didn’t....I could feel like exactly where it starts and where it begins, like how thick and hard like the inside of it was, like I guess from messing with it that morning, it had already progressed that fast like within three hours, like getting so hard and swollen. So then they did that and he was like, well, they opened it up, you know, washed it out, put all these things -- it felt like I was there for three hours, but it only took like 10 minutes max and he packed it. He was like, I’m going to leave it open. He [doctor] was like; this looks like it needs to stay open like, I guess to drain.

The pain associated with MRSA was echoed by all of the participants in various ways. Aaron mentioned how “painful” the wounds were with respect to affecting his activities while Erin was even more specific. She states,

It would, on a scale of 1 – 10 probably be a 9...how it affected me while I had it.

With other health things, I don't get sick very often. When I do it's just like a little cold, but if I ever do get a fever, of course that affects you and you can't help it and I would say staph would be the same thing. You can't do anything with how much it's affecting you. You've just got to deal with it until you get better. It put me in a really bad mood because it was so much pain constantly. It made me really emotional, that's what it did.

Another common thread that was present for each of the participants was the emotional factors that arose from their encounter with MRSA. A range of emotions were experienced such as trust, anger, anxiety (worry/scared), depression, frustration, and embarrassment associated with stigma. Anxiety was cited often by the participants as being connected to this range of emotions being felt. Mary talks about the aspect of being worried,

And it is just different when it [MRSA] happens to you than when it happens even to a loved one, because, you know, depending on how people handle information and to the degree that people need to feel informed, you know. I was curious about it with my father-in-law, but again, you know, we were dealing with Parkinson's and other things and the Medicare time ending and his benefit pay period where my mother-in-law would have to self-pay, we were dealing with different issues, but I think it did kind of cross over to a new level with me when I

was diagnosed with it, and in my home, you know, with my family because everyone understood and I was very vigilant about, you know, wiping down surfaces, almost to a point where I was hyper-vigilant, you know. So we were all very aware, so I think it did cross into a more serious and anxious area when it happened with me.

Likewise, Alvin talks about his concern with being immunocompromised and MRSA,

And we also tell people, with the general population, it's probably not going to hit most people as severely as it would somebody that has a compromised immune system. So, if we know that it is active, or if somebody has it that we know, we are not going to put ourselves in any close proximity with them, because we know how it can affect me and it affects me so hard and so fast. That's one thing that really hits me. It's that, when I get it, usually within 24 hours it has taken off like a rocket.

For many of the participants, the diagnosis of MRSA was frightening to consider,

Edward talks about his initial diagnosis and getting the information from his nurse.

This was the nurse. We never saw the doctor. And [a doctor] would not have told us that and then walk away. He would have sat and talked to us. Here's the thing too. Our daughter and her husband had been planning a trip for a long time to San Francisco for a week. So, we were going to keep our grandson. Well, actually we knew that with me, being where I was, my wife was going to do the keeping of the grandson, but still, that was in the plans. Well, his sister is a nurse and when he mentioned MRSA, well all sorts of red flags went up and they said you don't want to get your grandson near his grandpa. And, when we would say anything,

people were like, is this the flesh eating kind? And that was the first time I had heard of it. I said, flesh eating? They said, yea, it will just eat your flesh. Oh my God. What have I gotten myself into? I was scared to death.

Irene discussed her frustration with how MRSA led to a “ridiculous” amount of caution by her healthcare team. The caution is often necessary, but it still leads to frustration.

Now, it took longer than I thought – I just thought, put some medicine on it and it goes away. But even then after coming home from rehab, then I went back to home health. They still continued to treat it with the SANTYL and it was – it took, let me see, I came home in July – would say it was until about January 2009 that it became clear. And at that point in time, they stopped treatment. Since then, I have had no reoccurrence. I am very careful that, you know, I keep that area clean, that I don’t scrub it real hard. But it is periodically checked. And when I was at \_\_\_\_\_ the last time, they kept on putting on these gowns. I said this is ridiculous. It has been, you know, over a year, what are we doing? ...So I said well, I would appreciate you all doing the swab because this is getting ridiculous – all of you all coming in here having to dress and, to my knowledge, I’m not having any problems, and I think I would know immediately...

Six of the participants (Aaron, Trene, Irene, Edward, Becky, and Mary)

experienced anger, usually directed at healthcare. Some of them seemed to express higher levels of anger, but all of them made comments about being mad at someone. Aaron states,

I was so mad and upset that they [doctors] didn’t even think about staph after telling them that I went to the gym. I go to the gym, had gotten tattoos and stuff

like that, if they put two and two together, it still made me question their knowledge about something I hear goes around a lot in hospitals.

Likewise, Trene was disgusted with her initial hospital visit. She said, “I was like, I just paid \$500.00 for this visit and you didn’t tell me anything that I didn’t already know. I don’t know.” The remaining four had similar feelings of anger directed at issues of healthcare service, healthcare apathy, or being isolated from others. As one might expect, some who experienced anger in some form usually had parallel feelings of distrust of healthcare. However, distrust of healthcare was not only tied to participants that experienced feelings of anger. The participant’s experience with their healthcare interaction will be discussed later in this section.

A strong emotional component that seven of the ten participants (Aaron, Dora, Trene, Alvin, Edward, Erin, and Mary) experienced was the feeling of being stigmatized – either by the medical environment or by others in the public community, including family members. Dora felt “~~un~~understood” by the home health nurses that took care of her but when I asked her about how other people treated her, she said,

Just the nurses were really good and, of course, my doctor, you know... Other people were just really scared to come around me... Yeah, I felt like, you know, like I did when I was bedridden, just nobody really wanted to come, but when it was there, you know, I had the big bandage on my stomach, and people would sit way across the room from me and I said, that’s okay, it’s covered up, you know, and I’m on antibiotics, and I don’t think I can give it to you – these people were scared and I tried to, you know, tell them they don’t really have to be that scared of me anymore.

She said that when this happened it made her feel “like a little bitty ole ant that somebody wanted to smush.” Even her family wouldn’t give her hugs and it made her feel “just like an outsider.”

Trene talked about her experiences in the gym. If people knew she had MRSA, she equated that with “stay away from me.” She talked about her stance on this issue.

Yeah. I have no problem being like, I have a skin infection, don’t touch me. Or, don’t sit on my bed because it’s there. Me personally, I don’t have any problem telling people that. But, other people, just the stigma of staph, is just like, oh, you just roll around in dirt all day long and you don’t clean yourself, and you have all these nasty, open sores, kind of thing. People found out that I had it, and they were like, what? Because they know that I’m a clean freak.

Likewise, Mary discussed about how having MRSA affected her relationships with her family and friends with respect to feelings of stigma, she states,

And I’m cognizant that it could come back anytime. They say it is very hard to eradicate in your system – that it lies dormant. I don’t know if that is the case with me, if the clindamycin did eradicate it or if it is going to rear its ugly head in the future sometime, so I do kind of – it’s always in the back of my mind. But I will tell you too, though, at the time that I was struggling with it, *the feeling of being a leper* [italics added], I mean – it was like I was cognizant of every hand I shook, every person I was in contact with, every – I wouldn’t – my mom and I would go out to lunch and we might share a taste of something with one another. I wouldn’t allow that to happen. I mean, it really did rock my world when I was going

through it and I think I really did stress out all of my family members because I was so vigilant.

The stigmatization that was felt by many of the study participants can be interpreted in light of social representations theory. For instance, most of the blame for MRSA is laid at the doorstep of *why it spreads* instead of its origins (antibiotic misuse). Ultimately, the blame is placed on poor hygiene of the hospitals and mismanagement, a form of *‘othering’* that is inherent in social representation theory (Washer & Joffe, 2006).

Interactions with healthcare personnel, whether positive or negative, were an important experience for every participant. The interaction was on multiple levels with a variety of healthcare providers – primary care physicians, ER doctors, specialists (infectious disease, orthopedic, etc.), nurses (hospital and home), physical therapists, office staff, and internists. In many instances, the interaction that occurred between them laid the groundwork for the reflective discourse that will follow later in this study (Chapter five).

Edward discusses his interactions with healthcare after having his knee replacement. He states,

When I got my original knee in, [doctor] put that knee in, [s/he] and I both made a mistake at that point in our lives, I mean after the knee was in and it was supposedly healing. Two weeks after the surgery we went into the doctor’s office and a young staff or someone in his office took the staples out. Well, there was a spot on top of the incision that was just really flowing, shall we say. It was just running down my leg. So, he tried putting some of these sterile [sic] strips on it to stop it and all that. We didn’t realize, but at that point we should have said, take a

culture let's see what's going on, why is this running that way. It's not just that, because it was oozing pretty heavily even before he took the staples out. But he took the staples out and it just kind of gushed then. If we had known, we're the customer, we're the patient, we would have insisted, take a culture and see what is going on here.

Conversely, Irene had a very positive interaction with her variety of healthcare providers.

Well, that's just what I'm saying, you know, I knew that they were doing the best that they could do and that I thought that I was getting the best treatment and, of course, I had the same thing said to me regardless of whether it was home health, our family doctor here, or the medical team at [location], so you kind of get some confidence when everybody is saying treat it the same way and also they are saying it is getting better... because I feel like I have gotten such good care with the diagnosis, once I said something.

*What was learned?* The content of *what* was learned from the participants during their MRSA experience was categorized into three areas: (1) general MRSA information, (2) MRSA care and prevention, and (3) antibiotic resistance.

*General MRSA Information.* In general, all of the participants were aware of MRSA but lacked detailed knowledge about the microbe. For instance, all of the participants knew what a "staph" infection was but they learned that MRSA was a specific type of staph infection that was resistant to treatment during their experience. Aaron, when asked if he knew what MRSA was states, "I had seen it. Like a little article about it in a man's fitness, like a Health and Fitness [magazine], I had barely even heard of staph or anything like that." Prior to their infection, only Dora and Nell knew exactly

what MRSA stood for as an acronym. Dora and Nell had been introduced to MRSA via formal training in their healthcare careers as a nurse and speech pathologist, respectively.

Nell states,

Well, I was working in a long term care facility and I've done a lot of hospital work as well. So, you use the universal precautions... I'm a speech language pathologist... I believe it was either on a quarterly or every six month basis. But, we would have formal training. Universal precautions... It was across the board, but since MRSA was coming to the forefront they emphasized that.

MRSA colonization and reservoirs were also major content items of learning for all participants. Dora was "surprised" to learn that "it can live, you know, other places than in your body, on the walls, and in carpets, and such... Oh, and another thing, I believe they [healthcare] said that I could carry it, carry staph in my body." The phrase *carry it* is medical jargon for colonization. Likewise, Aaron discusses learning about colonization. "...but then once I started learning about it more and listening to what they were saying, I figured out that it truly never does leave your body."

The participants shared common learning experiences with respect to their immune status, risk factors for acquiring MRSA, and CA-MRSA versus HA-MRSA. All of the participants discovered or were taught that MRSA can be severe, especially for those who are immunocompromised. For instance, Trene talks about her research,

I think maybe more people should just know about it. Because also when I was researching about it – that was a good point – when I was researching, I found out that it's very deadly to small children and older adults. I was like, I'm 21 years old. How did that happen? So, that didn't help me at all. I was like, older people

get it. I understand if they're in a hospital setting and somebody has it, it's easily passed. Ok, I get that. And I understand that their immune systems probably won't be able to fight it like mine can. And the same exact thing with newborns. I was like, well ok, how did I get it? I think if there was more information on the middle-aged range.

Erin also learned ~~that~~ "it was a serious infection" as did the other participants. Each of them had a version of being surprised to learn about the severity of the infection. Alvin also addresses how he feels most people deal with the seriousness of MRSA. He says,

People are kind of familiar with infections. I mean, you get a cyst or boil or something like that and it's no big deal for the most part. Yea, I've got a big zit, I've got an infected sore or something like that, and MRSA is the next step. *It's in a different league by itself* [italics inserted] and people don't realize that. They say, oh yea, I've got an infection. They'll clean it out and give me a shot of penicillin, which doesn't work, or some kind of antibiotic. And, I think a good part of it is that we rely on drugs. People are saying oh, they'll give me a shot for it, or I'll take a couple of pills for it and every things ok.

There is also a wide range of risk factors associated with acquiring MRSA that each of the participants discovered. For instance, Aaron discusses his risks and what he learned.

They didn't really have an answer to where I got it. I have had tattoos, but for the most part the staph weren't anywhere near my tattoos. They thought that I could have possibly gotten it from working out at the gym.

Becky had an in-depth discussion with a physician at a SHC concerning risk factors. She states,

I had my follow-up appointment that Monday or whatever and [doctor] looked at it, but [doctor] called me like a week after that, like a couple of times, telling me about your study and then asked me about it, then doing like an in-depth like questionnaire about, you know, where I've been, what, you know, do I shower, do I stay in my clothes, do I go to the rec, where do I work out, like do I go outside a lot, like all these questions about my lifestyle and like what kind of shorts or pants I work out in, like seeing if, you know – yeah, like do I wait to shower after I've been sweating or shower immediately, do I shower too much, like all those questions. He [doctor] asked me a lot, which is very surprising to me because I wouldn't expect that just from a Health Center, but he is very nice.

Finally, each of the participants shared that they had learned that MRSA was not just a hospital problem. Trene learned that —it's not just a disease that runs in hospitals.”

Likewise, Edward mentions,

Well, I didn't realize that. He [doctor] said it's just a germ out there. We have all kinds of germs on our skin. Then MRSA, I thought that was just some big, bad germ that lurked in the dark hollows of the hospital and you don't get it [in the community].

*MRSA care and prevention.* The second major component of content learning for the participants was about the care and prevention of MRSA. Once the MRSA diagnosis had been made for the participants, a consistent message about wound care, medication, and how to prevent the spread (transmission) of MRSA was delivered by the respective healthcare professionals involved in each case. The participants seemed to be startled and

surprised by the ubiquity of MRSA, especially with respect to its presence in the environment outside of healthcare. Alvin discusses his understanding,

It's [MRSA] always present. You go into a doctor's office and you sit away from people, you try not to touch stuff, you wash your hands. They're wrinkled, you wash them so much. There's the [bacteria] on shopping carts. You wipe the handles on them before you use them... We cut down on our traveling. Especially more aware of what's going on with my body. If I get a pimple or sore of some kind, it's not something I say, oh I got a zit or something like that. I really keep an eye on it and watch it and am very, very much aware of my [MRSA environment], my awareness is totally heightened.

Edward also discusses what he learned with respect to control and prevention. He says,

We [he and his wife] did a lot of preventative things like his leg was washed... this is something we don't want to get from here to there, so we bought a sack of white washcloths. Those were mine. I used one a day and when I got through with it we'd put it in bleach water and then wash them in the bleach water. Nobody else used that washcloth. I still do that, everyday. Everything that we used on this leg and around the area, where the MRSA was, we would use gloves. We would wash it, clean it and change the dressing and put everything in a bag, tie it in a knot, and put it in another bag. We knew to keep that away from the open air, so no one else would come into contact with it. That's how we did it.

All of the participants also learned the critical role hygiene played, both with care and prevention of MRSA. Erin talks about her learning with respect to preventing MRSA infections. She states,

Yea, I definitely learned to when you have it [MRSA], to not be around people as much in a close, close quarter and to wash your hands a lot more and to definitely take a bath everyday and clean it with medical soap and hand stuff if you have it.

And, she continues with respect to what she has learned about hygiene,

Yea, if I ever get cuts or scrapes or fall, I usually don't care. I actually don't even usually wash them out, I mean I take a shower, but I don't go out of my way to put hydrogen peroxide on it unless it's a big cut. If it's a little something, I usually don't care about it, *but now I do* [italics inserted]. Because, I don't want that to happen again, because it could have been, it's any little ol' thing and it turns into this huge infection, you can't even believe it's living in you...

Wound care is an important issue when handling an infection, especially those caused by antibiotic resistant organisms like MRSA. Dora learned to clean her wound from her home health nurse by using —some stuff called Hibiclens that I would clean it with two or three times a day.” She also was reminded to —sterilize all the sheets” and to keep the wound(s) covered between cleaning. Mary gave an extensive answer when I asked her about what she learned with respect to care. She states,

Sure. The information that I had kind of delineated all the steps that you should take to kind of keep your infection to yourself, I guess. You know, that gave me good counsel as far as knowing that when I had that abscess drained and that was considered kind of an open wound in the area, to keep that antibiotic ointment on it and to keep it covered. So I got good counsel from that while I was battling the infection and what I could do to prevent others from getting it. But in my reading, I saw a little bit of a disconnect between what the seriousness of how this

infection can play out in a person versus society. I think I am seeing more with hospitals having, you know, hand sanitizers at every stop and I am very, very cognizant of that all the time now, but it just felt to me like people did not understand the seriousness. People even downplay it surrounds us everywhere, well, it is, but you know, in certain environments, if you are susceptible, you know, if you have any open wound, it should be covered and things like that.

*Antibiotic resistance.* The ability of microbes to undergo mutations which leads to resistant strains of the organism has been well-documented in the world of microbiology. It is also a topic commonly misunderstood by the general community. This study revealed that most of the participants learned about the specific types of antibiotics used for MRSA infections and, in general, why resistance had occurred for this organism. Each of the participants also discussed learning about the importance of having a culture done, and a subsequent antibiotic susceptibility test to treat the infection appropriately with the correct antibiotic. Mary states,

Okay. I realized that having a firm culture diagnosis is essential because I was taking Augmentin and that was not effective at all, I was told, on what this was resistant to. So having the abscess drained and having the clindamycin was kind of the ticket, I thought, in stopping it in its tracks with me. I also learned the importance of acting quickly because of the way that lump can grow and multiply in a short period of time... You know, I used to let air kind of heal my wounds and did not worry too much about it, but now I use a staph septic type of ointment even if I get a cut or something and I cover it. So that's so me – all my life, I've

never taken such action, but I understand how easy this is to enter into your system.

Nell answered in response to a question about the relationship between antibiotic usage and bacterial resistance, “Um hmm. Well, I believe it stems a lot from a misuse of antibiotics – overuse of antibiotics – and that type of thing. Plus, a certain germ can mutate into something else.” Likewise, Edward said that,

I know your body can become resistant to antibiotics at any time and any kind of antibiotics. Where it [antibiotic] doesn't do its job because you've had so much of it sometimes... So, your germ acclimates to what you've been putting in your body... the germ is going to survive somehow because unless we can eradicate it... like with the smallpox vaccine, until we can get it to that point, it's going to continue to evolve.

It's important to mention that a couple of the participants (Aaron and Becky), while learning about antibiotic resistance during their MRSA journey, continued to have some poor understanding about the topic. For instance, Aaron mentioned that MRSA was a virus during the interview. Viruses are in a different microbial group than bacteria and antibiotics are useless against them; antibiotic use against viral infections contributes to bacterial resistance to antibiotics. Becky was even more confused when I asked her what causes bacterial resistance. She says, “I don't know. See, I don't know why I got it – that's the whole part of why I didn't understand it and how it happened so fast.” She even compared getting a flu shot to receiving antibiotics.

*How did learning occur?* Alvin made a very insightful observation during his interview – “You don't even know what questions to ask until you start learning about

it.” Learning by the participants in this study was achieved primarily through two channels – people and media. People (social networks and healthcare professionals) were important as sources of information about MRSA and in the explanations that they delivered to the participants for their understanding about the disease process. Likewise, the media (print and electronic) was critical as sources of information for the participants to grasp in their learning about different features of MRSA. Learning by the participants was primarily self-directed, experiential, and in some cases, transformational.

*People.* As with any issue including health concerns, people are critical as teachers of information and as sources of information to those being affected by a particular disease. In this study, the interviews revealed two groups of people who helped the participants learn about MRSA. First, social networks as a group will be discussed. For this study, social networks consisted of family, friends and other peers. Second, healthcare professionals as a group will be characterized with respect to how they augment the process of learning for the participants.

A variety of family members played crucial roles in helping all of the participants learn about MRSA. For instance, Aaron received a great deal of assistance from his mother. He was living with his mom and dad at the time of his diagnosis and says that his “mom did a whole bunch of research on it [MRSA]...why I had gotten it, and stuff like that.” Aaron stated, “I honestly don’t know what I would have done if my mom wasn’t there...my mom was the one that kept pushing it and saying no, this isn’t right, it seems like there’s something else.” For Alvin, it was his spouse who made the contribution to his learning. He mentions that “after a few bouts of this [MRSA], [a friend] found out you [investigator] were heavily involved with it, so we contacted you and you sent us a

ton of information.” Alvin relied on his spouse to not only “gather information about MRSA” but also to help him screen and understand the variety of data that was uncovered. Likewise, Edward was insistent that his wife played a significant and crucial role in his learning. I asked Edward about his learning experience with MRSA and he stated,

Rodney, I feel as though if they had done that, I know my wife, and it would have soaked in with her and filed away and she would have been very cognizant of my wound and probably would have insisted on a culture. I might not have been as aggressive as she would have been because I’m still the macho, it will be all right. But, honestly, if we had been told infections are a possibility, and we need to watch that, and catch it quick and early, and stay on top of it, I’m sure I would have gone on with the surgery, I don’t think that would have scared me off. If we would have been told, visit one would have made visit two unnecessary with MRSA.

Children, siblings, in-laws, and cousins were also cited by the participants as being involved in the education and learning process with their fight against the infection. Interestingly, this study identified a high number of family members and friends that were also healthcare professionals. Obviously, this is an important network for learning and will be discussed further in chapter five.

Friends and peers who were experiencing the same diagnosis of MRSA were another important layer to the participant’s learning from their social network. For example, Becky had several former friends from her swim team who had experienced MRSA which influenced her early suspicion with her sore(s). Becky’s boyfriend has also

experienced MRSA on his arm. She mentioned that —he has already done this [MRSA] before...he had seen everything.” Likewise, Erin’s boyfriend and another friend had experienced MRSA too. She said —my friends told me it was staph because they looked at it and said it was probably staph. They were telling me...it’s a serious infection and I’d really not heard too much about it.” Nell talked with —other people that had experienced MRSA” and said,

If someone will mention MRSA or I know a friend or relative who has it, if I know the person well enough, I’ll ask some questions just to see what their course of treatment is. That’s how I began to learn that there are other things out there now.

Each of the participants utilized friends and peers as a vehicle to learn about MRSA. A couple of participants, Irene and Nell, also discussed how they relied on their own personal knowledge to help their learning. This was usually linked to having had volunteered in a hospital or another related aspect of a career that intersected with MRSA.

Healthcare professionals also played a very important role in how the learning process occurred for each participant. Often, these professionals laid the groundwork for how the participants pursued their overall learning about the disease – ranging from pre-care to post care of the MRSA infection. Additionally, they seemed to influence the participant’s attitude and belief in what they learned about the infection. The variety of healthcare professionals that interacted with the participants was very diverse – primary care physicians, ER physicians, clinic physicians, infectious disease physicians, physician

specialists (breast cancer, orthopedic), nurses (hospital, SHC, and home health), nurse practitioners, physical therapists, physician assistants, and a dentist.

Every participant had direct interaction with a physician at some point in their MRSA experience. Alvin discusses his learning experience during a medical visit,

No, they [doctors] were good. We'd ask a question and they'd tell us what they knew. The more information we got together, the calmer we became. This was not something that could not be dealt with successfully. [Doctor] immediately put me on Vancomycin on a Thursday. He said I just put you on that because I don't want you to have it... I just want to get a head start on it. So, I was on Vancomycin during surgery even. We go every day for an infusion, so we've talked to the infusion nurses about it. They see a lot of it. We've met other people through going up there that are going through the same process we are going through, except they'd had a hip joint or knee joint and maybe they're a little further along or maybe not as far along in the six week regiment, but we're getting feedback and we're giving them feedback about what we're going through. So, we're learning from this experience.

Nurses and physicians are often the first healthcare interaction that the participants learn from in their encounter with MRSA. Irene relied on both, but especially on home health nurses. She states,

Well, most importantly is to keep it [wounds] clean at all times, and also they [home health nurses] made it very, very emphatic to me that I had to move, that, you know, I couldn't just stay in one position. I think they are probably the two things that were just emphasized and over-emphasized.

Likewise, Dora says that ~~it~~ was the state nurse that came out and educated me.”

The nurse helped Dora to understand the importance of hand washing, sterilizing her sheets and other linens, and other precautions to prevent transmission of the bacteria.

Becky felt like her doctor (a SHC physician) did an outstanding job. He discussed the importance of why he was culturing the bacteria and then the critical need to perform an antibiotic susceptibility test. He explained ~~a~~ little bit about what it was...the many different kinds [MRSA]...so you have to find the right prescription for it to work.” She also was impressed that he followed up with her by phone to discuss reservoirs for staph and transmission precautions. When this type of interaction occurred for a participant, it created an important open and safe environment for learning. Becky says,

He was like I don't want to rush you – he made me very comfortable. Then giving me my own time, letting someone come with me, calling me a week later...not just once, like multiple times...I asked him a million questions about it, like how this, what's this...

In contrast, the interaction sometimes did not help the participant with respect to learning. For instance, Mary discusses returning to a clinic that provides quick care because she had acquired a yeast infection due to taking antibiotics for her MRSA infection. She simply wanted to understand if she was in any danger. She states,

And I went back to [doctor] because I also had contracted a yeast infection which made me feel like, uh oh, now what is happening to my system, and I understand that was probably a direct result of the clindamycin cleaning everything out of my body. I understand that can happen, but I also thought this sometimes begins a downward cycle with people that they, you know, one thing after another after

another after their immunities are compromised, they are just more susceptible to things, and what's next, you know, is the way I was feeling about it at the time...And that doctor was almost angry with me at how this was playing on my mind. I don't think he was angry in a medical vein, I think he was just upset by my being upset and that he could see that this had gotten to a point with me that he did not feel was appropriate. And he made me feel – when I asked for the retesting, he said, “I'm doing this just for you,” you know, instead of really kind of taking [anytime with me]...

Interestingly, each of the participants could cite both positive and negative interactions with the different healthcare professionals. So, while learning did occur via the various healthcare professionals for all in this study, in some instances an opportunity was missed because of the environment that was created from a negative encounter.

*Media.* There were two main types of media identified in this investigation – print and electronic. Each of these will be discussed in relation to their link with participant learning.

Six (Aaron, Trene, Alvin, Becky, Nell, and Mary) of the participants utilized various print media to learn about MRSA. Usually, this was in the form of handouts or brochures from the healthcare environment. Trene said “the lady at [a health center] gave me a sheet about cellulitis...she gave me a thing on bleach baths and she gave me a sheet on staph.” Becky also mentioned receiving a “pamphlet, like a piece of paper telling me about it.” Aaron, on the other hand, had heard of MRSA due to his involvement of working out at gyms. He remembers reading about the staph issue in a popular health and fitness magazine. Alvin found some articles from a popular physician (Dr. Oz) and said

his were very good...especially one that flared up in different parts of the country.”

Mary received papers that explained MRSA a little bit, kind of like a hospital brief, or medical brief. She also found a book that was extremely helpful to her learning. She says,

Then it was not until I found a book called “MRSA Secrets Revealed” in my research that it sort of made me try to look at [things], and this is over a course of a few weeks. It made me sort of try to balance a little bit at how this bacteria is everywhere in the soil and on all kinds of surfaces and you can come in daily contact with it, and trying to eradicate all germs from the environment is not the best thing to do because the body still has to continue to try to battle these things, the good and the bad bacteria that are on your skin and in your system. So that helped me to kind of balance a little bit more in my thinking.

To a lesser extent, another type of unexpected print media was identified by the participants. For instance, Alvin discussed how the signage in hospitals and other medical facilities played a role in his learning about precautions and hygiene with respect to an infection. Signage was discussed by other participants in regards to their quarantine experience in a hospital. Dora, Irene, Becky, Alvin, and Mary also discussed how the recent swine flu scare signage raised awareness regarding precautions against infections in the general society as part of their learning opportunity.

Many of the participants also took advantage of electronic sources as vehicles for learning about their condition and the microbe. Trene, Alvin, Becky, Erin, Nell, and Mary all utilized a wide range of electronic media. Trene “googled it and looked at all the Dr.net and I just...what I got out of it was its resistant to antibiotics...and it was a form of staph...” All six of them used the electronic media, some more intensively than others.

For example, once Alvin found out what he was dealing with, he ~~hit~~ the internet really hard.” He talks about his use of internet sources,

Yes. I was very careful of the sources I went to. It would be a source like the CDC, the Mayo clinic. It would be an established source. It wouldn't be Joe Blow writing a blog or something like that. I looked at the sources, and some of them you just throw out, I didn't even go to because it was just something I wasn't familiar with. Things like the Mayo clinic or all kinds of people like that, that I went to. There were a couple of really good shows on television too. Oprah had a couple shows on there, she had Dr. Oz. His were very good...I think they had a guy die from it. So, we watched all those programs. Some of them were in detail. So many of them were like 30 second sound bites. But, the good shows like 60 Minutes or 20/20 would delve into it a little bit. And then Oprah shows with Dr. Oz really went into it in detail.

Alvin talks about how he used TV to screen the information. He says,

No. What they [TV] did primarily for me is they would highlight something, and then you could go on the internet and go deeper into what they alerted you to. Basically, it was more of an alert. I don't think they were slanting anything, other than them saying, hey this is out there, you need to be careful. And, this is serious and this is very widespread.

Becky used the internet even prior to her first doctor visit. She used WebMD to find basic information. However, unlike Alvin, Becky also ~~looked~~ at people's comments and postings and all that they had said, like some [blogs].” When asked about how that initial online search influenced her learning and decisions, she states,

Yes and no. I didn't do an extensive search because I already knew about it, like more of an idea. I just wanted to see kind of what the signs were more in extent, like actual pictures and stuff. I had seen that. But comparing to a picture and what I had in my mind from seeing people actually who had it, I didn't think that's what I had because mine looked nothing like that, and it didn't hurt at the time until the next morning.

Erin says she pretty much just looked it up online and did a lot of research about it and tried to figure out what to do about it..." She also liked WebMD. She said,

...Web MD, I probably would consider that a more trustworthy website than maybe Google or something random that pops up about it that someone's written. So, every time it's something medical, I always go to Web MD or I'll...I Google too, but then like I said I go to all the different ones and look at what looks more, you know trustworthy.

While the internet was the primary electronic source for all six of these participants, they also briefly mentioned television and radio – especially public service announcements – as informational sources for learning about their MRSA infections. Interestingly, some of the older participants also mentioned electronic social networks as being part of their tools for learning.

*Part II: Adaptation – “People make the difference”*

The second objective for doing this study was to understand how people adapted to a diagnosis of MRSA. The interview questions allowed the participants to answer questions about the impact that the infection had on their daily lives. The investigation also asked each of the individuals to reflect on their journey with *living with MRSA*.

Within the theme *Adaptation*, three subthemes – *Self-reliance*, *Reliance on others*, and *Reflections on the MRSA journey* – were identified after a comparison of findings across interviews.

*Self-reliance*. As with any illness or disease, a diagnosis of MRSA is often associated with an adaptation to the disease or condition over time. As learning occurs, the individual often exhibits strategies and mechanisms to live with the challenges linked with having a health concern. The subtheme, self-reliance, which developed in many of the participant's stories, was about how they made decisions, managed the condition, and handled aspects of prevention.

Most of the participants felt that being proactive with how they handled the impact of MRSA in their lives was an important factor to adapting to the condition. All but two participants, Aaron and Trene, consistently talked about how critical it was to take this infection seriously and how MRSA had influenced their thinking and decision making with respect to handling the issue. Alvin was adamant during his interview about not being afraid to ask questions when going on your doctor's visit. Edward was passionate about the process of being proactive for your health. He states,

Oh boy. Find out first what strain of MRSA it is because if it's with the real bad kind, yea there is a protocol to make sure that the loved ones are taken care of and protected from it so that you don't spread anything. *Don't be afraid to ask questions* [italics added]. Not just ask questions, but question the doctor. Ask them what they're doing, why they're doing it, because that way you get educated in what to do also. If the doctor says you have MRSA, don't just put out both arms for them to do what they want to. Ask them about it, what's going to

happen, how do we handle this. That way you've got something to work with and you've got something to tell people when they ask. There are different types of MRSA, because I just thought MRSA was MRSA. Also, it's tied to the other word, staph infection. We've heard for a long time that other people have had staph infections and that you get in the hospital. That's where you get staph. My wife's sister had a terrible time with staph and she was a nurse. So, my advice to someone, in fact we've got a lady at the church that's fixing to have knee replacement, I'm going to talk to her and say, watch the wound. If you've got any kind of problem, any kind of problem, you ask that doctor to take a culture and stay on top of it. Our doctor is a great doctor but busy. They don't always have time to see you so the PA or tech does things like take the staples out and the reason they're not a doctor is they don't have the schooling. They should be limited on what they can do and they need to be overseen. It's a vicious cycle because the doctors are so busy so they need the PA's but they really need to be watched.

Becky –asked a million questions” as a method to adapt to what was happening to her. Like the others, a consistent message from healthcare was crucial for the adaptation process. Nell believes that it's important to –ask some questions...that's how I begin to learn.” She came to terms with MRSA by the realization of the ubiquity of the microbe. When I asked Nell about adapting to MRSA, she said,

I will tend to go see my doctor if I am concerned about something, rather than hesitate. My days of a wait and see approach is far fewer than they were... Well, I realize it's around. I realize it's everywhere. I also realize that I can be prone to

get it again... I self monitor a lot. Having MS muddies the waters a little bit. But, I don't think I'll ever forget how I felt that night. And, if I get anywhere close to that level of confusion and just being out of it, I'd be extremely concerned...

Well, to coin a phrase and maybe an overused phrase, of life is precious and I think we need to do everything we can right now, especially, to guard against the viruses and MRSA and things that are out there. We do whatever we can. If I can just add something, I know the emphasis right now is on H1N1, and in a sense that bothers me because there certainly are other concerns. I believe MRSA is one of those.

For Mary, the issue of *controlling* the health environment is important to her. She says,

And not everybody has the same degree of responsibility to care. So what, I've got it [MRSA], you know, I don't care if – it led me to wonder about AIDS and things like that, you know. People's responsibility and mindset about, you know, protecting society, because we are totally dependent on that. If somebody has a wound and it's oozing and they go on a piece of equipment and they don't have the responsibility to society to clean it up – to make sure that is sanitized for the next person, then there you are, ready to just bring your open wound and get infected again, you know. I mean – so I would rather not count on that. *I would rather kind of control what I can control within my own environment to the degree that I can control it* [italics added].

Management of the condition was another contributing factor to self-reliance. All of the participants felt that it was important that they take care of themselves (physically

and mentally) as a means of adaptation to MRSA. In many instances, these were behavior changes. Aaron talks about how MRSA has changed his hygiene behavior. He states,

Before this all happened and before I got MRSA I didn't care at all to wash out any cut or scrape. The first thing on my mind wasn't washing it out and cleaning it up; I just never ever did that. And now, it's not even a thought if I get a little scrape, I'll go wash it. I'm just more worried about MRSA or a skin rash. I'm real worried about coming into contact with them, just because I already have a weakened immune system from this. It's not debilitating, but it's always in the back of my mind, thinking about it.

Likewise, Dora talked about her management of wounds. She said ~~any~~ bites we get, ants, mosquitoes, anything, we go and put alcohol on them immediately, you know, and just keep your fingernails clean, under your fingernails, wash your hands, wash your hands, wash your hands." Interestingly, Erin took self-management to the extreme with respect to caring for herself. She discussed her experience with how she took care of herself before even visiting the doctor. She says,

So, I got really scared. So, before I went to [a health center] I was freaking out that they were going to have to cut my leg off or something, and then when they told me I just needed to take some medicine or something and take care of it and drain it. They asked me what I had been doing to it and I had opened it myself to drain it because I have ulcer and medical supplies at my house because of my mom [nurse], so I did the whole procedure because I had went three days with it just under my skin and it was getting real pressure and horrible, so I drained it. And that was horrible... Yea, I did it with a medical razor, had gloves on. I put

lidocaine on over my knee and all sorts of stuff. It was really horrible. So, when I went to [a health center], they didn't have to do anything to it but drain it out a little bit more and bandage it up and give me some medicine and tell me to... Yes, but they [a health center] didn't say anything about me. I guess I did it right. It was horrible. So, after that, and then looking it up online, I'm a big researcher, I research things when I find out I have them and stuff. So, that's what I did.

Edward talked about how MRSA affected his decisions with respect to caring for his body as compared to what he might have done in his past.

You didn't realize how vile something like that could be. How devastating it could be to your body. A long time ago, infection was just infection. Put a little cure all on it and it would feel better. Now days, yeah after having gone through the MRSA, especially the MRSA, I'm going to be very cognizant of both of us. If we've got a problem, a wound, do everything possible to keep it clear and clean. We don't want to get the flesh eating MRSA.... We've learned that with proper care and precaution while you're caring for it, you can contain it and you can actually get rid of it. It's a big price to pay. Six weeks out of your life going through IV infusions for something like that .... It's in the forefront of your mind. When you see something getting a little red you might say, I need to get that checked out, whereas before, I'd wait and use the iodine on it and give it a week and see how it looks.

Each of the participants adapted to the MRSA infection by changing how they viewed cuts and wounds. They no longer overlooked small abrasions or cuts. They managed their sores, insect bites, and other wounds quickly and with extra care.

The final component connected to self-reliance for adaptation to a MRSA infection centered on the prevention and control of the infection. Primarily, the participants discussed how their behavior and attitude changed towards hygiene, infection control, and the environment. Alvin and his wife are retired. They were very active prior to the MRSA issues and its reoccurrences. He discussed how he has changed his life due to MRSA with respect to precautionary measures, —We avoid emergency rooms if at all possible. That’s one of the things we did. We cut down on our travel so we’d be closer to our doctor’s office here.” He states, —so ~~w~~ really didn’t think much about our health with making decisions like retirement or traveling or, we even had our [special travel] places, doing things. It wasn’t a factor. But once this [MRSA] came up, it definitely became a factor.” Alvin discusses the issue further,

It has certainly affected what we’ve done in life. When these flare up we basically quarantine ourselves quite a bit. When my immune system’s down, and I don’t want to risk giving it to someone else, so really we shut stuff down when it’s active. When it’s not active, our big concern is I don’t want to be in [distant location] and have this flare up. We want to be close so we can get back home quicker so we know what we’re dealing with in the way of doctors. Because the first doctor that we dealt with was in an emergency room and all he said was, oh there’s some nasty stuff going around in [here].

For some of the participants, their behavior adaptation was compulsive when it related to their health. Trene talked about how she became obsessive about things. She says,

Well, I'm an asthmatic, and I have really bad allergies, I'm allergic to grass, most people really don't believe me. So, I've felt like I've always kind of lived in a bubble. I don't go to public gyms, because there's grossness everywhere. Yes, they clean them, but they clean them at night and then people get on them during the day. They have the cleaning stuff, but who uses it? Nobody. So, I'm really cautious about that. I am a clean freak. I will go home on Friday, to [city], and I will come back and my roommates will have terrorized the kitchen and my cat brings in dirt, so I am an impulsive cleaner. I can't do anything unless everything is clean. So, I'll clean the entire kitchen. I'll Clorox bleach everything. I'll Swiffer all the floors. I'll clean all the bathrooms.

When I followed up about her behavior prior to MRSA, she states,

Yes, but it wasn't really impulsive. It wasn't obsessive. Now, everything has to be clean. I don't keep anything on the bathroom tub. I have hanging things for everything and one of my roommates has 18 bottles of stuff, so nothing's on there to soak up bacteria, soap and water. I clean the sink almost every day. I have a toothbrush cap on my toothbrush. I think it makes me a little over the top with cleanliness, but I know that in the end it will help me...

Each of the participants talked about how their health behavior was more rigorous with respect to protecting themselves and others. Mary showed concern about ~~being~~ a carrier and transmitting MRSA to others." She states,

Yeah. And my son is a college student. It is in a commuter campus, but he is living in a house that the bathrooms are not very clean and I said – what, are you crazy? You know, I said you need to clean those bathrooms. He does, well I put

soap on my skin and I'm okay when I wash off and I'm thinking – and that's another thing is you think just soap and water would do it, but it doesn't. I mean, right, I mean... in the shower, you know, is there differences in the types of soaps you use that can strike a better balance with keeping – that deplete your body of all bacteria, but, you know, I didn't know about that. I didn't really understand that – I think we think that because we shampoo and we bathe everyday and we use Caress soap that everything is okay and not necessarily, you know. And I also learned that the bathtub is the dirtiest place in your house, that you have to really, you know, before you soak in a nice hot bath, you should probably, you know, scour that... I mean these are things that – you know, I clean house every week and I change sheets and I change towels, but my husband and I don't share towels anymore, we don't share razors, we don't even share toothpaste, you know, I don't even share toothpaste with him or deodorant. We used to share deodorant, you know... *It has changed my life in those regards* [italics added]...

*Reliance on others.* The relationships that participants formed with family, friends, and healthcare professionals were a crucial component to the adaptation process involved with MRSA. The message of others helping them through the MRSA experience was echoed by all participants many times in this study. Aaron, in particular, relied almost exclusively on his family – especially his mother. Aaron was living with his mom and dad when he found out he had MRSA. He said that –“honestly don't know what I would have done if my mom wasn't there...” His mother transported him to the doctor and took care of his wounds. His mother did most, if not all, of the research for him about MRSA and in his words –“she will always research it...she's persistent” with

the doctors and what tests to perform. Aaron's reliance on his mother, who was also a registered nurse, seemed to create an almost apathetic stance towards his own healthcare that will be discussed in chapter five. Certainly, he summed up his dependence on her when he stated, "Without her to help me, surely it would have been a lot harder and probably could have been a lot worse too."

Alvin and Edward relied heavily on their spouses to be both advocates and emotional supporters during their MRSA ordeal. Alvin says,

And like I've said before, [spouse] goes with me on almost every visit. Whether it's the oncologist or a regular doctor's visit... You need that extra set of ears there and somebody taking notes when you're dealing with something like this.

Alvin said his wife "thinks MRSA is actually worse than the lymphoma to deal with" because "she says it's something that can be spread to other people" and she constantly made him "aware of it at all times" with respect to not being "far away from your doctors because of it." Edward and his wife supported each other emotionally during the crisis. He says "It just scared my wife. She shared that with me, and we prayed and she cried in my room, just she and I and it just scares the bajeebers out of you." Edward also said that his wife helped him through his "depression" during the long antibiotic treatments that he had to endure.

Irene relied upon others due to her immunocompromised state. When I asked her what or who helped her the most when it came to her health and MRSA, she matter of fact said that "it would be people for me." Irene's daughter was a physical therapist and she talks about having "four friends and I don't call them acquaintances, but that are good friends of ours that are physicians, and I have a cousin who I am very close to that is a

physician.” Like Aaron, Irene and those who had family and friends who were healthcare professionals realized the advantage it gave them. As Irene stated, “Oh, it’s a definite plus...it’s a definite plus.” She states,

Well, the awareness, most importantly, and then too, it’s easy, you know, to have these people around you that you are close to that if you have a problem that you feel like you can discuss it with, whether it be [daughter], whether it be a friend, whether it be a family member... And I feel very, very badly for people who for some reason or not, do not have any awareness. Particularly our lower income people who might not seek help or advice regardless of where it be, the internet, television, regardless of where. I just happened to seek mine from where I did.

Erin’s mother was also a registered nurse who helped with her condition. This important feature was echoed by many of the participants and will be discussed further in chapter five.

The participants’ reliance and trust in healthcare professionals (non-related) was evident in several of the interviews. As previously mentioned, Becky felt her learning was enhanced because of the *comfortable environment* that was created by her doctor. She relied on her *patient-doctor* interaction as a mechanism to deal with and adapt to her MRSA infection. She was very grateful for his patient and understanding manner while she asked “a million questions” and for his thorough follow-up with her on multiple occasions. Likewise, Trene discussed her trust and reliance on doctors and healthcare in general. In her words, she had “been a sick child” most of her life and, “so, I’m used to the antibiotic routine...I trust the doctors that I had been to.” She also mentioned that because her mother had been to some of the same doctors she had, she had trust in the

healthcare system. She talks about her experience with healthcare and doctors, “I guess I’ve been around doctors my whole life and my parents have just valued doctors and their opinions and stuff like that. This *trust* was important for Trene because it helped her to *focus on her problem* and adapt to the situation at hand.

Finally, each of the participants also took advantage of the investigator’s expertise to learn about different MRSA topics during the interview session when the opportunity presented itself. As mentioned previously, the investigator is an associate professor in Clinical Laboratory Science and specializes in infectious disease. MRSA is a primary research area for the investigator.

*Reflections on the MRSA journey.* The participants were all reflective about their MRSA experience. As might be expected, those who had a more severe MRSA infection or had multiple reoccurrences with the infection were often more insightful about their journey. Reflection occurred as part of the interviews primarily when the participants were questioned about (a) living with MRSA and how it may have changed their life, (b) advice they would give to someone diagnosed with MRSA, and (c) advice they would give to healthcare to help individuals diagnosed with MRSA. These reflections were often cited by the participants as being helpful for their understanding and adaptation to their MRSA experience.

Living with MRSA seemed to influence the participants to become advocates for educating others about their experience. By educating others about this growing public health threat, the participants felt like it helped them to warn others while also letting them work through the adaptive phase of their infection. Alvin and his wife were active in educating friends. He talks about his experiences with telling others about MRSA,

While we're talking about this, this is kind of on the side maybe, but we were up at the [park] again this summer and one of our friends up there had to go home. She had a sore on her arm and she went to the emergency room somewhere in [city], I think it was, and the guy said, oh you have MRSA. He put her on medication and said you can go back and deal with people and everything else. We're real leery when somebody has it. We back off and we stay away from them too. We said, how does he know it was MRSA? Did he take a culture? He hadn't taken a culture; he was shooting from the hip. He gave her no information about MRSA. He just told her MRSA and she knew nothing about it. She went back after she talked to us about it because we said this is serious stuff, or it really can be. She went back to the doctor and actually got the same one, which was not her choice, but he did a culture and it was MRSA. She asked if it was contagious and he said, oh yes. She said, you told me nothing. She got a patient advocate to follow up on things, because she felt her treatment had not been quality at all... We gave the information to our manager at the park, because she had told her she could come back; deal with the public and everything. We said do you know what MRSA is. She said no. We said you'd better get knowledge of this before you just say it's ok, because it's not... We know of several people that have had MRSA... We have this guy at church and he had active MRSA and came to church services with active MRSA... Well, we were made aware of this, because the lady who was actually doing, in charge of home communion and stuff like that, this guy wanted to take communion to people who were homebound and sick, and we said no.

For Becky, it was important to help her friend who thought he might have MRSA. She discussed the information (a SHC pamphlet) with him that she had been given and also the internet sources she had used to learn about the infection. Finally, she referred him to the physician that she felt had done such a great job with her MRSA condition. She continued with her stance on educating others,

So I've seen how bad it can be and, apparently, I thought that it couldn't go that fast, but it can be like 24 hours like from okay to going and getting antibiotics in the hospital, so I completely changed that and now I think like all the time – like I talk about it, like everyone, most of my friends, everyone who I've lived with knows about it, like everyone has heard of it mostly, no one that I have talked to has not heard of it [because of me].

Nell called herself a “messenger” when it came to warning others about MRSA. She always carried hand sanitizer and was “always willing to share hand sanitizer with anyone who will use it, especially before meals and that type of thing” She wanted to be able to “offer them my experience” because she did not want others to suffer with MRSA a second or third time like she had experienced. Mary also was “willing to share her story” with anyone to help them take it seriously. She states,

And I would share with what I – you know, I have stacks of information I have printed off. I would be glad to share some of my reading. But my bigger concern is for people who want to remain ignorant when they know that something is not right in their bodies like a lump. You know, go find out what that is because if it is MRSA and it is treatable, and sooner might be better than later.

Each of the ten participants was in some way, large or small, advocates for educating others about the dangers of MRSA by way of their journey. By being active in telling their story, the participants found it therapeutic for their own healing.

The opportunity to give advice to others about the steps they had taken to understand and live with MRSA was also a means for the participants to adapt to their own condition. First, I will discuss how having MRSA impacted the participant's reflections on advice for someone who had just been diagnosed with MRSA. Advice for the healthcare environment will follow.

The participants all discussed how important it would be for others diagnosed with MRSA to be wary of what they learned from healthcare about MRSA – to be proactive in their questioning of healthcare professionals. They also all gave advice about risk factors associated with MRSA (athletics, etc.) and the correct medical testing that needed to be done to identify the infection. Aaron talks about what advice he would give someone who is learning about the infection,

It's definitely good to research it and do all that kind of stuff when you have it. So it's more than just a doctor saying that you have staph. You actually have an idea of what's going on and how you could have gotten it, that's just the main thing. Looking at all the options and kind of learning about the areas that make you more susceptible to staph, like the gyms and stuff like that. I didn't really notice it before, but then after I started noticing all the articles, like in fitness magazines, about athletes and people getting staph in gyms or in football practice. I didn't really think about it until I had an outbreak. It clicks every time I see it... It's hard to give advice. Someone already diagnosed, but I'd probably just tell them to be

really, really cautious and think about every place you're going – especially if you're in gym, or somewhere where you're coming into contact with other people's skin and sweat. Not to do stuff that can jeopardize them, like tattoos or piercings that create an open wound where it's real easy to infect.

Trene wanted others to be aware of their environment. She would tell them to clean everything for sure. And if you have a significant other, get them tested. And don't sleep in the same sheets." She also discussed the importance of not being passive with your physician. She states,

And, I would tell them to bust down the doors of their doctors and be like, what is this? What am I doing with it? I guess for me it just kind of bombarded me the first time because I went to so many doctors, I went home, and I think at that point I really didn't care. I just wanted it gone... Maybe if I had known more about what it was doing to me. Because a lot of it was, they were asking me questions about how I got it. I was like, I have no idea because I don't go to gyms, I don't cut myself and leave it open with everybody. So I think having more information may have been helpful. It may have made me feel a little bit better.

Alvin had specific advice for anyone diagnosed with MRSA with respect to the seriousness of the infection and the critical importance about the testing that must be done. Because Alvin was immunocompromised (lymphoma), he had reoccurrences with MRSA and had some bad experiences with ER physicians. He states,

The advice we have given people is, one, make sure you know what you're dealing with. We've given a lot of information on it to other people. The second thing I would tell them is, don't take it lightly. We've got a friend who was

hospitalized with it because it got into the bloodstream. She almost died. She was in intensive care for a few days... First of all, make sure that's what you're dealing with. If they think it is MRSA, do the culture. We've had two that didn't... So, make sure they know what they're dealing with. And second, this is my understanding and if it's incorrect you need to set me straight, my understanding is they have to do the culture to know what antibiotics will work with that strain of MRSA.

Edward, who had a knee replacement go bad due to a MRSA infection, echoed Alvin's advice with respect to dealing with MRSA and the doctors you might encounter. He says,

Oh boy. Find out first what strain of MRSA it is because if it's with the real bad kind, yea there is a protocol to make sure that the loved ones are taken care of and protected from it so that you don't spread anything. Don't be afraid to ask questions. *Not just ask questions, but question the doctor* [italics added]. Ask them what they're doing, why they're doing it, because that way you get educated in what to do also. If the doctor says you have MRSA, don't just put out both arms for them to do what they want to. Ask them about it, what's going to happen, how do we handle this? That way you've got something to work with and you've got something to tell people when they ask. There are different types of MRSA, because I just thought MRSA was MRSA. Also, it's tied to the other word, staph infection. We've heard for a long time that other people have had staph infections and that you get in the hospital. That's where you get staph. My wife's sister had a terrible time with staph and she was a nurse. So, my advice to

someone, in fact we've got a lady at the church that's fixing to have knee replacement, I'm going to talk to her and say, watch the wound. If you've got any kind of problem, any kind of problem, you ask that doctor to take a culture and stay on top of it.

Erin discussed the issue of proper antibiotic usage. She would ~~tell~~ them definitely don't skip on the pills...the antibiotics...even if you think your infections getting better, that it's a stronger infection than anything normal so you have to definitely take everything that they give you" and to use proper hygiene at all times with hand washing and wound treatment. All participants echoed these lessons that they had learned and wanted to share with the general public.

Advice for the healthcare professional and the medical arena was an important way for the participants to voice what they had experienced with their MRSA walk. Most of the participants discussed how healthcare professionals could improve the interaction between the two parties by offering examples of what they felt had worked or not worked for them during their experiences. By doing so, the participants all reiterated that the reflective advice was helpful to them – that maybe our story will help others.

Nell wanted to tell those in healthcare about the ~~state~~ of cleanliness or uncleanliness" at the facility where she had worked. For her, she had suspicions about acquiring MRSA in the hospital environment and that offended her. She also felt it was important for those dealing with patients to ~~speak~~ in terms that lay people would understand." Each of the participants felt it was important for the healthcare professional to have empathy for the patient and a plan. Mary talks about this feature in her interview,

Compassion. *Counsel with compassion* [italics added]. Put in the hands of people accurate information. Outline a plan for follow-up and for subsequent cysts, or whatever. And I guess there is comfort in talking to someone else who has had it, but I know that, you know, healthcare professionals cannot – I mean maybe they could have MRSA support groups... And even in a hospital setting, if they did test you upon bringing you in and they did put you on a floor where everybody else had MRSA, for a person like me, that could be a little bit comforting, because then I wouldn't have to worry about infecting somebody else, but it also can make you feel like you are in a leper ward...two sides to the story I guess.

Likewise, Becky thought that physicians should always “give you options, be supportive,” and have a “plan of what to do – step by step.” She also wanted doctors and others to offer “encouragement for doing research” and to recommend patient education and seeking other opinions. The *consistent message* from healthcare was echoed by all of the participants as being crucial for becoming comfortable with their diagnosis of MRSA. Edward had some significant advice for healthcare with respect to “what patients should be told to look for” with respect to infections and wounds. He says,

But he took the staples out and it just kind of gushed then. If we had known, we're the customer, we're the patient, we would have insisted, take a culture and see what is going on here... In a way, I kind of feel as though it was, because I feel that if we had been a little more educated in the fact that you can get infections. See, we had a lot of people at our church that had knee replacements. Several people had both knees replaced at the same time and they were up and walking and everything, and no one had ever had an infection. I didn't really

realize that you could get an infection or any kind of infection, I mean, I'm under doctor's care. So, we went on and continued with physical therapy. I did go back and the PA saw me and he said, let's put some antibiotic cream on it and bandage it and see if that doesn't heal it. Well, there was another opportunity for a culture and we didn't insist on it... When we look back, I'm saying, if we'd have just insisted on someone check this out, way back early at the two week point or four week point maybe it would have been a simple little infection. A gram negative bacilli or whatever. They'd have cleaned it up, gave me some antibiotic for a few weeks, six weeks, whatever, and I'd have been up and walking today and probably not even talking to you... It may be MRSA to you, but it is life-threatening to me. They [doctors] see a lot of people with MRSA at its mildest and they see MRSA at its worse, but I don't care where I fall in that span, I'm the one that has it, so take the time, educate me, and don't put me off. Before I got the original knee, we went to the hospital and sat in a class with some people that were also going to get knee replacements, and they were very good about showing us what the prosthesis looked like, and how it was going to work, and so forth and once they got it in you could be up and standing on it within a day or two and all of that. *All of that was good information, but no one ever said; now there is always a possibility of an infection* [italics added].

Several of the participants (Dora, Irene, Edward, and Nell) also discussed how spirituality and prayer helped them get through their respective MRSA experiences. For each of these four participants, their relationship with God and their usage of prayer helped them to adapt and accept what trials they were going through. It also gave them

strength to endure the pain and emotional rollercoaster that they were on during the infection process.

### Summary of Findings

The ten participants in this study had insightful and interesting stories to share about their MRSA journey – the main connective threads were MRSA learning when *it happened to you* and the adaptation to the infection through mainly *people*. Each of the participants discussed the *seriousness and pain* associated with MRSA and how that was a major factor in the content and process of their learning about it. All of the participants had strong feelings about the interaction with healthcare and the relationships formed with people that helped them understand and adapt to MRSA.

There were four participants who were in a young adult group, with the remaining six approaching retirement or being retired. These two subgroups had commonalities across the themes and subthemes; however, there appeared to be a degree of apathy and passive learning in the younger group that was not as evident in the older group. The older group also exhibited more signs of *reflective hindsight* and an *appreciation for life* due to their encounter with MRSA. The majority of the participants acquired most of their knowledge and learning about MRSA after the diagnosis. However, three of the participants had either worked or volunteered in the healthcare environment prior to their MRSA diagnosis which influenced their actions towards learning and adaptation. Interestingly, a majority of the participants also had close family or friends that were employed as a healthcare professional.

Seven of the participants experienced feelings of being an outcast, “~~a~~ leper”, or stigmatized by healthcare, family, or friends. This feeling of perception by others,

*labeling*, or using *anchors*, to describe oneself may be interpreted in light of social representations theory that will be discussed in greater detail in chapter five.

The content of what the participants learned was primarily about (a) general MRSA information, (b) MRSA care and prevention, and (c) antibiotic resistance. In general, all of the participants were aware of MRSA and/or staph but they lacked detailed information about the organism and its dangers. The participants acquired this information through a variety of sources – media in the form of print and the internet were the two primary vehicles for delivery of informational content to the participants. Learning by the participants was primarily self-directed, experiential, and in some cases, transformational.

The participants adapted to their MRSA infection primarily through two mechanisms – self reliance and/or a reliance on other people. Additionally, participation in this study gave them a voice and an opportunity to share their stories. For some, these reflections about their experiences and journey with MRSA during the interview were self-described as helpful and therapeutic in this regard. The universal lesson from this study is to always be questioning and proactive in interacting with healthcare. Their personal stories were raw, honest, and insightful accounts that are useful for improving communication between the healthcare-medical environment and the general community about adaptation to MRSA.

## CHAPTER FIVE

### DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

#### Summary

Methicillin-resistant *Staphylococcus aureus* (MRSA) is probably the best-known example of a resistant bacterium and has been the focus of intense scientific and political interest around the world (Darzi, 2007). MRSA was initially reported in the 1960s and it quickly became known for its ability to cause large hospital outbreaks and become endemic. MRSA has also evolved in the community and is unrelated to the evolution of healthcare-associated MRSA (HA-MRSA) in hospitals. These community-associated strains, known as community-associated MRSA (CA-MRSA), have been isolated from people without the commonly known risk factors. Both HA-MRSA and CA-MRSA infections have significant mortality and morbidity rates ranging from 8% to 49%, respectively (Austin, Austin, & Coleman, 2003; Hartstein & Mulligan, 1996; John & Barg, 1996; Talon, Woronoff-Lemsi & Limat, 2002). Although there are high levels of awareness and concern about MRSA among healthcare personnel and hospital patients, there has been little research focused on the general public. The purpose of this study is to investigate how people in the community who have MRSA develop their understanding and knowledge about antibiotic resistance. The intention is to explore how members of the general public who have a *need to know* discover, learn, and adapt to MRSA.

### *Literature Review*

A review of the literature for this study focused on three main areas – MRSA knowledge and awareness in the healthcare environment, MRSA knowledge and awareness in the general public, and theoretical influences which related to bridging gaps in MRSA knowledge, learning needs, and adaptation to the condition. Specifically, an examination of learning theory (self-directed and transformational), the ecological perspective of health, and social representation theory were conducted in regards to theoretical lenses.

While this study focused on the general public, it is important to consider MRSA knowledge and adaptation in the healthcare environment to establish a foundation for MRSA issues with respect to its origin and eventual transition into the general public. In a current review of the literature, Gould and his colleagues studied knowledge, sources of information, and perceptions about healthcare-associated infection (HCAI), particularly MRSA, in patients and the public (2009). With respect to patients, the overall findings from 16 studies in the healthcare arena demonstrated that fear of acquiring HCAI, especially MRSA, is the single greatest worry of individuals contemplating hospital care. Importantly, the review reports that in all accounts, people expressed anxiety about the risks and consequences of HCAI. The most frequently reported source of information was the media. Individuals often do not appear to access credible sources, and if they do, do not appear to understand them well (Gould et al., 2009). In the US, patients were dissatisfied with the information they had received about risk factors, infection rates (Miller & Farr, 1989), and HCAs (Guinan et al., 2005; McGuckin et al., 2006). Unfortunately, studies in the US have focused primarily on the prevalence and genetic

relatedness of HCAI, particularly MRSA (as documented in the introductory chapter of this document), while only recently investigating perceptions, knowledge, or awareness.

However, if one looks abroad there is considerably more literature about MRSA knowledge and awareness in the healthcare arena. Patients are unaware of what antibiotic resistance is and how it arises (Brooks et al., 2008), nor do they have a clear understanding of MRSA infection or comprehend the reasons for source isolation (Newton, Constable, & Senior, 2001). Multiple studies also document that the media plays a greater or at least an equal role in acting as a source of information for the patient (Abbate, Giuseppe, Marinelli, & Angelillo, 2008; Gill, Kumar, Todd, & Wiskin, 2006). Practically, all of the remaining studies report similar findings with respect to patients being aware of MRSA but not understanding the critical aspects of transmission, infection control, and prevention (Lugg & Ahmed, 2008; Madeo, et al., 2008; McNulty, Boyle, Nichols, Clappison, & Davey, 2007; Trigg, Timmons, & Pynegar, 2008). It appears that even with all of the misunderstanding and low levels of knowledge about this organism, that at least there is an opportunity for hospital patients to cross paths with correct knowledge about MRSA – that is not always true in the general public.

Little research has been conducted on the awareness and knowledge of MRSA within the general public. Gould et al. (2009) found six studies in their literature review that examined MRSA and HCAI awareness and knowledge in the public. They categorized the studies of the public as —those that set out to explore the knowledge and perceptions of people who had not undergone recent healthcare interventions and were not about to use the health services” (p. 3). An examination of the US literature in this area identified that people in the general public knew about MRSA and HCAs but had a

sense of apathy towards the problem (McGuckin et al., 2006). Other studies reported on the sources (lay persons, practitioners, media, etc.) of information which coincided with diverse and often incorrect answers with respect to MRSA knowledge (Brinsley-Rainisch et al., 2005). In one of the most comprehensive qualitative studies to date, researchers found interviewees were confused or uncertain about what bacterial resistance meant and their understandings were not consistent with current medical concepts. Threat perception and perceived importance of the topic were low. As with other studies mentioned, the media was found to be a main source of information. Very few understood they could help the resistance problem by expecting antibiotic prescriptions less often, or taking them according to prescription instructions and even fewer understood the importance of frequent hand washing. A majority of participants felt like MRSA was a hospital problem and not a community problem (Hawkings et al., 2007). This is a critical problem with all antibiotic resistance – blaming healthcare and not taking personal responsibility in the issue.

Similar findings about MRSA knowledge, learning, and adaptation are found outside the US too. For instance, in two studies of the public (McLaughlin et al., 2008; Vonsberg et al., 2008), similar results were found in which German and Irish Republic individuals, respectively, knew about HCAs and MRSA but didn't appear to comprehend the importance of infection rates within hospitals. Likewise, Washer et al. (2008) interviewed 60 people described as demographically diverse living in Greater London to explore perceptions of HCAs. Most participants attributed risk of MRSA to poor environmental conditions in hospitals arising through mismanagement, thus

reflecting media accounts. Awareness of the role of antibiotic over-prescription and misuse in the origin of resistant bacterial strains was not reflected in responses.

The rapid increase in the number of studies investigating lay perceptions about the risks associated with MRSA and other like infections reflects the growing importance of this public health threat to all. While these studies document awareness and perceptions fairly well, they lack in other analyses of how the individual with MRSA is impacted, what they need to know, and how they take efforts to learn and adapt to the illness. These are the questions that were addressed in this study. The literature also suggests that the media (print and electronic) heavily influences lay knowledge and attitudes toward risk instead of more credible sources of information about MRSA. This finding differs from previous findings about the behavior of people with chronic illnesses for whom newspapers and television are not the preferred sources of information and an explanation for this difference is unclear (Coulter, Ellins & Swain, 2006). Coulter et al. (2006) found that for individuals with a variety of chronic diseases or other health-related concerns, doctors and other health professionals are the most frequently used resource.

Lastly, a number of theoretical frameworks have been identified which offer possible lenses through which to interpret data that has been collected as part of this study. One might consider these frameworks – learning theory, ecological perspective, and social representation theory – as sensitizing concepts (Patton, 2002) of this study. These concepts may offer ways of seeing, organizing, and understanding the experiences of those impacted by MRSA.

Briefly, there are several well-established adult learning theories which may help to understand learning about MRSA. For instance, self-directed learning (SDL) has been

described as the ability of individuals to initiate, either alone or with the help of others, the diagnosis of their learning needs, formulation of their learning goals, identification of resources for learning, selection and implementation of learning strategies, and evaluation of learning outcomes (Knowles, 1975). It has been reported that most adult learning is self-directed learning (Candy, 1991). A diagnosis of a disease or life-threatening condition often initiates a deep desire for SDL for the individual and for family members and close friends. Caffarella (Merriam & Caffarella, 1999) discusses her own experience with SDL after being told she had a serious illness. She was in a constant learning mode with respect to treatment regimens and new medications. Holland (1992) reports on the SDL learning efforts of individuals dealing with multiple sclerosis (MS) in her dissertation and Hollingsworth and Scott (2008) detail the learning of a multiple kidney transplant recipient attempting to balance the effects of the disease and the treatment and maintain her role as wife and mother. The SDL in these types of environments often include a catalyst around a diagnosis such as an individual being told of a MRSA diagnosis.

Transformational or transformative learning (TL) is about change. The change may be sudden or occur over an extended time period. Whatever the timeframe may be though, the change prompts a major shift in the way individuals see themselves or the world. TL theory has typically been approached from two perspectives based on the locus of learning – individual versus sociocultural (Merriam et al., 2007). Mezirow's individual locus of TL theory (1981) describes four main parts of the TL process: experience, critical reflection, reflective discourse, and action. The experience is often set in motion by a *disorienting dilemma* such as a life threatening illness or death of a loved one. A

MRSA diagnosis appears to have the characteristics of a disorienting dilemma. These events cause one to critically self-examine the assumptions and beliefs that surround the experience. In doing so, one revises specific assumptions about themselves to the point of transformation of the structural make-up of assumptions. Two studies applying TL theory were identified that informed the current study on MRSA. In a study of healthy lifestyle change after a cardiovascular disease diagnosis, Montoya (2008) reported that TL was a critical aspect of lifestyle change. Likewise, Baumgartner (2002) conducted a study of the same 11 participants in 1995, 1998, and 1999. The study sought to understand how individuals with HIV/AIDS continued to make meaning of their chronic illness. Four major findings emerged including (a) TL occurred, (b) meaning changes were acted upon, (c) new meaning structures were a higher appreciation for the human condition and an enlarged view of intimacy, and (d) interaction (socially) was crucial to the learning process.

Health issues, such as public knowledge of MRSA, can be examined from a global lens with respect to the ecological perspective (Table 1) created by McLeroy and colleagues in 1988. The ecological perspective emphasizes the interaction between, and interdependence of, factors within and across all levels of a health problem. It highlights people's interactions with their physical and sociocultural environments. Two key concepts of the ecological perspective help to identify intervention points for promoting health: first, behavior both affects, and is affected by, *multiple levels of influence*; second, individual behavior both shapes, and is shaped by, the social environment (*reciprocal causation*). The ecological perspective includes a network of interrelated theories which

can be examined in light of knowledge, learning strategies, and adaptation to antibiotic resistance issues, particularly MRSA.

Finally, social representation theory (SRT) allows one to study the passage of knowledge from scientific thinking, via the mass media, to lay thinking. One of its major concerns is the way in which new threats to a society are constructed, with the media being a key player in the evolution of public thinking (Moscovici, 1984). Two key tenets of this theory are anchoring and objectification. For example, in the case of the coverage of severe acute respiratory syndrome (SARS), the (alarmist) anchors used to describe the new disease were the Spanish influenza epidemic of 1918 and the Black Death (Washer, 2004). Objectification coats an unfamiliar thing with more familiar images, symbols and metaphors that are easier to grasp (Moscovici, 1984). The process of objectification overlaps with that of symbolism (Joffe, 2003). Washer and Joffe (2006) utilized this process when they examined MRSA in Britain over the 10-year period by analyzing newspaper coverage of the disease from 1995-2005. The study utilized SRT and embedded MRSA within the framework of other emerging infectious diseases. Key findings were that MRSA is the new ‘superbug’ and its rise has marked the failure of the golden age of medicine conquering disease. The study also found that MRSA is built around an *it could be you or me* set of assumptions played out in the media. Finally, the blame for MRSA is laid at the doorstep of why it spreads instead of its origins (antibiotic misuse). Ultimately, the blame is placed on poor hygiene of the hospitals and mismanagement, a form of *othering* that is inherent in SRT. This is seen as having a close fit with the current investigation.

### *Methodology*

This qualitative study with a theoretical framework focusing on the concepts of constructivism and grounded theory was designed with the purpose of gaining a better understanding of the impact and the consequences of a MRSA infection on an individual in the general public. Participants were recruited through three different mechanisms – prior contact, referrals from the university health center, and snowballing. Ten participants (four male and six female) who ranged in age from 21 to 73 were selected. Nine identified themselves as Caucasian – White and one as Vietnamese – French Canadian. Two subgroups emerged – a young adult group (four) and a retired or approaching retirement group (six). Most participants had college degrees with several having advanced degrees (Table 2). They received e-mails and/or personal phone calls requesting participation and an invitation letter (Appendix A) explaining the study. All ten agreed to participate and constituted the purposeful sample for this study. After rapport was built through an initial phone or email contact, but before the taped interviews began, consent forms (Appendix B) were signed and demographic information was obtained via email. Participants were assigned their pseudonyms after completion of the interview. The primary method for gathering information was the use of an open-ended, semi-standardized interview guide (Appendix C). This approach added focus and ensured collection of information in the same general areas from each interviewee while allowing for flexibility within individual interviews. The interview guide was piloted with two individuals who did not meet the inclusion criteria but had had a *close encounter* with MRSA (e.g. the sibling of someone who died of MRSA). The interviews

were digitally recorded, ensuring that the data were accurately recorded for analysis, and transcribed. The transcripts were coded, and themes emerged from the data.

Trustworthiness, or confidence, in the data was established through the process of triangulation, using different data sources (interviews, demographic Emails, and a research journal with analytic memos), and analyzing the interviews through three sensitizing concepts (lenses). The three lenses were SDL, TL, and SRT. Credibility was established through member checking at various times during data analysis; this ensures participant experiences were reconstructed as they remembered sharing them during the interviews. Likewise, prolonged engagement with the participant and data saturation contributed to credibility. The in-depth interviews enabled me to offer thick descriptions, thus, facilitating transferability. The findings also have commonalities to other studies' findings regarding the MRSA experience and should be relevant for future investigators. Dependability was established through triangulation that established validity and through member checking that established credibility. The technique for establishing confirmability for this study was through the audit-trail of records including transcripts, and my own reflective journal.

Approval for the project was obtained from the IRB at Texas State University-San Marcos. The participants were informed of their rights as research participants, asked to read and sign consent forms, and advised that they could stop the interview or drop out of the project at any time. In addition, they were advised that their information would remain confidential and their assigned pseudonyms would protect their identities.

### *Key Findings*

Two main themes and six subthemes emerged from the analysis of the data.

## (1) Learning

- (a) Experiences with MRSA: The participants experienced pain and a range of emotions (e.g. trust, anger, anxiety, depression, frustration, embarrassment associated with stigma).
- (b) What was learned? The participants learned general MRSA information, MRSA care and prevention, and about antibiotic resistance.
- (c) How did learning occur? Learning was primarily achieved through people and media. Learning was self-directed, experiential, and in some cases, transformational.

## (2) Adaptation

- (a) Self-reliance: Participants demonstrated self-reliance primarily about how they made decisions, managed the condition, and handled aspects of prevention.
- (b) Reliance on others: The relationships that participants formed with family, friends, and healthcare professionals demonstrated the message of *others* helping them.
- (c) Reflections on MRSA journey: Reflections were often cited by the participants as being *helpful for their understanding and adaptation* to their MRSA experience.

## Discussion and Conclusions

This study was specific to individuals in the general community who had experienced a diagnosis of MRSA. The literature (empirical and theoretical) addressed issues of individuals' learning and adaptation to MRSA and similar health concerns (e.g. HIV, multiple sclerosis, etc.) with commonalities and differences among those findings

and with the findings of this study. The key findings of this study will be examined and discussed in regards to a model for MRSA learning and adaptation. The model, as constructed during discussion, consists of the following main components: Pre-diagnosis, diagnosis, post-diagnosis, learning (seeking, what, how), adaptation, and disclosure (Figure 1).

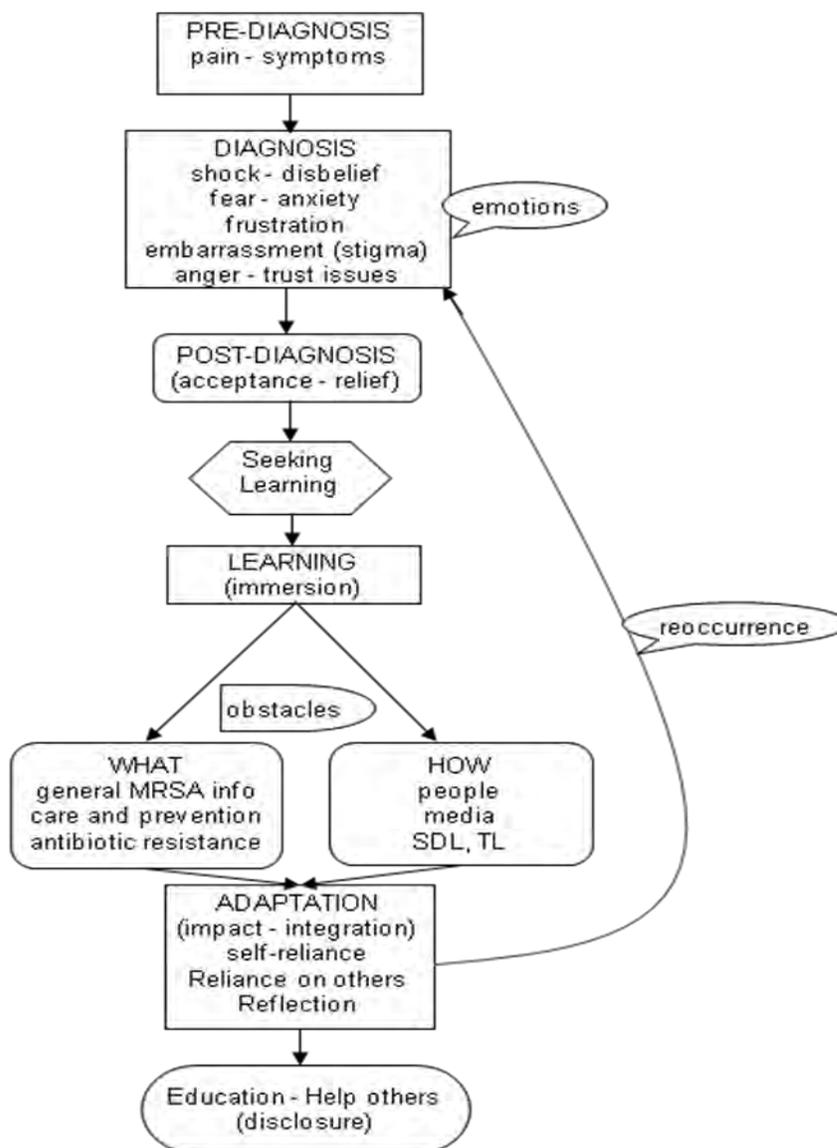


Figure 1. MRSA Model of Learning and Adaptation.

It is important to emphasize that the investigator believes that this is the first study documenting this phenomenon (learning and adapting) with MRSA. Likewise, one must consider the fact that a diagnosis of MRSA is not always considered chronic but individuals often have reoccurrences. Further, while MRSA can be life-threatening, it typically is not viewed in the same light as a diagnosis of HIV, for instance.

### *Pre-diagnosis*

All ten participants in this study experienced a time period, prior to a confirmed MRSA diagnosis, in which there was a physical experience associated primarily with pain and symptoms. This finding was surprising in that the original conceptual framework for this study did not consider a pre-diagnosis category, yet both age groups discussed this feature. A MRSA infection typically begins as a very painful boil like skin infection which can progress to more serious systemic involvement. For instance, Erin said, —You can't do anything with how much it's [pain] affecting you. You've just got to deal with it...It put me in a really bad mood because it was so much pain constantly. It made me really emotional..." Interestingly, this pre-diagnosis physical experience did not appear to be linked directly to the SDL catalyst as discussed by Knowles (1975) nor a TL disorienting dilemma as discussed by Mezirow's (1981) individual locus of adult learning. The pre-diagnosis experience by the participants was either ignored until the pain became too severe, and thus led them to seek a medical intervention or tipped them off that it might be a typical staph infection. This study aligns with a study of the experiences of women with heart disease conducted by Murray, O'Farrell, and Huston (2000) in which the pre-diagnosis stage was not expected and in which the participants were often misdiagnosed by their physicians. None of the participants in this study linked

their pre-diagnosis experience with triggering a response to learn about what was happening to them. Importantly, the *actual diagnosis* as a MRSA infection (discussed next) aligned strongly with the SDL (1975) catalyst or TL disorienting dilemma (1981).

### *Diagnosis*

The actual medical laboratory diagnosis of a MRSA infection in this study emerged as either a catalyst for SDL or as a disorienting dilemma for TL by the participants. However, a range of emotions was also experienced by most participants that started with the physical pain during pre-diagnosis and transitioned into the diagnosis time period. These range of emotions included trust, anger, anxiety (worry/scared), depression, frustration, and embarrassment associated with stigma. While emotions originated early with a MRSA infection, the participants experienced emotional peaks and valleys throughout their MRSA experience. A discussion of these emotions in relation to adult learning follows.

As Denzin (1984) suggests, —To understand who a person is, it is necessary to understand emotion” (p. 1). There is a broad amount of literature associated with emotions and how they play a role in adult learning. It was not the intent of this study to conduct an exhaustive review of the literature associated with the emotional self but this area has important implications for further research. Since the participants experienced a range of emotions during their MRSA experience, it is an important area to address. In particular, John Dirkx and Carolyn Clark offer a perspective on this topic that aligns with this study. Briefly, Dirkx (2001) —argues that personally significant and meaningful learning is fundamentally grounded in, and is derived from the adult’s emotional, imaginative connection with the self and with the broader social world” (p. 64). Put

plainly, since emotions refer to self then these emotions provide us with a means of developing knowledge about ourselves (2001). The consciousness is inhabited by ~~multiple~~ "multiple voices" and the ~~experience~~ "experience of emotion often reveals a multiplistic, contradictory self" (Clark & Dirks, 2000). For instance, a common paradox occurred with my study participants – they experienced a combination of fear, anxiety, and anger directed at the physician, other healthcare professionals, or the general healthcare environment when they were told of the seriousness of what a MRSA diagnosis meant, yet they also realized that they needed to trust the very establishment that had diagnosed or misdiagnosed their condition. Six of the participants (Aaron, Trene, Irene, Edward, Becky, and Mary) experienced anger, usually directed at healthcare. Aaron stated, ~~I~~ "was so mad and upset that they [doctors] didn't even think about staph after telling them that I went to the gym" but he also acknowledged his need to trust ~~them~~ "for treatment" of his infection. Many of the participants mentioned these contradictory feelings towards the healthcare establishment.

Another strong emotional component that seven of the ten participants (Aaron, Dora, Trene, Alvin, Edward, Erin, and Mary) experienced was the feeling of embarrassment associated with being stigmatized – either by the medical environment or by others in the public community, including family members. They used labels like *leper* or *outsider* to discuss how they were made to feel. For instance, Dora ~~had~~ "the big bandage on my stomach, and people would sit way across the room from me" even though she told them that the sores were properly covered and she was being treated with antibiotics. She was conflicted over being labeled by the very people, her family, which she needed to have ~~give~~ "give her hugs." Mary also expressed this feeling strongly,

And I'm cognizant that it could come back anytime. They say it is very hard to eradicate in your system – that it lies dormant. I don't know if that is the case with me, if the clindamycin did eradicate it or if it is going to rear its ugly head in the future sometime, so I do kind of – it's always in the back of my mind. But I will tell you too, though, at the time that I was struggling with it, *the feeling of being a leper* [italics added], I mean – it was like I was cognizant of every hand I shook, every person I was in contact with, every – I wouldn't – my mom and I would go out to lunch and we might share a taste of something with one another. I wouldn't allow that to happen. I mean, it really did rock my world when I was going through it and I think I really did stress out all of my family members because I was so vigilant.

Mary, like many of the other participants, felt the sting of embarrassment associated with stigma and they often used words like *outsider* and *leper* as anchors to transfer their feelings about themselves into words or phrases that had prior meaning to them from the mass media. In SRT, objectification coats an unfamiliar thing with more familiar images, symbols and metaphors that are easier to grasp (Moscovici, 1984). Mary, like others, used words like *leper* to try and represent what MRSA felt like to her in light of what the greater community and her former experiences had meant to her. Washer and Joffe (2006) state that, ultimately, the blame is placed on poor hygiene of the hospitals and mismanagement, a form of 'othering' that is inherent in SRT. Indeed, most of the participants of this study shared feelings of blame directed at healthcare and the *dirty* hospital environment for what they believed to be a major reason for CA-MRSA.

Frustration as an emotional component was primarily associated with *the system* either due to a misdiagnosis or what Irene referred to as the ridiculous amount of precaution with respect to isolation or quarantine post MRSA treatment. Again, the participants were tormented knowing that their frustration was part of the process of relying on healthcare. In a broader sense, it's feasible that the participants were making meaning of their emotional experiences where they intersected with their past and current healthcare experiences. For example, Dirkx (2001) believes "the meanings we attribute to emotional states also inform us about ourselves and the broader social world" (p. 64). It is possible the participants' emotional reactions and feelings were a reflection of their past interactions with the healthcare system, good or bad. Likewise, Dirkx (2009) also tells us that "adult learners experience affect and emotion in a range from positive and energizing to negative and distracting" (p. 9). It is not a huge leap to see that negative experiences with the healthcare system were often distracting; in many cases it led to a postponement for the participants to seek learning. Conversely, a positive experience (e.g. physician created an open, comfortable environment for questions to take place) led to a more rapid procession towards the post-diagnosis and learning stages.

While the focus of adult learning during this study will be directed on SDL and TL in the next section, one can't ignore the important contribution of the emotional self that was experienced by the participants in this study. These emotions laid the groundwork and foundation that transitioned the participants into the post-diagnosis and learning stage.

### *Post-diagnosis and Learning*

The post-diagnosis component of the MRSA learning model consists of two primary features: (a) acceptance/relief and (b) a move towards seeking learning. During post-diagnosis, the interaction between the healthcare provider and the participant (whether positive or negative) often provided the foundation for learning to occur. One cannot draw hard lines of division within the MRSA model. In actuality, the participants were transitioning towards post-diagnosis and learning during the latter time period of the diagnosis component. As mentioned previously, the actual medical laboratory diagnosis of a MRSA infection in this study emerged as either a catalyst for SDL or as a *disorienting dilemma* for TL by the participants. However, it's important to examine how the interaction with the different healthcare personnel influenced the post-diagnosis and learning components. For instance, in the case of a negative experience or misdiagnosis the participant tended to postpone the learning component associated with a correct diagnosis and treatment plan. Conversely, a positive experience had the opposite effect for the participants. Irene demonstrated this feature in the following statement,

Well, that's just what I'm saying, you know, I knew that they were doing the best that they could do and that I thought that I was getting the best treatment and, of course, I had the same thing said to me regardless of whether it was home health, our family doctor here, or the medical team at [location], so you kind of get some confidence when everybody is saying treat it the same way and also they are saying it is getting better... because I feel like I have gotten such good care with the diagnosis, once I said something.

The consistent message from healthcare and a step-by-step plan of how to proceed was an important transition period for participants, like Irene, to accept the diagnosis of MRSA and move on to the work of learning about the issue. In many instances, there was relief to finally have the correct diagnosis and a treatment plan that allowed for the participants to accept their condition and move towards an immersion in learning about MRSA.

Learning was a major theme for this study. The subtheme concerned with the MRSA experiences of the participants in light of their emotions and feelings was discussed in the diagnosis phase. The other two subthemes concerned with *what* was learned and *how* learning occurred will be discussed in this section. The content of *what* was learned from the participants during their MRSA experience was categorized into three areas: (a) general MRSA information, (b) MRSA care and prevention, and (c) antibiotic resistance.

In general, the participants in this study were aware of MRSA but lacked detailed knowledge about the microbe. For instance, all of the participants knew what a staph infection was but they learned that MRSA was a specific type of staph infection that was resistant to treatment during their experience. Aaron ~~had~~ barely even heard of staph or anything like that.” Only Dora and Nell knew what the acronym MRSA meant, primarily because they had both been introduced to it via formal training in their healthcare careers as a nurse and speech pathologist, respectively. Likewise, the participants shared common learning experiences with respect to their immune status, risk factors for acquiring MRSA, and CA-MRSA versus HA-MRSA. All of the participants discovered or were taught that MRSA can be severe, especially for those who are

immunocompromised. Finally, the participants learned that there were a wide range of risk factors (e.g. tattoos, personal hygiene) associated with acquiring MRSA and that it was not just a hospital problem. These findings support those of several U.S. studies including findings by Brinsley-Rainisch et al. (2005) on MRSA knowledge in the general public; McGuckin et al. (2006) on what the public knew about infection rates in hospitals and how HCAI's transitioned into the public; Hawkings et al. (2007) on attitudes of the general public to bacterial resistance; and McBrien et al. (2008) on the needs of those living with MRSA in the general public. Additionally outside the US, Mattner, Mattner, and Zhang (2006) and Guinan et al. (2005) evaluated public knowledge of HCAI and found that people claimed to have heard about HCAIs, like MRSA, but did not identify it as a major problem. These factors appear to be critical for those in the public to understand and move towards gaining insight into the seriousness of a MRSA infection.

The second major component of content learning for the participants was about the care and prevention of MRSA. Once the MRSA diagnosis had been made for the participants, a consistent message about wound care, medication, and how to prevent the spread (transmission) of MRSA was delivered by the respective healthcare professionals involved in each case. The participants seemed to be startled and surprised by the ubiquity of MRSA, especially with respect to its presence in the environment outside of healthcare. Alvin discusses some of these features in great detail,

It's [MRSA] always present. You go into a doctor's office and you sit away from people, you try not to touch stuff, you wash your hands. They're wrinkled, you wash them so much. There's the [bacteria] on shopping carts. You wipe the handles on them before you use them... We cut down on our traveling. Especially

more aware of what's going on with my body. If I get a pimple or sore of some kind, it's not something I say, oh I got a zit or something like that. I really keep an eye on it and watch it and am very, very much aware of my [MRSA environment], my awareness is totally heightened.

These findings are supported by McBrien, Felizardo, Orr and Raymond (2008) who conducted a study about the needs of those dealing with a MRSA infection. Their study indicated the public needed information centered on transmission of MRSA to family members (especially children), duration of infection, MRSA affecting daily living, clarification about knowledge (e.g. MRSA lifecycle, colonization versus infection), and how to deal with recurrent infections. Likewise, Brinsley-Rainisch et al. (2005) found that respondents gave diverse (and often incorrect) answers with respect to what they knew about this issue (flesh eating, impetigo, heart disease, etc.) and they often did not understand how it was transmitted. The participants in the current study emphasized the care and prevention aspect with respect to what they had learned. Erin sums it up for most of the participants,

Yea, I definitely learned to when you have it [MRSA], to not be around people as much in a close, close quarter and to wash your hands a lot more and to definitely take a bath everyday and clean it with medical soap and hand stuff if you have it...If it's [cuts, etc.] a little something, I usually don't care about it, *but now I do* [italics inserted]. Because, I don't want that to happen again, because it could have been, it's any little ol' thing and it turns into this huge infection, you can't even believe it's living in you...

The participants were most concerned about reoccurrences of the infection and how to prevent the infection from spreading to others, especially their loved ones.

The last major component for content learning in this study related to antibiotic resistance; most of the participants learned about the specific types of antibiotics used for MRSA infections and, in general, why resistance had occurred for this organism. Each of the participants also discussed learning about the importance of having a culture done, and a subsequent antibiotic susceptibility test to treat the infection appropriately with the correct antibiotic. Hawkings et al. (2007) found interviewees were confused or uncertain about what bacterial resistance meant and their understandings were not consistent with current medical concepts. Very few understood they could help the resistance problem by expecting antibiotic prescriptions less often, or taking them according to prescription instructions. Likewise, outside the US Washer et al. (2008) found that awareness of the role of antibiotic over-prescription and misuse in the origin of resistant bacterial strains was not reflected in responses. Mary detailed a critical event in this content area,

Okay. I realized that having a firm culture diagnosis is essential because I was taking Augmentin and that was not effective at all, I was told, on what this was resistant to. So having the abscess drained and having the clindamycin was kind of the ticket, I thought, in stopping it in its tracks with me. I also learned the importance of acting quickly...

It's important to mention that a couple of the participants (Aaron and Becky), while learning about antibiotic resistance during their MRSA journey, continued to have some poor understanding about the topic.

Finally, studies in the US (Hawkings et al., 2007) and outside the US (Washer et al., 2008) found that a majority of participants felt like MRSA was a hospital problem and not a community problem and attributed risk of MRSA to poor environmental conditions in hospitals arising through mismanagement respectively, thus reflecting other studies and media accounts. Several participants in this study corroborated this notion about placing the blame totally on healthcare. For instance, Edward stated,

Well, I didn't realize that. He [doctor] said it's just a germ out there. We have all kinds of germs on our skin. Then MRSA, I thought that was just some big, bad germ that lurked in the dark hollows of the hospital and you don't get it [in the community]

The other subtheme of *how* learning indicated knowledge about MRSA was achieved primarily through two channels – people and media. Alvin made a very insightful observation during his interview – “You don't even know what questions to ask until you start learning about it.” People (social networks and healthcare professionals) were important as sources of information about MRSA. How people delivered their explanation to the participants for their understanding about the disease process was also critical. Likewise, the media (print and electronic) was critical as sources of information for the participants to grasp in their learning about different features of MRSA.

For this study, social networks consisted of family, friends and other peers; healthcare professionals consisted of a variety of people including primary care physicians, ER physicians, clinic physicians, infectious disease physicians, physician specialists (breast cancer, orthopedic), nurses (hospital, SHC, and home health), nurse

practitioners, physical therapists, physician assistants, and a dentist. Learning by the participants was primarily self-directed, experiential, and in some cases, transformational. Each will be discussed next.

A variety of family members played crucial roles in helping all of the participants learn about MRSA – mothers, spouses, children, siblings, in-laws, and cousins. This study is believed to be the first to document the actual relationship to the participant of those who provided information about MRSA. Aaron stated, “I honestly don’t know what I would have done if my mom wasn’t there...my mom was the one that kept pushing it and saying no, this isn’t right, it seems like there’s something else.” Many of the other participants stated similar strong comments. This finding about the crucial role that family members play in the acquisition of knowledge about MRSA appears to play the strongest role in this study. Other studies (Brinsley-Rainisch et al., 2005; Hawkings et al., 2007; and, McBrien, Felizardo, Orr & Raymond (2008)) document *personal experiences* and *lay persons* delivering information about MRSA as playing a minor role while others document primarily the strong role of media in influencing the MRSA learning of the public (Gould et al., 2009).

Friends and peers who were experiencing the same diagnosis of MRSA were another important layer to the participant’s learning from their social network. Nell talked with “other people that had experienced MRSA” and said,

If someone will mention MRSA or I know a friend or relative who has it, if I know the person well enough, I’ll ask some questions just to see what their course of treatment is. That’s how I began to learn that there are other things out there now.

A couple of participants, Irene and Nell, also discussed how they relied on their own personal knowledge to help their learning. This was usually linked to having *volunteered* in a hospital or another related aspect of a career that intersected with MRSA. These findings corroborate those found by Brinsley-Rainisch et al. (2005) who reported participants hearing about this issue from person(s) with staph or MRSA or a class or work-related training. Interestingly, I originally planned to interview those who had been given a MRSA diagnosis and those who experienced a *close encounter* with someone who had MRSA (e.g. a family member). It was believed that the learning experiences of these two types of participants would be different and deserved to be in different cohorts of study. While this study cannot document the actual *learning* of those close to someone who has MRSA, I believe it does contribute to the literature in the sense of how critical and crucial a family member or other member of the social network plays for the participants of this study.

Healthcare professionals also played a very important role in how the learning process occurred for each participant. Often, these professionals laid the groundwork for how the participants pursued their overall learning about the disease – ranging from pre-care to post-care of the MRSA infection. Additionally, they seemed to influence the participant's attitude and belief in what they learned about the infection. Every participant had direct interaction with a physician at some point in their MRSA experience. Alvin makes this point,

No, they [doctors] were good. We'd ask a question and they'd tell us what they knew. The more information we got together, the calmer we became... we're

getting feedback and we're giving them feedback about what we're going through. So, we're learning from this experience.

Brinsley-Rainisch et al. (2005) states that participants reported hearing about this issue from a health care provider (22%) but they do not report the importance of *back and forth* exchange of information or the creation of a safe environment for learning as several of the participants did in this study. Gould et al. (2009) and Hawkings et al. (2007) primarily report on the role of the media as being the prime channel for those in the public to gain knowledge about MRSA. This occurrence is also true of the nurses and other healthcare professionals in this study.

In contrast, interactions with healthcare providers sometimes did not help the participant with respect to learning. Mary talks about this phenomenon upon returning to the doctor,

...And that doctor was almost angry with me at how this was playing on my mind. I don't think he was angry in a medical vane, I think he was just upset by my being upset and that he could see that this had gotten to a point with me that he did not feel was appropriate. And he made me feel – when I asked for the retesting, he said, “I'm doing this just for you,” you know, instead of really kind of taking [anytime with me]...

Interestingly, each of the participants could cite both positive and negative interactions with the different healthcare professionals. So, while learning did occur via the various healthcare professionals for all in this study, in some instances an opportunity was missed because of the environment that was created from a negative encounter.

There were two main types of media identified in this investigation – print and electronic. Six (Aaron, Trene, Alvin, Becky, Nell, and Mary) of the participants utilized various print media to learn about MRSA. Usually, this was in the form of handouts or brochures from the healthcare environment. To a lesser extent, signage in hospitals and other medical facilities played a role in learning about precautions and hygiene with respect to an infection. Signage was discussed by other participants in regards to their quarantine experience in a hospital and specifically, Dora, Irene, Becky, Alvin, and Mary discussed how the recent swine flu scare signage raised awareness about infections in the general society as part of their learning opportunity. Mary also utilized a book on MRSA.

As expected, many of the participants also took advantage of electronic sources as vehicles for learning about their condition and the microbe. Trene, Alvin, Becky, Erin, Nell, and Mary all utilized a wide range of electronic media. All six of them used the electronic media, some more intensively than others. Some, like Trene, just “Googled” it, while others, like Alvin, “hit the internet really hard.” The primary sources were the CDC, the Mayo Clinic, and WebMD. Additionally, public service announcements, popular TV shows (Oprah, Dr. Oz) and special news shows (20/20 or 60 Minutes) were also utilized. The participants utilized these sources prior, during, and after their MRSA diagnosis. Interestingly, some of the older participants also mentioned electronic social networks as being part of their tools for learning.

The literature substantially documents the use of the media as a major channel for learning about MRSA, as well as many other acute and chronic diseases in both the healthcare and general public setting (Gould et al., 2009). Abbate, Giuseppe, Marinelli, and Angelillo (2008) document patient’s acquisition of knowledge, understanding,

attitudes, and experiences of HA-MRSA in Italy. Importantly, 69% reported receiving information about HCAI from the media, with only 15% reporting receiving information from health professionals. Gill, Kumar, Todd, and Wiskin report a high awareness of MRSA from U. K. patients and healthcare workers (94% & 100%, respectively), although for patients the most common source of information was the media (2006). Similarly, an English study found high levels of awareness and that the media is at least equal in prevalence to health care professionals with respect to information dissemination (Hamour, et al., 2003). Likewise, in the US general public Brinsley-Rainisch et al. (2005) and Hawkings et al. (2007) document that the media was found to be a main source of information about MRSA. The participants in this study documented the important contribution that the print and electronic media had on their learning and it appears that each was used equally.

All of the participants in this study adopted self-directed learning as the primary way to understand how MRSA was affecting their life. Knowles (1975) describes SDL as the ability of individuals to initiate, either alone or with the help of others, the diagnosis of their learning needs, formulation of their learning goals, identification of resources for learning, selection and implementation of learning strategies, and evaluation of learning outcomes. Each of the participants fit Knowles description of SDL with respect to their learning needs either by seeking the help of their health providers, social networks, and/or through the different types of media that was available to them (print and electronic). As an example, Alvin states,

*Don't be afraid to ask questions* [italics added]. Not just ask questions, but question the doctor. Ask them what they're doing, why they're doing it, because

that way you get educated in what to do also. If the doctor says you have MRSA, don't just put out both arms for them to do what they want to. Ask them about it, what's going to happen, how we handle this. That way you've got something to work with and you've got something to tell people when they ask.

Typically, after the initiation of learning through a healthcare professional, the selection of learning resources and formulation of learning goals occurred via their social networks and/or the media. The selection, implementation, and evaluation component of SDL occurred primarily through the *consistency of message* from whatever source the individual was using. For example, when participants used the internet before and during their MRSA infection, it was important to see a consistent message that could be compared to what their physician had told them. It was also important for the participants to utilize trustworthy sources (e.g. WebMD, CDC, Mayo Clinic, etc.) as compared to sensationalistic blogs. The participants were constantly comparing what they were learning to what the experts (healthcare, peers who had similar experiences with MRSA, etc.) had taught them. Becky discussed how the interaction with her healthcare provider was part of her comfort with the information she was gaining about MRSA. She states,

He was like I don't want to rush you – he made me very comfortable. Then giving me my own time, letting someone come with me, calling me a week later...not just once, like multiple times...I asked him a million questions about it, like how this, what's this...

Finally, the participants found that it was very important to have a *step-by-step* plan with respect to dealing with their infection. This feature characterized a learning and implementation strategy used by most individuals in this study.

Candy reports that most adult learning is SDL (1991). This study appears to support that finding, at least with respect to a learning effort associated with a serious health condition. This study supports the findings of several studies including findings by Caffarella (Merriam & Caffarella, 1999) that adults use SDL during a *constant learning mode* about a serious illness; Holland (1992) on the SDL learning efforts of individuals dealing with multiple sclerosis; and Hollingsworth and Scott (2008) on the SDL of a multiple kidney transplant recipient. The SDL in these types of environments, like this study, often include a catalyst around a diagnosis such as an individual being told of a MRSA diagnosis.

Transformational or transformative learning (TL) is about change. The change prompts a major shift in the way individuals see themselves or the world (Merriam et al., 2007). Mezirow's individual locus of TL theory (1981) describes four main parts of the TL process: experience, critical reflection, reflective discourse, and action. The experience is often set in motion by a *disorienting dilemma* such as a life threatening illness or death of a loved one. A MRSA diagnosis appears to have the characteristics of a disorienting dilemma for some, but not all participants in this study. The key component of TL – a major shift in one's self view or their view of the world – is the feature used in this study to identify TL.

In addition to SDL, Alvin, Edward, Nell, and Mary all had transformative experiences due to their MRSA journey. MRSA has had a major impact on each of these individuals, and I believe for Alvin and Edward's spouses too. It has affected their choices about work, travel, and other normal activities of life. It has influenced their health behavior with respect to caution and hygiene. Their experience with MRSA

affected them on many levels – involvement with the direct education of others and acting as advocates of educating others. Examples include, (a) Alvin and his wife helping a friend who was hospitalized with a MRSA bloodstream infection that almost died, and (b) both of them devoting time with others in their church and at a state park to tell their story and the lessons they had learned about MRSA. Each of these individuals has been affected on a cognitive and emotional level by their experience with MRSA and it has changed their worldview. Nell stated powerfully at the end of her interview, “I don’t believe I’m dying of multiple sclerosis, but I was dying of MRSA.” These types of MRSA experiences created dramatic shifts in how each of these four participants viewed their future with respect to their health and it gave them a deeper perspective about society and where it intersected with the broad problem of antibiotic resistant infections.

The findings of this study support two similar health related TL studies by Montoya (2008) on healthy lifestyle changes after a cardiovascular disease diagnosis and Baumgartner (2002) on TL with HIV/AIDS patients. This study closely aligned itself with several of the factors identified in the HIV study. TL occurred via (a) an appreciation for life and (b) an interaction via people (social networks, etc.) as being crucial to the learning process.

Health issues, such as public knowledge of MRSA, can be examined from a global lens with respect to the ecological perspective (Table 1) created by McLeroy and colleagues in 1988. The interaction between, and interdependence of, factors within and across all levels of a health problem is highlighted by people’s interactions with their physical and sociocultural environments in regard to a health issue. Two key concepts are found: first, behavior both affects, and is affected by, *multiple levels of influence*; second,

individual behavior both shapes, and is shaped by, the social environment (*reciprocal causation*). It appears that the participant's MRSA experience found in this study supports this perspective. Certainly, the behavior of individuals in this study was affected by multiple levels – physical, emotional, and self – in regards to learning strategies and, ultimately, their adaptation to MRSA. Further, their individual behavior was itself changed (personal hygiene, interaction with healthcare professionals, etc.) while also changing their social environment (healthcare arena, family, friends, broader society via print and internet) via their education efforts.

As mentioned in the diagnosis component, seven of the participants experienced feelings of being an *outcast*, a *leper*, or *embarrassment* associated with stigma by healthcare, family, or friends. These components can also be seen as having a place during the learning component of the MRSA model. The feeling of *perception by others*, *labeling*, or using *anchors*, to describe oneself with a MRSA infection may be interpreted in light of SRT. SRT allows one to study the passage of knowledge from scientific thinking, via the mass media, to lay thinking. It assesses new threats to a society by how they are constructed, with the media being a key player in the evolution of public thinking (Moscovici, 1984). Two key tenets of this theory are anchoring and objectification. Like Washer's study (2004) on SARS, many of the participants in this study used anchors like *superbug* or *flesh-eating bacteria* to link MRSA understanding with HIV or the current H1N1 (swine flu) scare. These anchors are links to the current media environment. Objectification coats an unfamiliar thing with more familiar images, symbols and metaphors that are easier to grasp (Moscovici, 1984). The process of objectification overlaps with that of symbolism (Joffe, 2003). This study supports

findings by Washer and Joffe (2006) on MRSA being the new ‘superbug’ and how its emergence has documented the failure of the golden age of medicine conquering disease. Likewise, this study supports their findings (2006) that MRSA is built around an *it could be you or me* set of assumptions played out in the media and that the blame for MRSA is laid at the doorstep of *why it spreads* instead of its *origins* (antibiotic misuse). Ultimately, the blame is placed on poor hygiene of the hospitals and mismanagement, a form of ‘othering’ that is inherent in SRT (Moscovici, 1984; Washer & Joffe, 2006). Numerous statements by the participants in this study laid the blame at the doorstep of the *dirty* hospital and *screwed up* healthcare arena or system.

Finally, it’s important to discuss several unique findings about this study in the arena of adult learning. There were four participants who were in a young adult group, with the remaining six approaching retirement or being retired. These two subgroups had commonalities across the themes and subthemes; however, there appeared to be a degree of apathy and passive learning in the younger group that was not as evident in the older group. This was especially identified in Aaron who relied heavily on his mother to “learn about MRSA for him.” His comment concerning how he would live his life regardless of health issues was very telling in this respect. The older group also exhibited more signs of reflective hindsight and an appreciation for life due to their encounter with MRSA. Perhaps, this contributes to why only the older group (four of six) experienced TL.

The majority of the participants acquired most of their knowledge and learning about MRSA after the diagnosis. However, three of the participants had either worked or volunteered in the healthcare environment prior to their MRSA diagnosis which influenced their actions towards learning and adaptation. Interestingly, a majority of the

participants also had a close family member or friend that was employed as a healthcare professional. This was unexpected, but obviously an advantage in regards to access of information. The participants self-described this advantage as a friendly environment with respect to asking questions and learning about MRSA. It is also important to mention that one participant, Dora, had some obstacles that arose during her experience – no access to the internet and other major health issues (traumatic brain injury from a car accident) – that hindered her learning in some aspects.

### *Adaptation*

While the adaptation component of the MRSA model follows the learning event, one should not assume that the process of adapting to MRSA was not a continuum of events starting as far back at the post-diagnosis event. In fact, one can think of a MRSA experience as sometimes living in two worlds – MRSA infection and post-MRSA. These participants consistently discussed swinging back and forth between these two worlds because of their worry about reoccurrences with MRSA. Adaptation is the second major theme in this study with subthemes of self-reliance, reliance on others, and MRSA reflections. Adaptation in this study can be interpreted by the impact MRSA had on the integration of the condition into the participant's life. The adaptation stage is also intertwined and supportive of the main tenets of SDL – initiation and diagnosis of learning needs, formulation of learning goals, identification of resources for learning, selection and implementation of learning strategies, and evaluation of learning outcomes (Knowles, 1975). As one learns more about a health issue, the individual often is able to manage a particular illness either alone or with some help.

As with any illness or disease, a diagnosis of MRSA is often associated with an adaptation to the disease or condition over time. As learning occurs, the individual often exhibits strategies and mechanisms to live with the challenges linked with having a health concern. The subtheme, self-reliance, which developed in many of the participant's stories, was about how they made decisions, managed the condition, and handled aspects of prevention. Being proactive and taking this illness seriously were common traits in this subtheme. Becky "asked a million questions" as a method to adapt to what was happening to her. Like the others, a consistent message from healthcare was crucial for the adaptation process. Nell believes that it's important to "ask some questions...that's how I begin to learn." Mary went as far as wanting to control her health. She said, "*I would rather kind of control what I can control within my own environment to the degree that I can control it* [italics added]."

Management of the condition was another contributing factor to self-reliance. All of the participants felt that it was important that they take care of themselves (physically and mentally) as a means of adaptation to MRSA. In many instances, these were behavior changes that ranged from minor (stop neglecting minor cuts and scrapes) to major (conducting incision and drainage procedure on oneself). The final component connected to self-reliance for adaptation to a MRSA infection centered on the prevention and control of the infection. Primarily, the participants discussed how their behavior and attitude changed towards hygiene, infection control, and the environment. Each of the participants talked about how their health *behavior* was more rigorous with respect to protecting themselves and others. Mary showed concern about "being a carrier and

transmitting MRSA to others.” Mary demonstrated how MRSA was transformative for her regarding life changing behavior (Merriam et al., 2007),

I mean these are things that – you know, I clean house every week and I change sheets and I change towels, but my husband and I don’t share towels anymore, we don’t share razors, we don’t even share toothpaste, you know, I don’t even share toothpaste with him or deodorant. We used to share deodorant, you know... *It has changed my life in those regards* [italics added]...

The participant’s ability to be self-reliant was a critical adaptive aspect in this study.

Reliance on others was the strongest adaptive process in this study. The relationships that participants formed with family, friends, and healthcare professionals were a crucial component to the adaptation process involved with MRSA. The message of others helping them through the MRSA experience was echoed by all participants many times in this study. Immediate family (mother for Aaron and daughter for Irene) or spouses (Alvin and Edward’s wives) played huge roles in everyday events and in regards to emotional support. The participants’ reliance on and trust in healthcare professionals (non-related) was also evident in several of the interviews. As previously mentioned, Becky felt her learning was enhanced because of the comfortable environment that was created by her doctor. She relied on her patient-doctor interaction as a mechanism to deal with and adapt to her MRSA infection. She was very grateful for his patience and understanding manner while she asked “a million questions” and for his thorough follow-up with her on multiple occasions. Likewise, this trust was important for Trene because it helped her to “focus on her problem” and adapt to the situation at hand.

Finally, each of the participants also took advantage of the investigator's expertise to learn about different MRSA topics during the interview session when the opportunity presented itself. At multiple points during interview sessions, the participants would inquire about MRSA information from the investigator. Edward specifically mentioned that the "interview felt like therapy" for he and his wife because they were able to unload some of their anxiety and fear about reoccurrences or other concerns with MRSA. In this way, the participant was using the interview session as a strategy for adaptation.

The final component of adaptation centered on the participant's reflections about their MRSA journey. As might be expected, those who had a more severe MRSA infection or had multiple reoccurrences with the infection were often more insightful about their journey. Reflection occurred primarily when the participants were questioned about (a) living with MRSA and how it may have changed their life, (b) advice they would give to someone diagnosed with MRSA, and (c) advice they would give to healthcare to help individuals diagnosed with MRSA. These reflections were often cited by the participants as being helpful for their understanding and adaptation to their MRSA experience.

Living with MRSA seemed to influence the participants to become advocates for educating others about their experience. By educating others about this growing public health threat, the participants felt like it helped them to *warn others* while also letting them work through the adaptive phase of their infection. Nell called herself a *crusader* when it came to warning others about MRSA. She always carried hand sanitizer and was "always willing to share hand sanitizer with anyone who will use it, especially before meals and that type of thing" She wanted to be able to "offer them my experience"

because she did not want others to suffer with MRSA a second or third time like she had experienced. Mary also was willing to share her story with anyone to help them take it seriously. Each of the ten participants was in some way, large or small, an advocate for educating others about the dangers of MRSA by way of their journey. By being active in telling their story, the participants found it therapeutic for their own healing.

The participants all discussed how important it would be for others diagnosed with MRSA to be *wary* of what they learned from healthcare about MRSA – to be proactive in their questioning of healthcare professionals. They also all gave advice about risk factors associated with MRSA (athletics, etc.) and the correct medical testing that needed to be done to identify the infection. Alvin had specific advice for anyone diagnosed with MRSA with respect to the seriousness of the infection and the critical importance about the testing that must be done. Because Alvin was immunocompromised (lymphoma), he had reoccurrences with MRSA and had some bad experiences with ER physicians. He states,

First of all, make sure that's what you're dealing with. If they think it is MRSA, do the culture. We've had two that didn't... So, make sure they know what they're dealing with. And second, this is my understanding and if it's incorrect you need to set me straight, my understanding is they have to do the culture to know what antibiotics will work with that strain of MRSA.

Erin discussed the issue of proper antibiotic usage. She would ~~te~~ll them definitely don't skip on the pills...the antibiotics...even if you think your infections getting better, that it's a stronger infection than anything normal so you have to definitely take everything that they give you" and to use proper hygiene at all times with hand

washing and wound treatment. All participants echoed these *lessons* that they had learned and wanted to share with the general public.

Advice for the healthcare professional and the medical arena was an important way for the participants to voice what they had experienced with their MRSA walk. Most of the participants discussed how healthcare professionals could improve the interaction between the two parties by offering examples of what they felt had worked or not worked for them during their experiences. By doing so, the participants all reiterated that the reflective advice was helpful to them – that maybe our story will help others. Nell thought it was important to lobby healthcare about the importance of a sterile environment while Mary, and many others, discussed how important it was for physicians to have what she called the ability to “counsel with compassion.” Becky wanted “options, support, a plan, encouragement to do research, recommendations for other opinions” from healthcare. All echoed that the *consistent message* from healthcare about MRSA was necessary and critical in their becoming comfortable with the diagnosis and entering an adaptive state with the illness. Finally, several of the participants (Dora, Irene, Edward, and Nell) also discussed how spirituality and prayer helped them “get through” their respective MRSA experiences.

The MRSA model of learning and adaptation concludes with a transition that appears to be a subtle change within the adaptation component. It appears that as participants begin to “help others” through education and advocacy – by telling others about their MRSA journey – that the process is coming to disclosure, and for some, closure.

### *Conclusions*

There were five conclusions based on the above mentioned findings and links to extant literature. The five conclusions are: (a) there appears to be a common model of *MRSA learning and adaptation*; (b) the nature of adult learning is primarily self-directed, and for some, transformational; (c) the major content learned was general MRSA information, care and prevention, and antibiotic resistance issues (d) the nature of adaptation is interconnected with self and others; and (e) a consistent message with a step by step plan of how to deal with MRSA from healthcare is important upon diagnosis.

The experiences of the ten participants in this study have emerged to create a common model of how a person with MRSA in the general public learns and adapts to the infection. The model is not static, but rather flows in a continuum; however, reoccurrences of MRSA may drop the individual upstream in the model. The model (Figure 1) is initiated with a pre-diagnosis. In order, the model continues with diagnosis, post-diagnosis, learning, adaptation, and disclosure/closure. It is not the intent of this investigation to align this model with the plethora of other health models in the literature, but rather to identify a possible way of understanding how those in the general public deal with MRSA. Of particular interest is the unexpected finding of how this study aligns with a study of the experiences of women with heart disease conducted by Murray, O'Farrell, and Huston (2000) in which the pre-diagnosis stage was not expected and in which the participants were often misdiagnosed by their physicians. None of the participants in this study linked their pre-diagnosis experience with triggering a response to learn about what was happening to them. Likewise, the diagnosis stage appears to have a link with the emotional self in regards to learning (Clark & Dirks, 2000; Dirks, 2001).

It is clear from this study and from the literature that the nature of adult learning during a MRSA experience is self-directed, and for some transformational. All ten of the participants satisfy the key tenets to SDL (Knowles, 1975) and support the previous findings that most adult learning is self-directed (Candy, 1991). Likewise, a few of the participants also experienced a TL experience with MRSA. Primarily, Mezirow's individual locus of TL theory (1981) consisting of four main parts: experience, critical reflection, reflective discourse, and action are corroborated by the findings of four participants. For all participants, a MRSA diagnosis was a catalyst and/or a disorienting dilemma that is associated with SDL and TL, respectively. Further, learning occurred via two channels – people (social networks and healthcare professionals) and media (print and electronic). Lastly, an association with SRT (Moscovici, 1984; Washer & Joffe, 2006) was found in regards to how participants with MRSA were influenced by the media in regards to anchors and objectification of the condition.

The participants had a wide range of knowledge about MRSA based on a number of factors discussed previously. Key learning content was associated with the difference between regular staph and MRSA, the actual care and prevention of MRSA to self and transmission to others, and how antibiotic resistance developed to MRSA. This content was in context of the individual participant. For instance, some participants had one MRSA infection while others had multiple reoccurrences. Also, some participants were healthy while others were severely immunocompromised. Obviously, these factors led to different experiences with learning content due to the individual severity of infection. The participants often had poor knowledge about antibiotic resistance in general prior to

the MRSA diagnosis which supports the literature associated with both HA-MRSA and CA-MRSA (Gould, 2009).

Participants in this study underwent an adaptation process that was interconnected with reliance on self and with others. The adaptation process supported the tenets of SDL as presented by Knowles (1975) and other studies previously described. The participants utilized both self and others in how they learned to adapt to the MRSA journey.

However, a reliance on others was the strongest adaptive feature. Likewise the adaptation component in this study supported the tenets of TL with respect to how a few participants had a dramatic shift in their life view (Mezirow, 1981).

Lastly, a strong message for healthcare emerged from the participants of this study. Most all individuals had important advice for professionals about the nature of a *consistent message* for a *MRSA plan*. The embedded features of this plan were that people make the difference in these life-changing diagnoses. Likewise, all participants echoed the need for consistency of MRSA information and a step-by-step plan to manage the condition.

### Implications

The implications for practice and research based on the literature and results of this study indicate a need to address issues of how the general public discovers, learns, and adapts to antibiotic resistant infections, especially MRSA. Likewise, this study emphasizes the critical importance of informing healthcare professionals and health educators (e.g. universities, schools, and other related institutions) about the need for better programs of patient education and continuing education surrounding the pre and post diagnosis of MRSA infections.

*Practice*

The literature indicates that the both HA-MRSA and CA-MRSA are serious public health issues in our society. The CDC reports that in the past few years MRSA has become a major health concern. It appears that more people in the US now die from MRSA, especially hospital acquired, than from HIV/AIDS (CDC, 2009; Klevens et al., 2007). The literature also documents numerous studies showing low levels of public knowledge and understanding of antibiotic resistant infections (Gould et al., 2009). These two issues, MRSA incidence and low levels of literacy about antibiotic resistant infections in the general public, are on a collision course. The health implications for society are startling and this brewing public health storm should be a wake-up call for all involved in the prevention and treatment of MRSA. A plan should be instituted to amend current patient education programs about antibiotic resistant infections. Particular attention should be paid to the following areas: (a) the patient-healthcare provider interaction, specifically to create an open and non-threatening environment for learning to occur, (b) the delivery of critical information about the importance of having a MRSA diagnosis based on *laboratory culture and antibiotic susceptibility testing*, (c) specific education on *what a MRSA infection looks like*, including images/pictures and *MRSA stories* for patients, (d) the use of podcasts, digital video, and other electronic media (e.g. Facebook) to provide patient education beyond the initial MRSA diagnosis, (e) specific education about infection care, control, and prevention to themselves and others, and (f) guidance for individuals about sources of information and the credibility of sources. In regard to the use of podcasts and other electronic media, the message should be formed with a combination of stories from MRSA survivors and healthcare professionals to build

a strong, synergistic media tool. Through the use of podcasts and other media, healthcare professionals can address the issue of a patient's readiness to learn when they are overwhelmed with educational material at initial diagnosis. For instance, a podcast would allow the patient to go back and review educational material after the shock of a MRSA diagnosis has lessened. Further, healthcare professionals (physicians, nurses, physician assistants, physical therapists, etc.) involved in the direct care of MRSA related infections, pre and post diagnosis should be required to participate in continuing education that includes the patient education objectives previously described and instructed that continuing contact with the patient after diagnosis is crucial in patient understanding of care and prevention.

Likewise, public health authorities and professionals at all levels (national, state, and local) are urged to implement a MRSA media campaign targeting the general public. The public health campaign message should include the objectives previously mentioned for patient health education. Additionally, an emphasis should be made on the importance of peer to peer education within the social network of families/friends. The participants in this study all emphasized the critical nature of talking to others that had already experienced MRSA with respect to getting an insider's perspective on lessons learned. Finally, the participants in this study appeared to utilize self-directed learning to challenge the healthcare system in regards to what content they needed about MRSA and how they might best learn to understand the disease. It may be possible to build on this desire to impact the healthcare system by inviting individuals who have experiences with MRSA to join a healthcare associated advisory committee.

*Research and Theory*

Study findings imply the need for further research on the subject. Antibiotic resistant infections will continue to increase, both in numbers and types, if current predictions hold true. Research on this subject will help in better defining and understanding how the lay public accesses, interprets, learns, and adapts to MRSA infections and will aid healthcare professionals and health educators in planning for continuing education and public health education programs. Additionally, it is important to continue to document and capture the stories and lessons learned from the general public. These stories are underreported in comparison to accounts from the healthcare environment and add important, often overlooked, aspects about MRSA infections and its impact on society. Research on this subject will continue to add to (a) the knowledge base and potential development of theory re acquisition of knowledge about MRSA within the general population, (b) the identification of learning strategies and mechanisms of those individuals who find themselves impacted by MRSA, and (c) the identification of potential strengths and weaknesses in publicly available information about MRSA. Likewise, research may add to existing explanations for prevention and control of outbreaks in the general public and why other public health campaigns may have succeeded or, more importantly, failed. Finally, research on this subject can be used as an example to build better communication about adaptation to MRSA between the healthcare-medical environment and the general community.

The results of this study add to the overall body of knowledge concerning how adults learn and adapt to a MRSA infection. Importantly, I believe it is the first study to document a model for adult learning and adaptation to this growing healthcare threat in

the general public. As with many health related issues, both acute and chronic, one typically is faced with a need to learn about their condition for a variety of reasons – care, prevention to self and others, and adaptation physically and emotionally. Knowles' (1975) theory of SDL is primarily focused on how individuals direct their own learning. The participants in this study all satisfy the key tenets of SDL in regards to their experience with MRSA. Likewise, a few of the participants satisfy Mezirows' (1981) individual locus of TL theory. For all participants, a MRSA diagnosis was a catalyst and/or a disorienting dilemma that is associated with SDL and TL, respectively.

Further, learning occurred via two channels – people (social networks and healthcare professionals) and media (print and electronic) and an association with SRT (Moscovici, 1984; Washer & Joffe, 2006) was found in regards to how participants with MRSA were influenced by the media in regards to anchors and objectification of the condition. This study corroborated findings of these studies and previously described studies (Gould et al., 2009) with respect to how the media is a common source of information for the general public. However, this study suggests that both people and media are used roughly equally in regards to how the public accesses information about MRSA. Regardless of the sources used, this study supports the findings of others that misinformation in the media and elsewhere help to amplify the sometimes irrational and exaggerated concerns about HCAs.

### Recommendations

The findings of this study yield recommendations for practice and further research on the subject of knowledge, learning, and adaptation to MRSA infections for adults. As an aging population becomes more prevalent and their healthcare needs continue to

increase, meeting their needs through program adjustments and continued research will benefit all of the stakeholders involved.

### *Practice*

There are several recommendations for practice based on the research findings that can influence patient and healthcare education surrounding a MRSA infection:

1. Healthcare providers should implement new continuing education programs, or adapt current models, to address the patient-healthcare professional interaction.

Participants in this study stressed how negative encounters with healthcare professionals postponed their very nature of learning about their condition, while positive encounters jumpstarted their learning stance on all aspects of MRSA.

Specifically, participants said that they need an open, non-threatening relationship so that they can ask questions without fear of being made to feel unimportant.

2. Healthcare providers should implement new continuing education programs, or adapt current models, to address the need to provide a *consistent message* and a *step-by-step* plan about MRSA from pre diagnosis and continuing through diagnosis to post diagnosis. The participants in this study discussed how *they didn't even know what questions to ask* about MRSA when they were diagnosed and often healthcare professionals did not guide them in this aspect. The healthcare professionals often only asked them if they had any questions which the participants indicated did not help them. They need prompts and perhaps specific education about infection care, control, and prevention to themselves and others. This should include *what a MRSA infection looks like*, including images/pictures and *MRSA stories* for patients.

3. Healthcare providers and public health educators (e.g. universities, schools, and related institutions) should implement new patient education programs and health education initiatives, respectively to address the delivery of critical information about the importance of having a *MRSA diagnosis based on asking for a laboratory culture and antibiotic susceptibility test*. A majority of the participants in this study were misdiagnosed in their initial visit to their healthcare providers due to empirical diagnosis and often, incorrect prescribing of an antibiotic. It is imperative that the general public be made aware of the importance of being proactive in asking for a laboratory diagnosis of these critical infections. A misdiagnosis often leads to high morbidity and mortality. Likewise, healthcare providers should be adamant that infections even resembling MRSA should be diagnosed on laboratory data, not best guesses. Indeed, all infections where possible, should be based on current laboratory testing and data!

### *Research*

There are several areas of potential research that can add to the body of knowledge concerning the phenomenon of adult learning in the area of antibiotic resistant infections, specifically MRSA infections:

1. A comprehensive study, perhaps a mixed method model, which includes interviews and questionnaires involving those who have had *close encounters* with MRSA (e.g. spouses, children, and siblings of those with MRSA), may help us to understand why some individuals are active versus passive learners, especially where it intersects with being proactive about one's health.

2. For this study, only participants who had recently been diagnosed with MRSA (at least a month prior but not longer than year) were interviewed. Perhaps research using a longevity model may give us insight into how people in the general public deal with the concern of MRSA reoccurrences which many participants in this study lived in continual fear of happening to them.
3. For this study, the participants all had some college education, with a majority of them having undergraduate and graduate degrees. Perhaps more research regarding the experiences of adults without any college education will offer additional insight and help public health institutions and healthcare professionals develop better education programs for individuals. Are individuals with less formal education affected more by the media? Are they less likely to ask the right questions of their healthcare providers? Are they less proactive in their interactions with healthcare professionals? Why?
4. For this study, two subgroups emerged based on age – a young adult group and an older retirement or approaching retirement group. Target research focusing on those in their 30's and 40's may give us a more complete understanding of adult learning strategies for dealing with MRSA.
5. This study looked at a relatively small number of participants (10), the majority of which were Caucasian. Future research should focus on a larger and more ethnically diverse group of men and women of lower incomes and education.
6. This study uncovered an unexpected pre-diagnosis stage connected to physical symptoms, especially with respect to how pain and misdiagnosis impacts learning.

Research focused on this component may help us to better understand issues of *turning off* or *postponement* of learning and adaptation.

7. This study uncovered the importance of the *emotional self* (Clark & Dirkx, 2000; Dirkx, 2001) in regards to how those diagnosed with a MRSA infection learn and adapt. Further research on this particular topic may provide deeper insight into why and how people deal with significant health issues.
8. A look at the aspect of religion, prayer, and spirituality may give us an understanding of how some people adapt better than others. How does adaptation differ among those who report relying on spirituality as part of the process?
9. A comprehensive study focused on the media and aspects of mass communication and how it influences learning and adaptation will help us to better understand the impact of *stigmatization* along with the delivery of health *meanings* to the general public. Perhaps it may be used as an example to build better communication strategies about adaptation to MRSA between the healthcare-medical environment and the general community.

### Final Thoughts

We are living in an era of rapidly growing emerging and reemerging infectious disease – both in the healthcare environment and in the general community. Based on the literature and this study, explanations for prevention and control of outbreaks in the general public and why other public health campaigns may have failed appears to be linked to *what* and *how* people learn about MRSA. The implications for healthcare providers and health educators to implement new and effective strategies for people to learn about their health conditions may be more pertinent than ever. The findings of this

study should be utilized in the development of specific health education and promotion activities for those who are at greater risk for acquiring MRSA or who are currently colonized. It can be used to aid in the identification of antibiotic resistance misinformation and poor educational trends occurring in the general public, assist healthcare officials in the control and prevention of MRSA with respect to risk factors, and help one to gain an understanding of the educational needs of individuals who have experienced MRSA infections and their subsequent actions to deal with this condition. This research contributes to the fields of health education, public health, health social science, infectious disease, and epidemiology. By understanding individual perspectives on MRSA, we can try to better translate personal health knowledge construction to public health personnel and policymakers. Thus, the findings in this study should be used to build better planned and more successful public health campaigns against antibiotic resistance in general, and MRSA in particular.

Instead of separating the person from the *bug* (MRSA), I attempted to draw on the *stories* of my participants in this study. As a clinical laboratorian, I have conducted research using primarily quantitative design to uncover important associations between MRSA and risk factors as well as the incidence and prevalence of disease. Importantly, this study offered a holistic approach to *get at* the underlying needs of individuals who have lived through a MRSA infection. Their stories were important and by combining them with insights from the literature, I believe it will help advance health education theory and public health prevention and control efforts in the area of antibiotic resistant understanding. Ultimately, I believe the findings of this study can be used to develop MRSA health education materials and approaches for those who are diagnosed with the

condition and all who are involved in the fight against the growing resistance of microorganisms.

APPENDIX A – RECRUITMENT AND SCHEDULING FLIER

***MRSA Knowledge, Learning, and Adaptation Study***

Be part of an important public health study.

- Are you over the age of 18?
- Have you been diagnosed with Methicillin Resistant *Staphylococcus aureus* (MRSA) within the past year?

If you answered YES to these questions, you may be eligible to participate in an important research project.

The purpose of this study is to investigate how people in the community who have MRSA develop their understanding and knowledge about their condition. The intention is to explore how members of the general public who have a “need to know” discover, learn, and adapt to MRSA.

Participants will receive an incentive payment. No medication will be given.

Participants will be interviewed about their MRSA experience for 1-2 hours. A potential follow-up interview may be required.

Adults over the age of 18 with a diagnosis of MRSA at least one month prior to the interview and within the past year are eligible.

This study is being conducted at Texas State University, 601 University Drive, San Marcos, TX 78666 USA

Please call Rodney Rohde at (512) 245-2562 or email at [rrohde@txstate.edu](mailto:rrohde@txstate.edu) for more information.

*This study has been approved by the Texas State University-San Marcos Institutional Review Board (IRB 2009z4233)*

## APPENDIX B – LETTER OF INTRODUCTION / CONSENT FORM

IRB# 2009z4233

### **Purpose**

The purpose of this research study is to find out how people learn and adapt after they have been diagnosed with a resistant form of a bacterium called *Staphylococcus aureus*, often referred to as MRSA or “mersa”. My name is Rodney Rohde and I am a Ph.D. student in the Education Department (Adult Professional Community Education) at Texas State University – San Marcos. I am also an Associate Professor at Texas State in the Clinical Laboratory Science Program. You are being asked to be in this study because you are from the general community, an adult above the age of 18, and have been told you have MRSA. I hope to have 10-12 people in this study. If you have any questions, please ask me. You can contact me (512-245-2562, [rrohde@txstate.edu](mailto:rrohde@txstate.edu)) or my advisor, Dr. Jovita Ross-Gordon (512-245-8084, [jross-gordon@txstate.edu](mailto:jross-gordon@txstate.edu)).

### **Voluntary Participation**

Participation in this research project is completely voluntary. **You** are deciding if you want to be a part of this project. You should be over the age of 18 and not involved in the healthcare industry. You will be asked to participate in an interview which will be audio recorded. This will take approximately 60 to 90 minutes of your time. You may also receive a follow-up phone call or email at a later date to clarify your answers from the interview or possibly to ask a few additional questions. You can choose not to participate in this study. Just tell me that you do not want to participate. If you decide to participate now and later decide you don’t want to remain in the study, that’s okay. In that case, I will not use your interview information. If at any time during the study, you feel uncomfortable you may quit. Participation is entirely voluntary and you may withdraw from the study at any time without prejudice or jeopardy to your standing with this university or any other organization.

### **Confidentiality**

I will be the only one who knows you were in this study. I will not share your name with anyone. Once all of the interviews are completed and the data is analyzed, my dissertation will be based on the study and further educational conference papers or professional journal articles may be generated. No indications of your actual identity will be made in any of these documents. Pseudonyms will be used for the participants in an effort to preserve your confidentiality. I will change any identifying information or revealing details. However, if you are interested in the findings of this research study, a

summary of the findings will be provided to you if requested. You may choose to offer your email as a means of obtaining the completed results. Your email address will not be used to link you to the results. The audio tapes will be erased within 12 months. Should you decide to, you may withdraw from the study at any time.

### **Potential Benefits and Risks**

It is anticipated that your participation in this project will be meaningful and rewarding to you and will require no longer than approximately one to two hours of your time in the initial interview and any follow-up. In addition, you will be helping my and others' understanding of the learning strategies and knowledge building of participants with a MRSA diagnosis. It may provide me with the information needed to construct a model for better control and prevention of this condition. Little or no risk to you is anticipated, although it is possible you may find it difficult to discuss personal medical issues. I have 16 years of public health experience and will do my best to help you feel comfortable discussing these issues. This study will be supported financially by a grant I received from the American Society of Clinical Laboratory Science (ASCLS). If you decide to participate in this study, you will receive \$100.00 for your time (\$50.00 for the first interview and the remaining \$50.00 for a follow-up interview, if one is needed).

### **Contact Information**

If you have any questions about the research, your rights, and/or research-related injuries to participants, please contact the IRB chair, Dr. Jon Lasser (512-245-3413 – [JL@txstate.edu](mailto:JL@txstate.edu)) or the OSP Administrator, Ms. Becky Northcut, at 512-245-2102.

If you have any questions or concerns about this project, please feel free to ask me now.

Thank you for your consideration for participation in this research project. If you agree to participate, please bring this authorization form to the interview session. You will be asked to sign the authorization notice below at that time.

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**Authorization:** I have read and understood the description of the above study. I have asked for and received satisfactory explanation of any language that I did not fully understand. I agree to participate in this study, and I understand that I may withdraw my consent at any time. I also understand that the data collected from the interview is intended to be used strictly for analytical, research and educational purposes and I give my permission for release of possible quotes from the interview in the public domain, without my name attached as outlined above. I understand that I will be compensated for my participation as detailed in the above consent form. I have received a copy of this consent form if requested.

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Signature of participant

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Date

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Print name of participant

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Signature of researcher

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Date

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Print name of researcher

## APPENDIX C – INTERVIEW GUIDE

1. Tell me about when you were first diagnosed with MRSA. How did you learn about this and what happened next? [experience and learning]
2. Would you explain how you tried to get a better understanding of MRSA after your diagnosis? What methods did you use to learn more about it? [sources]

### *Possible Probes*

- *How information sources influence decision making process*
- *Obstacles and strategies used to overcome them*
- *Role of media as information source*
- *People as sources of information (lay and professional)*
- *Other sources?*

3. What have you learned about MRSA? [knowledge]

### *Possible Probes*

- *What does the word infection mean to you?*  
*(Risks, how contracted, bodily reaction)*
- *Tell me what you understand about bacterial resistance.*  
*(Why it occurs, consequences)*
- *Connection between antibiotic use and spread of infections like MRSA*
- *Control and prevention of resistant infections like MRSA*

4. In what ways do you think your MRSA diagnosis has influenced how you go about making decisions regarding your health? [adaptation and reflection]

*Possible Probes*

- *Usual decision making process?*
- *Differences in decision making style or strategies for health-related life decisions*

5. How have you learned to live with MRSA? [adaptation and reflection]

*Possible Probe*

- *What has helped you come to terms with being MRSA positive?*

6. How has MRSA changed your life? [reflection and closing]
7. What advice would you give to a person you met who had just been diagnosed with MRSA? [experience, learning, sources, adaptation]
8. What advice do you have to offer to the health care arena to help individuals diagnosed with MRSA? [experience, learning, sources, adaptation]

APPENDIX D – CROSS REFERENCE MATRIX

<b>Research Questions</b>	<b>Data Collection Sources</b>	<b>Subject Category</b>
1. How do participants construct knowledge about MRSA?	<ul style="list-style-type: none"> <li>• Opening introductions</li> <li>• Interview guide question 1</li> </ul>	<ul style="list-style-type: none"> <li>• Opening</li> <li>• Experience</li> <li>• Learning</li> </ul>
1a. How do participants who have MRSA describe their experiences with learning about MRSA?	<ul style="list-style-type: none"> <li>• Interview guide question 1</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> </ul>	<ul style="list-style-type: none"> <li>• Experience</li> <li>• Learning</li> </ul>
1b. How do participants acquire their knowledge about MRSA?	<ul style="list-style-type: none"> <li>• Interview guide question 2</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> </ul>	<ul style="list-style-type: none"> <li>• Sources</li> </ul>
1c. What understandings do participants have of MRSA and antibiotic resistance?	<ul style="list-style-type: none"> <li>• Interview guide question 3</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge</li> </ul>
2. How do people adapt to their condition?	<ul style="list-style-type: none"> <li>• Interview guide question 4</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptation</li> </ul>
2a. What strategies for living with MRSA are apparent among those who have a diagnosis of this condition?	<ul style="list-style-type: none"> <li>• Interview guide question 5</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> </ul>	<ul style="list-style-type: none"> <li>• Adaptation/Reflect</li> </ul>
2b. What factors enhance or detract one's ability about this disease?	<ul style="list-style-type: none"> <li>• Interview guide question 6</li> <li>• Interview guide question 7</li> <li>• Interview guide question 8</li> <li>• Closing remarks</li> </ul>	<ul style="list-style-type: none"> <li>• Reflect/Closing</li> </ul>

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## VITA

Rodney Elton Rohde was born in Smithville, Texas, and graduated from Smithville High School. He attended Texas State University-San Marcos (formerly SWT) and graduated in 1990 from Texas State University-San Marcos, with a Bachelor of Science Degree in Microbiology. He graduated with a Master of Science in Biology (emphasis in virology) in 1992 from Texas State. He worked as a public health microbiologist and molecular epidemiologist at the Texas Department of State Health Services – Bureau of Laboratories and Zoonosis Control for a decade. In 2002, he became an Assistant Professor in the Clinical Laboratory Science Program at Texas State. He has certifications as a Specialist in Microbiology, Specialist in Virology, and Technologist in Molecular Biology from the American Society of Clinical Pathology. He also became an Associate Adjunct Faculty of Biology at Austin Community College in 1995 and continues to work there. He became an Associate Professor in 2006, the same year he entered the Ph.D. program with the College of Education at Texas State University-San Marcos and in the summer of 2010 completed his doctoral degree in Adult, Professional, and Community Education.

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