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# The Experience of Suicidal Ideation in Adults with Adhesive Arachnoiditis

Kathleen J. Haynes  
*Walden University*

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# Walden University

College of Psychology and Community Services

This is to certify that the doctoral dissertation by

Kathleen Jean Haynes

has been found to be complete and satisfactory in all respects,  
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the review committee have been made.

Review Committee

Dr. Susan Marcus, Committee Chairperson, Psychology Faculty

Dr. Tracy Masiello, Committee Member, Psychology Faculty

Chief Academic Officer and Provost  
Sue Subocz, Ph.D.

Walden University  
2025

Abstract

The Experience of Suicidal Ideation in Adults with Adhesive Arachnoiditis

by

Kathleen Jean Haynes

MS, Walden University, 2012

BA, Bridgewater State University, 1980

Proposal Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

February 2026

## Abstract

Suicide is the 11th leading cause of death in the United States. Chronic pain has been linked to death by suicide, and a considerable amount of research has examined how conditions that produce chronic pain increase the risk of SI and suicide attempts. Adhesive arachnoiditis (AA) produces chronic, intense pain and has not been well-studied. It was thought to be a rare condition, but the number of cases has grown dramatically in recent years. The purpose of this interpretative phenomenological analysis (IPA) study was to explore the experience of SI in individuals with AA. The interpersonal theory of suicide was used to guide the development of the interview guide and analysis plan. Eight participants from across the United States were interviewed. Analysis of participants' stories revealed that AA exists in the lived experience of relentless pain. Common themes were found in (a) the expression of SI over time, (b) perceived burdensomeness, (c) escape from pain, and (d) deterrents. SIs varied depending on the amount of pain and discomfort being experienced and was clearly linked to pain management and fear of losing the medications needed to experience a semblance of normal daily living. These findings can be disseminated to improve understanding of how people with AA live with chronic pain and self-manage SIs. Implications for positive social change include contributing to practitioners' clinical understanding of AA, educating them on how to better support their patients, and fostering compassion among caregivers, family, and friends. The results of this study may be disseminated to people living with AA to validate their experiences and desire to be heard.

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## Dedication

This study is dedicated to my mom, Genevieve Haynes, one of COVID-19's victims. Moms lived through my battle with this disease I write about, through its difficulties, giving me strength to battle it and persevere no matter how it ravaged my body. She insisted I finish my degree despite her own health battles, not wanting to be the reason I sacrificed my dream for her health. Moms, this one's for you. The little engine that could, would, and as I finish this part of the journey, I hope you know how much you meant to me on this journey, how much I love you, and continue to do so.



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To Forest Tennant, MD, mentor and friend. Your never-ending support to those who are afflicted by this horrific disease is firm and unwavering. All the participants in this study have a connection to you, your reach is far and wide. There should be a way to teach all medical personnel about AA and how to diagnose and treat it. The world would be a much better place if there were more physicians like you, so that those of us who endure would find solace in knowing more than one man was capable of easing our pain.

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## Chapter 1: Introduction to Study

I conducted this qualitative study to understand the lived experience of suicidal ideation (SI) in adults who live with Adhesive Arachnoiditis (AA). Suicide is the 11th leading cause of death in the United States (Racine, 2014; World Health Organization (WHO), 2010, 2014; IHME, 2024) and fourth in the world (WHO, 2010, 2014). Over 62 million people worldwide have died by suicide (WHO, 2019). More than 49,000 of those suicides were in the United States (CDC, 2023).

AA, once a rare disease, has emerged in modern times to affect what is estimated to be millions of adults. The disease produces intense chronic pain that interferes with physical, mental, emotional, and social well-being (Aldrete, 1980; Tennant, 2019, 2021, 2022). Like other chronic pain conditions, the medical sequelae and consequences have been well-studied. What has not been addressed is how consequential the challenges in daily life are, particularly on how adults with AA experience and reconcile SI.

In the following chapter, I will discuss the background, problem statement and purpose of the proposed study. The conceptual framework and how it relates to the proposed study's approach is discussed, as is nature of the study, definitions used, the assumptions, scope, and delimitations. The chapter ends with the study limitations and the potential significance of contributions to the body of knowledge and professional application.

### **Background of the Study**

Suicide is the 11th leading cause of death in the United States (Racine, 2010, 2014; IHME, 2024).and fourth in the world (WHO 2010, 2014). Understanding SI, the

precursor to suicide attempts and lethal suicide, is of prime importance in stopping lethal suicide (Van Orden et al., 2010). Research in SI has grown considerably in the last 15 years (Beşirli et al., 2019; Joiner, 2009; Kirtley et al, 2020; Racine et al., 2014).

Furthermore, as adult chronic pain has reached epic proportions, concern about SI in this population is of great concern from both research and treatment perspectives. These and other studies call for more research on the experience of SI in chronic pain patients.

AA is a condition that is characterized by chronic pain, which is a risk factor for suicide. SI has not been studied in this population, although one early study made mention of AA patients experiencing SI without further examining the phenomena (Anderson & Sumner, 2000). As more adults are diagnosed with AA, understanding the experience of SI in individuals who live with AA is an important area to address in research and in practice.

### **Problem Statement**

Chronic pain, regardless of the type, is a risk factor for suicidality (Beşirli et al., 2020; Calati, et.al, 2015; Kirtley et al., 2020; Petrosky, et al., 2018; Racine, 2018; Triñanes, et al., 2015; Wilson et al., 2017). In 2018, the CDC reported that 20.4 % of U.S. adults experience chronic pain, and 8.0 % of adults experienced “high impact” pain, defined as “chronic pain that frequently limits life or work activities” (Dahlhamer, et al., 2018). This study further reported that the direct medical cost of chronic pain is about \$560 billion (about \$1,700 per person in the US) every year. In addition to physical suffering, many studies have noted the financial and emotional costs of those suffering from chronic pain. Twenty to 30% of the world’s population has fallen victim to chronic

pain (Aldrete, 2000). Deaths attributable to suicide are two to three times more likely to occur when chronic pain is involved (Racine, 2017).

There is a call for more research on psychosocial issues, like SI, in rare and painful conditions (Beşirli, et al., 202; Calati, et al., 2015; Kirtley, et al., 2020; Racine, 2018; Triñanes, et al., 2015). AA is rare, but the incidence is growing, and the psychosocial consequences including SI have not been studied in this population. The results of this study can contribute meaningfully to academic literature and to the affected adults. One way to prevent suicide is to educate the providers who care for those suffering from AA so that assessments for SI and risk can be part of the treatment plan. The WHO has proposed all individuals aged 10 and up be comprehensively screened for SI if they have been identified as suffering from chronic pain (Racine, 2014; WHO, 2010, 2014) The WHO and the Samaritans believe it is possible to prevent loss of life (Anderson & Sumner, 2000; Bowersox et al., 2021; Racine, 2014).

### **Purpose of the Study**

The purpose of this qualitative study was to explore the experience of SI in individuals with AA, i.e., to describe and articulate the meaning of this experience from the perspective of the participants. The results of this study may contribute to a better understanding of the subject and some of the processes involved in the complex relationship between chronic pain and SI. This area needs research as there is no previous research that explores this topic in this population.

Understanding the experience and meaning of SI before it leads to suicide attempts and lethal suicide in adults living with AA was the intention of the study. AA is

a misunderstood disease, and the general practicing physician is often unaware of the disease and the etiology that this disease presents. Patients coming in with undiagnosed AA are often told to “suck it up,” or given a referral for psychological evaluation, or are simply written off as malingerers (Vittucci, 2019). My goal for this study was to produce results that would meaningfully contribute to a better understanding of this condition and its consequences in the medical community.

### **Research Questions**

Research Question 1 (RQ1): How do individuals with AA experience SI?

Research Question 2 (RQ2): How do individuals with AA experiencing SI reframe their thoughts and beliefs from acting on their feelings?

### **Theoretical Foundation**

The interpersonal theory of suicide (ITS) as posited by Van Orden, et al., (2010) is the theoretical framework used in this study. Van Orden described how people at risk for suicide develop an acquired capacity composed of both increased physical pain tolerance and reduced fear of death. This occurs through repeated exposures to the physically and/or fear inducing experience (the suicide method) to habituate to the physically painful and fearful aspects of self-harm.

Van Orden, et al. (2010) also theorized how passive suicidal thoughts can drift into an active desire for suicide by the simultaneous presence of perceived burdensomeness, thwarted belongingness, and hopelessness about these states. Perceived burdensomeness is the cognitive experience that others would be better off if the person in question were dead. Thwarted belongingness refers to a lack of social connectedness

as a fundamental need for psychological health and well-being, while hopelessness is the feeling or condition where there is no hope, but rather despair or desperation. These are the key dimensions of SI. Thus, according to this theoretical framework, perceived burdensomeness, thwarted belongingness, and hopelessness, coupled with the habituation to pain could be a crucial factor in the higher suicidality risk found in the chronic pain disorders (Triñanes, et al., 2015; Van Orden, et al., 2010). The ITS forms the theoretical framework in many research studies of chronic pain (Hooley, et al., 2014; Racine, 2018; Wilson et al., 2014; Wilson et al., 2016). For example, Racine's (2018) literature review and research is consistent with the evidence that chronic pain, regardless of the type, is a risk factor for suicidality. Further, Wilson, et al., (2014) described the interpersonal theory of suicide as highly relevant to the understanding of the psycho-social consequences unique conditions that are associated with chronic pain. I describe this theory and relevant research further in Chapter 2. In Chapter 3, I apply the key concepts of perceived burdensomeness, thwarted belongingness, and hopelessness in the interview guide development and analysis plan.

### **Nature of the Study**

I used interpretative phenomenological analysis (IPA) to address the research questions in this study. IPA is an approach to qualitative experiential and psychological research which has been informed by concepts and debates from three key areas of philosophy of knowledge: phenomenology, hermeneutics, and idiography (Smith et al., 2020). IPA has its roots in psychology and recognizes the role of the researcher in making sense of the personal experiences of the participants (Pringle, et al., 2011). The

aim of IPA is to provide a deeper and more interpretive analysis that draws the researcher away from original meanings, while encouraging the researcher to ‘go beyond’ the immediate apparent content. The quotes and metaphors that are used by participants further root the analysis directly in participants’ words and can also be used in titles or descriptions going beyond the ‘standard thematic analysis’ (Pringle, et al., 2011). This way of analyzing participants’ accounts of their lived experiences has been used in the study of the illness experience, as this approach allows for exploring the unique life experiences of participants as well as their commonalities (Dosanjh, et al., 2021; Pringle, et al., 2011; Smith et al., 2000).

I constructed an interview guide with questions developed from relevant literature, guided by the theoretical framework. In IPA, interviewing is like a one-side conversation, so that what is achieved is a participant-centered understanding of the phenomenon (Smith, et al., 2020). This is detailed in Chapter 3. I conducted my interviews online using Zoom (ease of access and recording features). I obtained verbatim transcriptions of data and followed the data analysis steps outlined in IPA methodology.

### **Definitions**

*Acute pain:* an unpleasant sensory, perceptual, and emotional experiences provoked by noxious stimulation produced by injury or disease (Tennant, 2020).

*Adhesive Arachnoiditis:* A spinal canal inflammatory disease where there is a clump or mass of cauda equina nerve roots that are glued to the arachnoid-dural covering of the spinal canal (Tennant, 2020).

*Arachnoid cysts:* outpouching of the arachnoid lining. They are usually considered congenital if they compress the spinal cord, the cauda equina or individual nerve roots. They can be associated with pain, sensory changes, urinary dysfunction, and weakness (Aldrete, 2000).

*Arachnoid membrane:* one of the three meninges, the protective membranes that cover the brain and spinal cord. So named it because of the semblance of a spider web. Derivative of the neural crest mesectoderm of embryo (Tennant, 2020).

*Arachnoiditis, non-adhesive:* inflammation of the arachnoid membrane or lay the spinal covering (meninges) without the nerve roots adhering to or “glued” to it. MRI cannot specifically diagnose this condition. It is the clinical diagnosis based on signs, symptoms, and laboratory tests (Tennant, 2000).

*Cauda equina:* roughly two dozen nerve roots that emanate from the spinal cord at about the thoracic level 12 (T12) or Lumbar1(L1) and are suspended in spinal fluid (Tennant, 2020).

*Cauda equina compression:* often caused by neoplasm or by lipoma constricting the fibrous bands or by chronic arachnoiditis, which usually produces burning pain or a sensation of a vice applied to a leg (Aldrete, 2000).

*Cauda Equina Syndrome:* when there is dysfunction of multiple lumbar and sacral nerve roots of the cauda equina (aans.com).

*Chronic AA:* thickening and adhesions of the leptomeninges in the brain and spinal cord, resulting from previous meningitis, or other disease processes, or trauma; signs and symptoms (Aldrete, 2000).

*Chronic pain:* a persistent pain for longer than two weeks beyond the usual course of an acute disease or a reasonable time for an injury to heal or that is associated with a chronic pathologic process that causes continuous or intermittent pain (Aldrete, 2000).

*Chronic Pain Syndrome:* encompasses persistent, intractable pain with a variety of symptoms, some of them exaggerated with psychological overtones and abnormal behavior. Acervuline, small granuli within the choroid plexus formed of concentric layers perceived at plain sight (Aldrete,2000).

*Complex Regional Pain Syndrome:* causes neuropathic pain. In this disorder, pain signals are processed abnormally by the brain and spinal cord. It typically occurs after an injury (mereckmanuals.com).

*Dura:* a thick membrane made of dense irregular connective tissue that surrounds the brain and spinal cord. The outermost of three layers of membranes are called the meninges that protect the central nervous system (www.bartleby.com).

*Focal arachnoidis:* A small area of damage in the spine (Aldrete, 2000).

*Intractable pain:* a severe constant, relentless and debilitating pain that is not curable with any known means and which causes a house-bound or bed-bound state and early death if not adequately treated, usually with opioids and /or interventional procedures. It is not relieved by ordinary medical, surgical, nursing, or pharmaceutical measures (Tennant, 2020).

*Lethal suicide:* method by which one uses to attempt suicide. The term “lethal” is important as there are various methods more harmful or destructive than others. For someone to choose a gun to end their life, the act is quick and almost always irreversible.

Conversely, other methods, such as an overdose of pills or inhalation of harmful chemicals allow for more time to reconsider or to be saved during an attempt.

(<https://www.mirecc.va.gov>).

*Near-lethal suicide:* a suicide attempt defined as an act that could have been lethal had it not been for intervention or chance, and /or methods that are associated with a reasonably high chance of death ([www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)).

*Pain catastrophizing:* a negative mental state towards pain stimuli and pain experience, and is associated with increased pain severity, pain interference, and lower social functioning, physical functioning, and mental health ([clinicaltrials.gov](http://clinicaltrials.gov)).

*Self-cutting, self-harm, or self-mutilation:* acts of deliberately inflicting pain (e.g., cutting, burning) and damage to one's body, and not meant as a suicide attempt.

*Skin channels:* spinal fluid that has seeped through the arachnoid-dural cover of the spinal canal may work its way to the skin surface and form tracks or channels on the skin surface (Tennant, 2020).

*Spinal canal:* also known as the thecal sac. The spinal canal is a structure like a closed pipe that carries the spinal fluid. The fluid is primarily produced in the brain and flows down the canal on one side and flows back up to the brain to be diverted into lymph nodes and the general blood and lymphatic systems (Tennant, 2000).

*Suicidality:* includes ideations and actual attempts. Approximately 70% of people with SI do not go on to make suicide attempts (<https://dictionary.apa.org/suicidality>).

*Thickening:* cauda equina nerve roots have a standard thickness. Thickening or enlargement means the roots have edema, inflammation and/or scarring (Tennant, 2000).

### **Assumptions**

The interview questions were designed to encourage honest, unbiased answers from the participants. However, this depended on the participants' capability and willingness. I assumed that I would be able to manage the interview process to account for any physical distress the participants experienced and adjust the length and timing of the interviews. This was essential for acquiring rich thick descriptions that can be used in the data analysis process. I assumed that the theoretical framework provided relevant insights into participants' experiences, particularly the concepts of burdensomeness, thwarted belongingness, and hopelessness. This is important because the interview question development was guided by the insights and concepts described in this theory. I assumed, using good qualitative methodological strategies, that I would be able to manage my own biases and expectations about the meaning of the participants' experiences. The efforts to minimize bias are further detailed in Chapter 3.

### **Scope and Delimitations**

The target population included were adults with AA who are 18 years of age or older, suffering for at least 2 years and have no other complicated co-morbidity. Excluded from this study were those with arachnoiditis or any other condition that causes extreme pain. AA is a specific disease whose pain is caused by a specific pathway. The study focused on the lived experiences of adults with this condition; significant others, friends and family, and medical personnel were not included as participants as they are important but not relevant to the study of the lived experience (Smith, et al., 2020).

### **Limitations**

I was concerned about sampling issues, as this is a rare condition. However, IPA does not have stringent sample size requirements. Considerations were given to possibilities that interviews would have to be conducted over several days, depending on the well-being of participants. As I was the sole researcher, I employed strategies (peer review, methodological assistance in coding) to enhance the trustworthiness and dependability of the study.

As there is no prior research on the SI of individuals with AA, I planned to compare my findings to other studies of people with different chronic pain conditions. However, there may be limitations of transferability because of the unique target group characteristics. I attempted to be rigorous and transparent in documenting my data collection, analysis, and interpretation, so that others can understand and apply what I have found to their areas of interest (Shenton, 2004).

### **Significance**

This interpretative phenomenological study examined how SI in individuals with AA is experienced. This once rare disease is now routinely found in individuals suffering with chronic low back pain, including women after having had an epidural block during childbirth. By taking a phenomenological approach, this study results may produce a better understanding of how SI is experienced in terms of the meaning of this experience from the perspective of the participants. The results of this study may contribute to a better understanding of these individuals and may contribute to positive social change by enriching the academic and medical profession's understanding of their pain and risks for

SI. It is hoped that the findings can add understanding to the scholarly literature and contribute to doctors' clinical understanding of how to better support their patients. I plan to present my findings at the Tennant Foundation (F. Tennant, Personal Communication, July 4, 2022) and the local professional medical community; and publish the study as well.

### **Summary**

Chronic pain has been linked to SI. AA is a disease where chronic pain is the main symptom, and it has been linked to suicide as well (Tennant, 2022). At this time there is no research on SI in people with AA, unlike the large amount of research on people with chronic pain. One of the challenges of this study is how to understand something so ubiquitous and yet personal, and changeable that can be difficult to access or describe. This study encouraged the voices of the participants to understand their lived experience with pain from AA (both physical and mental), and with the SI that is associated with the mental and emotional pain. The conceptual framework, ITS, was used to aid in the description of how individuals engage with SI (Van Orden, et al. 2010).

IPA was the qualitative approach used in this study. IPA is a psychological method dedicated to articulating and learning from the individual's personal view of the subject and it is social, cultural, and physical connectedness. It is ideal for the study of dynamic, multi-dimensional phenomenon where the individual inter-relates with a range of physical, social, and cultural processes and is the meaning inherent in the experience that is important (Smith et al., 2022).

I hope to contribute to the understanding of the experience of SI and the meaning of thwarted belongingness, perceived burdensomeness and hopelessness in adults who experience chronic pain because of AA. The intent is to describe the experiences but not reach into the domain of clinical interventions. Chapter 2 describes the literature on what is known about this condition as it relates to the larger research understanding of chronic pain and its relationship to SI.

## Chapter 2: Literature Review

### **Introduction**

The purpose of this qualitative study was to understand the lived experience of SI in adults with AA. AA is a progressive spinal disease that involves inflammation of the meninges of the spinal cord (Aldrete, 2000). Once considered a rare disease, it is now estimated to affect millions of people, in part due to the advances in modern medicine where spinal surgery, herniated discs, and epidural injections have caused or accelerated the condition (Tennant, 2020). The condition creates inflammation of the meninges and adhesions form and adheres to the lining of the spinal cord cover causing chronic unrelenting pain. Because it is a rare condition, extraordinarily little research exists on how people with AA cope with chronic pain (Aldrete, 2000).

Many other conditions have been studied, focusing on how individuals with chronic pain conditions manage the psychological, social, and quality-of-life consequences, including rheumatoid arthritis, fibromyalgia, and migraines (Dreyer, et al, 2010; Fuller-Thomas et al., 2016; Shim, et al., 2017; Triñanes et al., 2014; Wolfe et al., 2011). The literature on these other conditions has revealed that chronic pain has been implicated in raising the risk of suicide because of the ongoing physical and emotional suffering (e.g., anxiety, depression, and loneliness) (Racine, 2014). The WHO (2010, 2014) has suggested that all individuals who are seen for chronic pain over the age of ten be evaluated for SI, the precursor to suicide attempts (WHO, 2010, 2014). However, this target population has not been well studied, and researchers have been calling for more research to better understand how adults with AA experience and manage SI.

In the first section of this literature review, I present the theoretical framework proposed for the study is the ITS which attempts to explain why individuals engage in suicidal behavior and to identify those who might be at risk. Next, I will review the literature on the topic, starting with contemporary research on the treatment of chronic pain, and the risk of suicide. This is followed by studies examining pain management and suicide risk in other chronic diseases and conditions where individuals are living with chronic pain. The risk of suicide and SI is presented in detail. Finally, I will summarize the focus of this chapter and transition to the methodology to study the research problem.

### **Literature Search Strategy**

I used the following databases to access scholarly articles on suicide, SI and arachnoiditis: PsycINFO, PsycArticles, EBSCO, ProQuest, Science Direct, SAGE Collections, Thoreau, and Wiley ONLINE. I also used the search engines Google Scholar, Google, and ProQuest for published dissertations. The major search terms used were *attempted suicide, chronic pain, chronic illness, suicide, SI, arachnoiditis, AA, suicide and arachnoiditis, and suicidality.*

Because there is little research that relates AA to SI, I used *chronic pain* to search for conditions related to AA, which is characterized by the chronic pain that it presents with. The search engines and databases I used were the same as the previous search. The search terms I used to find peer-reviewed articles were *chronic pain, fibromyalgia, rheumatoid arthritis, suicide and chronic pain, suicide and fibromyalgia, suicide and rheumatoid arthritis, chronic pain, and SI.*

I also searched on terms defining co-morbidities that are known to be risk factors for SI such as borderline personality disorder, anorexia nervosa, and bulimia. These were also search terms I used to search for peer-reviewed articles. Specific search terms were *suicide and bulimia, suicide and borderline personality disorder, suicide and anorexia nervosa, chronic pain and bulimia, chronic pain and borderline personality disorder, chronic pain, and anorexia nervosa.*

### **Theoretical Foundation**

I chose ITS as the theoretical framework to guide the exploration of the phenomenon of SI in adults with AA (Van Orden, et al., 2010). To understand the phenomenon of SI, key suicide-related constructs and nomenclature are delineated first. The term “suicidal behavior” as used throughout the theory but is less than straightforward in consistent definition. Van Orden, et al., (2010) drew from a revised nomenclature credited to Silverman, et al., (2007). Silverman, et al., (2007) posited that suicide-related behaviors (previously referred to as suicidality) are now classified as ideations, (i.e., thoughts) communications, and behaviors. These behaviors are self-initiated and can vary in the presence or absence of an intent to die and the presence or absence of physical injury being sustained (Van Orden et al., 2010). In the absence of intent to die, the term self-harm is used (e.g., self-cutting in the service of emotion regulation). This is presented in Figure 1 and explained further below.

**Figure 1***Nomenclature for Suicide-Related Behaviors*

NOMENCLATURE FOR SUICIDE-RELATED BEHAVIORS		INTENT TO DIE BY SUICIDE	OUTCOMES				
			NO INJURY	NON FATAL INJURY	DEATH		
S U I C I D E - R E L A T E D  B E H A V I O R S	S E L F - H A R M	WITH NO SUICIDAL INTENT					
		WITHOUT INJURIES					
		SELF-HARM—TYPE I	NO	✓			
		WITH INJURIES					
		SELF-HARM—TYPE II	NO		✓		
	U N D E T E R M I N E D  S U I C I D E - R E L A T E D  B E H A V I O R S	U N D E T E R M I N E D  S U I C I D E - R E L A T E D  B E H A V I O R S	WITH UNDETERMINED SUICIDAL INTENT				
			WITHOUT INJURIES				
			UNDETERMINED SUICIDE RELATED BEHAVIOR—TYPE I	UNDETERMINED	✓		
			WITH INJURIES				
	S U I C I D E - R E L A T E D  B E H A V I O R S	S U I C I D E - R E L A T E D  B E H A V I O R S	UNDETERMINED SUICIDE RELATED BEHAVIOR—TYPE II	UNDETERMINED		✓	
			WITH FATAL INJURIES				
			SELF-INFLICTED DEATH WITH UNDETERMINED INTENT	UNDETERMINED			✓
			WITH SUICIDAL INTENT				
			WITHOUT INJURIES				
	S U I C I D E - R E L A T E D  B E H A V I O R S	S U I C I D E - R E L A T E D  B E H A V I O R S	SUICIDE ATTEMPT—TYPE I	YES	✓		
WITH INJURIES							
SUICIDE ATTEMPT—TYPE II			YES		✓		
WITH FATAL INJURIES							
S U I C I D E - R E L A T E D  B E H A V I O R S	S U I C I D E - R E L A T E D  B E H A V I O R S	SUICIDE	YES			✓	

*Note.* From ©2007 Silverman, et al.

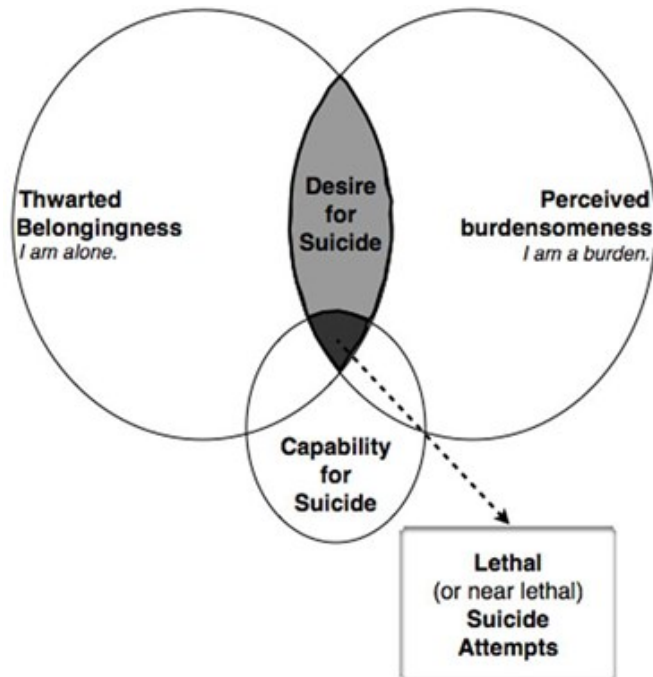
*Suicidal behaviors* rather than *suicidal-related behaviors* are used in the theory, as the theory is concerned with ideations, communications, and behaviors that involve some degree of intent to die. The theory, therefore, focuses on near lethal and lethal suicide

attempts (Van Orden, et al., 2010). *SI* refers to the thoughts, communications (verbal and written), and behaviors which can be gestures of self-harm without causing actual self-harm. SIs are self-initiated, according to the theory, and can vary in the presence or absence of intent to die or in the presence or absence of physical injury being sustained. Due to the theory's being multifactorial, SI results from the fewest number of co-occurring risk factors, while a greater number of results in suicidal *attempts* and the greatest number of co-occurring risk factors results in death (Van Order, et al., 2010).

ITS attempts to explain why individuals engage in suicidal behavior and to identify those who might be at risk. First described by Joiner (2005) as the interpersonal psychological theory of suicide (IPTS), the theory later became known simply as the Interpersonal Theory of Suicide (2010). The theory identifies three key components as necessary for the desire to turn deadly: thwarted belongingness; perceived burdensomeness; and capability for suicide. Figure 2 depicts this graphically with the small area overlapping in the Venn diagram, the small minority of individuals who possess both the desire and capability for suicide, ending in a lethal form of suicide, in a suicide attempt, or near-lethal attempt.

**Figure 2**

*Components Describing the Path to Suicide Attempt*



*Note.* From ©2010 Van Orden et al., (2010), permission obtained.

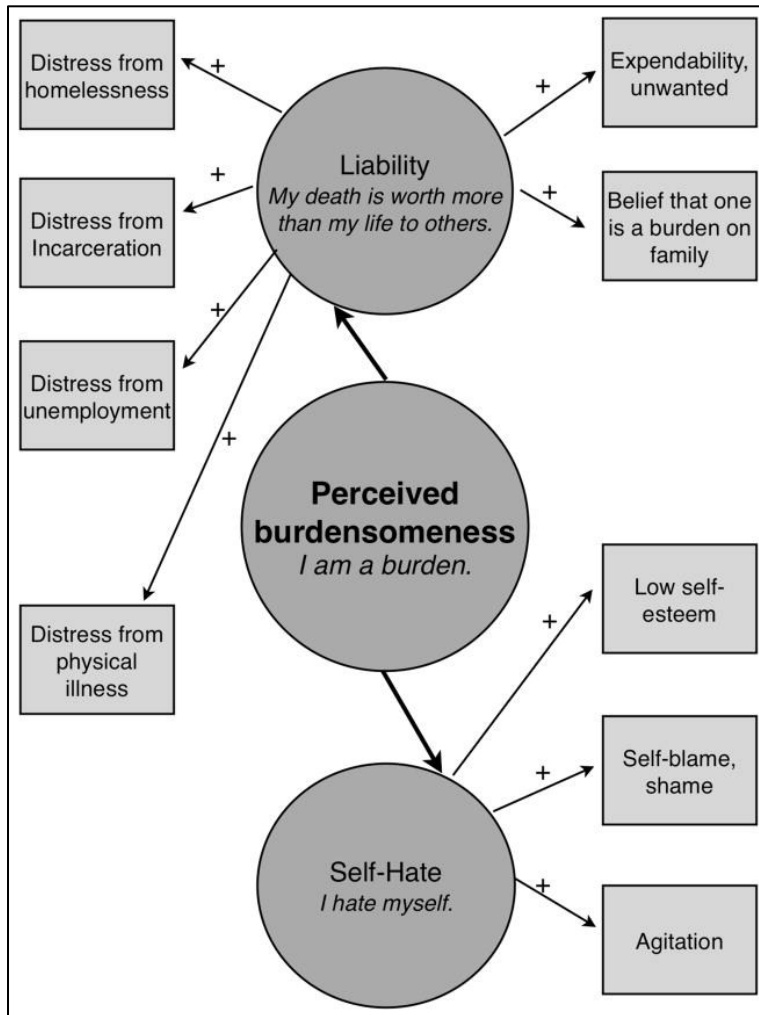
### **Thwarted Belongingness**

Thwarted belongingness emerges from identifying social connectedness as a fundamental need for psychological health and well-being. The lack of belongingness, as Baumeister and Leary (1995) wrote, constitutes severe deprivation, which results in a variety of illnesses. Framed positively, suicidal behavior is reduced with a greater level of social connectedness, i.e., the basic desire to readily form social attachments even under the most adverse conditions. The concept of thwarted belongingness is consistent with Durkheim (1897) and others who saw the absence of social connectedness as sourced at both the sociological (e.g. Durkheim (1897) and psychological level (Schneiderman,

1987). Baumeister and Leary (1995) went further to state that the need to belong is comprised of two facets people require to experience “belongingness”: (a) frequent, effectively pleasant, or positive interactions with the same individuals, and (b) interactions that occur in a framework of long-term, stable caring, concern. Van Orden et al., (2010) integrated these two dimensions of interpersonal functioning to describe thwarted belongingness as loneliness and the absence of reciprocally caring relationships.

### **Perceived Burdensomeness**

Perceived burdensomeness is a cognitive experience that others would “be better off if I were gone”. This perception arises from the combination of circumstance and self-reflection (Chu et al., 2017; Van Orden, et al., 2010). As shown in Figure 2, circumstances include situational constraints (“I have nowhere else to live”); physical and emotional illness (“I’m not well enough to take care of myself”; and/or other lack of resources (e.g., impoverishment; release from prison; natural and man-made disasters). These identified circumstances are perceived as “liabilities. The lower circle represents the self-reflections that are intra-personal judgments of low self-worth.

**Figure 3***Dimensions And Indicators Of Perceived Burdensomeness***Desire/Capability for Suicide**

The desire for suicide is considered an acquired capability since it is not an in-born trait (Chu et al, 2017). Fear of death is met with natural and powerful instincts, but repeated exposures to physical pain or provocative life experiences and emotions are

thought to diminish the fear of death. Instead, fearlessness and pain insensitivity are developed. Life experiences such as childhood abuse, witnessing a traumatic event, suffering from a severe illness or being severely injured, or engaging in self-harm behaviors are examples that can move individuals from life-affirming to suicidal thoughts (Joiner, 2005). Ohman and Mineka (2001) proposed an evolutionary-based model of life preservation that described how natural selection had shaped the human fear system so that fear's adaptive value lay in humans' ability to identify threats to survival. ITS draws upon these evolutionary models in positing that humans fear suicidal behavior since suicidal behavior exposes one to stimuli long associated with threats to survival.

### **Theoretical Propositions**

Van Orden et al. (2010) proposed the following hypotheses that have generated considerable research to evaluate the ability of the theory to predict suicidal risk and to identify patterns that move individuals from circumstance and self-reflection to SI, suicide attempt, and lethal success. These include:

1. Thwarted belongingness and perceived burdensomeness are proximal and sufficient causes of passive SI.
2. The simultaneous presence of thwarted belongingness and perceived burdensomeness, when perceived as stable and unchanging (i.e., hopelessness regarding these states), is a proximal and sufficient cause of active suicidal desire.
3. The simultaneous presence of suicidal desire and lowered fear of death serves as the condition under which suicidal desire will transform into suicidal intent; and,

4. The outcome of serious suicidal behavior (i.e., lethal or near-lethal suicide attempts) is most likely to occur in the context of thwarted belongingness, perceived burdensomeness (and hopelessness regarding both), reduced fear of suicide, and elevated physical pain tolerance. (p.49)

It should be noted that while this study did not test hypotheses, the implications and meanings of these constructions were explored in the qualitative research context.

### **Research Testing of These Hypotheses**

The published literature formally and informally studying the hypotheses and concepts generated by this theory are numerous. Two exceptional reviews have been published (Chu et al., 2017; Ma et al., 2016). Each of these is summarized here, pointing out the values and failures of the constructs and hypotheses.

Ma, et al., (2016) conducted a systematic review of the predictions of the Interpersonal-Psychological Theory of Suicide (IPTS) (Joiner, 2005, Van Orden et al., 2010) on fifty-eight articles, which comprised 66 studies, with the studies providing mixed evidence across the theories' main predictions. The perceived burdensomeness on SI was the most tested and supported relationship of the 206 tests throughout the studies. Other predictions were less supported, such as the interaction between acquired capacity on suicide attempts, which appeared to be less supported than originally stated in the IPTS. The two-way and three-way interactions of the theory constructs, the use of longitudinal designs, and further tests of alternative interactions and mediator effects that were identified by some studies need further high-powered studies.

Chu et al., (2017) conducted a meta-analysis comprised of a significant number of studies. Aiming to conduct a systematic review of the unpublished, along with the published peer-reviewed literature that examines the relationship between interpersonal theory constructs and suicidal thoughts and behaviors. Chu et al also sought to conduct a meta-analysis testing the IPTS hypotheses and to evaluate the influences of various moderators on these relationships. Using several databases, as did Ma et al., (2016), and 122 different published and unpublished studies, findings were supportive of the IPTS and the interactions between thwarted belongingness and perceived burdensomeness, which was significantly associated with SI. Significant weak-to-moderate positive relationships exist between greater thwarted belongingness and more severe SI, greater suicide risk, and continual suicide attempt history. Even though the effects were weak, greater capability for suicide was significantly related to suicide attempts and ideation, and capability was not significantly correlated to suicidal risk alone. These findings together are consistent with the theory and reveal significant associations between the interpersonal theory constructs and suicide-related outcomes.

Both meta-analyses identify areas of the theory that have yet to be tested or have inconsistent, conflicting, or null outcomes. Both articles go on to recommend that efforts be continued to develop and empirically test the efficacy and effectiveness of interventions based on their constructs. Additionally, both articles note that interventions that reduce the capability of suicide remain largely unexplored areas within suicide prevention research. Both note that scholars have postulated that suicide is likely a

culmination of hundreds of risk factors and that these meta-analyses revealed several gaps in literature requiring further empirical investigation.

### **Application of ITS to the Study**

ITS provides a comprehensive theoretical map for understanding all aspects of SI, attempts, and lethal aspects of suicide. For this study, I incorporated some of the key concepts of the theory (particularly the key concepts of perceived burdensomeness, thwarted belongingness, and hopelessness) into the development of the interview guide questions and data analysis plan. Of particular interest is the exploration of how people experience the intractability of these key concepts and still find meaning and reasons to go on.

### **Literature Review Related to Key Variables and/or Concepts**

#### **Arachnoiditis**

The exact date that the term “arachnoiditis” was used for the disease is unknown, although J.B. Lippincott & Co.’s Comprehensive Medical Dictionary (1873) includes the definition: “Arachnitis: A faulty term, denoting inflammation of the arachnoid membrane” (Tennant, 2022, p.47). In 1899, the first edition of the Merck Manual listed spinal meningitis with recommendations for chronic and tubercular meningitis along with drugs and measures for its care. Thirty-plus treatments were listed for its treatment, including measures still in use today. In 1909, Sir Victor Horsley recognized inflammation of the meninges to be from infection or hemorrhage, coining the phrase spinal meningitis, which established inflammation as being involved with diseases of the meninges.

In 1781 Dr. John Fothergill, a famous British physician treated a patient who had severe back and sciatic pain along with other symptoms compatible with arachnoiditis (Tennant, 2022). Sir Victor Horsley, a British neurosurgeon, authored the first clinical report describing what he believed to be tumors in the spinal canal. In 1909, Horsley operated on 21 patients that he believed to have a spinal canal tumor. Tennant (2022) wrote that these patients had varying degrees of paraplegia, along with distended spinal canals, which contained excessive fluid. Nerve roots, Horsley found, were edematous and “matted” together forming a mass with inflammation affecting all the layers of the meninges. All the patients had intervertebral herniated discs that required laminectomy. Cases of AA today have similar etiology. Horsley’s clinical report describes what today is viewed in an MRI, and specifically describes what is now known as AA (AA).

Harvey’s (1928) clinical report, and what is believed to be only the second clinical report to describe the inflammation of the dura layers (Tennant, 2020). The report, further, described both the arachnoid and dural layers as being “glued” together or stuck together by adhesions. These findings are relevant, as inflammation weakens the dura mater so that the tensile strength is lost, it dilates, and CSF will seep or leak into the epidural space and tissues surrounding the spinal column. If the seepage becomes chronic, which is evident on MRI, muscle contractures can occur along with the subcutaneous tissue and skin around the lower back causing back pain (Tennant, 2022). Ever since the clinical report by Harvey, this disease has been called AA (AA).

Poppen (1945) correlated the clinical signs and symptoms of the pathology of the intervertebral disc by radiological confirmation by myelography, increased the demand

for radiologic imaging of the spine and co-occurred with acquired AA by the myelography and /or procedures that eventually provoked it (Aldrete, 2000). AA became a nightmare as arachnoiditis can progress to a worsening of the adhesions, causing complications that AA presents with, leading to lifelong disability, chronic pain, and for some SI. For those who cannot cope with the unbearable suffering, lethal suicide can become a reality.

### *Anatomy of Arachnoiditis*

The arachnoid membrane is a thin delicate layer that loosely invests the spinal cord and the spinal nerve roots, containing the cerebral spinal fluid, the denticulate ligaments, and the “spectrum posticum” (Aldrete, 2000, p. 7). The cranial arachnoid is in continuity with the spinal arachnoid consisting of two layers of white fibrous and elastic connective tissue—the visceral and the parietal. The outer parietal layer faces the dura and loosely adheres to it, while the internal visceral layer is transparent and very thin so that it conforms to the pia-arachnoid. In between these layers is the sub-arachnoid, and the connection of the two layers are numerous trabeculae that form a sponge-like cover that creates numerous channels lined with mesothelial cells containing CSF. The trabeculae which are baffle bars then facilitate the mixing of a fluid substance that during invasive procedures (anesthetics, dyes, neurolytic agents, etc.) are injected into the subarachnoid space.

Between the dura and the outer layer of the arachnoid, a potential compartment exists which at times acts as a one-way valve admitting substances without allowing the fluid to flow out except for a “serous-sanguinolent show” in the amount of a few drops

that acts as a lubricant between the two close serous layers (Aldrete, 2000, p. 8). Aldrete reported that some arachnoid cells that make up the arachnoid membrane may overreact to certain inflammatory stimuli—bacterial, chemical, or tumor infiltration with hypertrophic scarring and proliferative fibrosis, fibrinolysis, and possibly calcifications and /or cavitations.

The condensation of the pia mater caudad to the conus terminalis is called the filum terminalis. Aldrete (2000) described this as descending into the center of the cauda equina beginning at the second sacral vertebra where it blends with the dura, goes down to the coccyx where it fuses with the periosteum, and then becomes the "ligamentum of the cord". The pia and the arachnoid layers have a closeness since they are both soft, compared to the dura even though the pia and the arachnoid are separated and have been labeled the "leptomeninges" in the literature given they are both in close contact and bathed in CSF. In arachnoiditis both are usually involved, and in most cases, given the brain, the spinal cord, and the spinal nerve roots are all covered by the pia. Fibrosis, scarring, inflammation, and immune response affect all the nerve roots and sub-arachnoid membranes.

A wide variety of factors can trigger the initial response leading to an acute inflammatory process at the cellular level creating a fibrinous exudate reaction that will initiate a cascade of events that will cause congestion, inflammation, and edema that in turn goes into a fibroblast proliferation with a collagen disposition that results in adhesions to adjacent structures with the obliteration of the subarachnoid space.

Occasionally, cyst formation, atrophy, and calcium deposits become osseous metaplasia eventually forming a complete calcification (Aldrete, 2000).

### ***Arachnoiditis and Chronic Pain***

As a reaction of the arachnoidea mater of multifactorial etiology, arachnoiditis is a non-specific inflammatory process resulting in fibrosis in the arachnoid membrane, thickening the membrane and adhering it to the pia and dura mater around the spinal cord and cauda equina. These changes range from clumping of nerve roots and blunting of nerve root sleeves to obliteration of the subarachnoid space (Aldrete, 2000, Tennant, 2022). This pathology may also obstruct the blood supply to the spinal cord and nerve roots, which changes might lead to interference with the epineural circulation which is a common pathogenic mechanism in neuropathology (Aldrete, 2000). The interruption in circulation may hinder 50 percent of the blood flow to local nerve fibers. The interruption reduces endoneural oxygen tension and causes damage to the nerve fibers. Depending upon the degree of injury and the chance of injury on the cellular level or demyelination and axonal injury, the neuropathic pain and sympathetic sprouting into the dorsal root ganglion three stages of arachnoiditis are possible (Aldrete, 2000):

1. Radiculitis: there is inflammation of the pia-arachnoid with associated swelling and hyperemia of the nerve roots that obliterate the fenestration or embossed surface (Aldrete, 2000).
2. Arachnoiditis: There is a progression of fibroblast proliferation and collagen deposition, due to the arachnoid's avascular fibrous bands that cannot be

eradicated. Instead, they form bridges for fibrocytes, causing adhesions of the pia and dura mater (Aldrete, 2000).

3. AA: This is the end stage of the inflammatory process. The dural pulse is absent, nerve roots are enmeshed in scar turn hypovascular and atrophy. Because there is tethering, the dura is open or torn. Cysts or pockets of cerebrospinal fluid or oil-based contrast may be formed by adhesions. Other complications may also occur. When this inflammatory process occurs and involves the nerve roots, it's considered Class I. Class II occurs if the subarachnoid space is involved, and Syringomyelia may occur if the spinal cord is involved (Aldrete, 2000).

Aldrete (2000) noted that the clinical presentation of arachnoiditis from mild to significant symptoms to a fulminating progression, which can ultimately produce paraplegia and even death. In between a burning sensation is found in 97% of patients with arachnoiditis. Painful spasms of the extremities occur with sexual dysfunction, and ocular, gastrointestinal, and hearing disturbances (Aldrete, 2000; Tennant, 2022). Back pain is often a focal point in which pain is distributed to both legs, with pain shifting over days or weeks and often overlaps in two or more nerve root distributions and tends to be bilateral. The sensory quality of pain is described as continuous stinging, burning, aching, gnawing pain that worsens in cold weather. Intra-abdominal pressure such as coughing, or sneezing aggravates pain. (Tennant, 2019). Painful spasms of the extremities may also indicate spinal cord involvement at a higher level (Aldrete, 2000, Tennant, 2022).

In summary, AA is a chronic inflammatory disease-causing extreme pain. This condition has a variety of neurological manifestations along with constant lumbar pain

with an intensity that changes with movement and positional changes. Comfort for people with AA may be achieved by changing positions and the opposite may also be true (Tennant, 2019) In short, finding relief for a person with AA is very difficult. The condition is complex, and provoked by injury, trauma, or because of medical procedures gone wrong. Understanding the complexity of the anatomy of the spine, nerves, and tissues that surround the spine and communicate functional impulses as well as pain is important, as it may provide insight into the pain experience.

### **Suicidality and Chronic Pain**

As defined in Chapter 1, suicidality includes both ideations and actual suicide attempts. Furthermore, as described in the theoretical framework (ITS), thwarted belongingness, perceived burdensomeness, and hopelessness appear to be the pre-conditions for SI and – given the acquired capability – the precursor to suicide attempts and lethal suicide (Racine, 2010, 2014; WHO, 2010, 2014). The research has demonstrated that people who experience chronic pain are at risk for SI (Beşirili et al., 2020, Calati et al., 2015, Kirtley et al., 2020, Petrosky, et al., 2018, Racine, 2018, Trifianes et al., 2015, Wilson, et al., 2017). This is because the emotional costs to those suffering from chronic pain are extremely high; along with the financial losses due to loss of employment; and the skyrocketing costs associated with medical care and medications. Dahlhamer et al (2018) estimated the direct medical costs for managing chronic pain to be at least 560 billion dollars annually.

The risk of suicide is at least double that in individuals with chronic pain with a lifetime prevalence of suicide attempts between 5 percent and 14 percent for those with

chronic pain (Tang & Crane, 2006). WHO's study on the burden of disease globally found low-back pain was behind 11 percent of overall years lived in disability (YLDs), making it the leading cause of YLDs in the world.

While there is no research on the issues of suicidality specifically in persons with AA, suicidality and chronic pain as experienced by people with other conditions have been studied extensively using the ITS model. Individuals with chronic pain have increased rates of suicide (Hooley, et al., 2014; Wilson, et al., 2014; Wilson, et al., 2016). Few studies have tested specific predictions from the (ITS), although chronic pain is a risk factor for suicide. Three studies will be presented that have tested the psychological constructs of the theory in persons with chronic pain: perceived burdensomeness, thwarted belongingness, and acquired capability.

Wilson, et al. (2014) evaluated 303 patients from a chronic pain rehabilitation program on measures of severity, duration, and disability, as well as cognitive-affected measures of depression and catastrophizing, and interpersonal measures of relationship distress and self-perceived burden to others, and two items about suicide. The latter measures are indices of belongingness and burdensomeness. They found that the ITS may have merit in explaining the elevated rates of SI that is evident among individuals with chronic pain.

Wilson et al. (2016) engaged 282 patients from an interdisciplinary pain clinic for a cross-sectional study using hierarchical regression analysis to test the ITS hypotheses that (a) perceived burdensomeness and thwarted belongingness would show stronger associations with SI than other established risk factors; (b) perceived burdensomeness

and thwarted belongingness would predict SI after adjusting for demographic, psychological, and pain-related variables; and (c) the interaction between perceived burdensomeness and thwarted belongingness would be a further unique predictor of SI in patients with chronic pain. The results revealed that perceived burdensomeness was especially relevant for understanding SI, emerging as a significant predictor of SI even after controlling other risk factors. The interaction between perceived burdensomeness and thwarted belongingness lead to a synergistic augmentation of SI.

Hooley, et al. (2014) conducted a review of the literature on why pain conditions are linked to increased suicidal risk. This review offered new insights into the psychological processes that individuals with chronic pain are facing that are important for understanding suicide. The researchers found that chronic pain elevates the risk of suicide; and that those who suffer from non-cancerous pain conditions, such as arthritis, back pain, migraine, neuropathy, tension headaches, fibromyalgia, as well as psychogenic pain are at the greatest risk of suicide.

Findings from the studies described above suggest that chronic pain conditions place patients at a particular risk of reaching a point where suicide is something they are willing to consider (Hooley, et al., 2014; Ilgen et al., 2013). Psychogenic pain, for instance, is especially interesting due to the ambiguous diagnosis, stigma, and additional burdens associated with it. Psychological pain is an even more powerful predictor of death by suicide (Hooley et al., 2014), and many studies have identified the link between depression and suicide intent. Gerrit and colleagues (2013) assessed 614 participants at baseline levels of pain. During a four-year follow-up, 15.5 % of participants developed a

first-incident episode of depression. Higher chronic pain severity, it was found, was a significant predictor of the onset of depression, as were the number of locations where the pain was experienced. Thus, pain and depression are definitively intertwined, highlighting the importance of the role that physical pain and psychological pain play in the risk of suicide. Hooley et al. (2016) suggested clinicians involved in the treatment of patients with physical pain conditions be aware of the increased risk factors for suicide in their patients since physical pain holds the potential to set into motion a cascade of events that are linked to elevated suicide risk.

### **Suicide Prevention**

The epidemiology of suicide has been extensive, and considerable research has focused on understanding who is at risk and how the process occurs. There also exists a substantial body of research examining the prevention of suicide which can be summarized from recent reviews and meta-analytic studies looking for common strategies that demonstrate some measure of success. A consensus for suicide prevention does not exist, although there is widespread agreement that something needs to be done to stop the epidemic of suicide, especially among young people. Zalsman, et al (2016) cited ideas gleaned from 1797 studies, such as restricting access to lethal means, especially analgesics, and limiting access to hot spots for jumping. Awareness programs have been shown to reduce SI and suicide attempts. Furthermore, clozapine and lithium have been substantiated as have other pharmacological and psychological treatments of depression that are showing importance in the prevention of suicide. The limitation of

this paper was the paucity of randomized control trials for the evaluation of preventative interventions (Zalsman, et al., 2016).

On the other hand, Doupnik, et al., (2020) in a total of 14 studies show that brief suicide prevention interventions were associated with a reduction with reduced suicide attempts. when linkage to follow-up care but were not associated with a reduction in depressive symptoms. When prevention was delivered in single person encounters suicide attempts may be effectively reduced, as long as follow-up health care was provided. A limitation of this study was the limited studies used in the meta-analysis (14 studies) and only subsets with relative outcomes were included., and the authors were not able to examine whether brief suicide encounters ultimately reduce lethal suicide since none of the studies included death as an outcome (Doupnik et al., 2020).

### **Summary and Conclusions**

Chapter 2 summarized the key points of the literature on suicide, suicidality, and chronic pain. Suicide is a public health problem (CDC, 2022, WHO, 2014), where suicide is known as a precursor to the path of suicide (Beşirli et al., 2020, Calati et al., 2015, Kirtley et al., 2020, Petrosky, et al., 2018, Racine, 2018, Trifianes et al., 2015, Wilson, et al., 2017). Suicide rates as of 2020 rose above 46,000 deaths, or 11 deaths every 11 minutes. The rates of suicide rose 30 % between 2000 and 2020. Rates of suicide vary by age with ages 10-14 and 25-24 years being the second cause of death. Veterans and people in rural areas are also at greater risk.

The framework of ITS was described as a way to conceptualize the experience of suffering from psychological pain (Joiner, 2007; Van Orden, et al., 2010). This theory

posited that experiencing thwarted belongingness, perceived burdensomeness, and hopelessness enhanced the potential for SI. Extensive testing of the hypotheses generated by ITS has, for the most part, supported the theory.

This chapter also summarized the considerable research examining the experience of SU in persons who suffer from chronic pain. Consistently, research has shown that persons in chronic pain are at a greater risk for SI, suicide attempts, or lethal suicide when they are experiencing psychological states akin to the ITS, as well as any number of states that lead to chronic pain (Chu, et al., 2017, Hooley, et al., 2014, Ma et al., 2016, Wilson et al., 2014, Wilson, et al., 2016).

For this study, AA was the focus of discussion, describing the complexities of this inflammatory disease that includes severe neurological manifestations along with intense lumbar pain with movement. AA is a condition in which changes in position and orr treatment are marginally helpful and can help lead to a state of hopelessness, due to constant, extreme pain (Aldrete, 2000, Tennant, 2022). Comfort is hard to realize for a person with AA (Tennant, 2020).

While much is known about the medical and physiological aspects of AA, little is known about how SI is experienced by people with AA (Aldrete, 2000, Tennant, 2019, 2021, 2022). The aspects that AA differs in are the severe physiological problems that AA leads to such as stinging, burning, aching, and gnawing pain that can occur in just one individual with the chance for sexual dysfunction, ocular, hearing, and gastrointestinal problems also co-occurring (Aldrete, 2000, Tennant, 2019, 2021, 2022).

Indications of spinal cord involvement are also evident with painful spasms of the extremities also occurring leading to psychological manifestations, as well.

This chapter ends with a brief overview of the current understanding of suicide prevention. This subject has been the topic of much research (CDC, 2022, Doupnik et al., 2020, Zalsman et al., 2016), but without consensus on the best way to prevent suicide. As the literature points out, no single strategy will lead to the prevention of suicide (CDC, 2022). Strategies tailored to specific culture; needs and strengths addressing the multiple factors suicide involves and partnering with different sectors to leverage expertise and implementing strategies are important (CDC, 2022). Patient support measures in the acute care setting, with linkage to follow-up care are recommended by Doupnik et al., 2020), and restricting access to lethal means, rather than analgesics or hot spots for jumping or firearms are advocated by Zalsman et al., 2016).

In sum, this chapter represents the efforts to summarize the known literature and illuminate the next steps for contributing to scholarly and professional understanding of the proposed research problem. Chapter 3 describes the methods and procedures for addressing this gap.

## Chapter 3: Research Methods

### **Introduction**

The purpose of this qualitative study was to explore the experience of SI in individuals with AA. In this chapter, I provide a description of the research design and rationale and discuss the role of the researcher. This is followed by a description of the methodology, which includes selection and recruitment of participants, instrumentation, and data collection. The final sections include a description of the data analysis plan, issues of trustworthiness and ethical procedures.

### **Research Design and Rationale**

#### **Research Questions**

RQ1: How do individuals with AA experience SI?

RQ2: How do individuals with AA experiencing SI abstain from acting on their suicidal thoughts?

The central phenomenon of this study is SI. SI is described as thoughts, communication, both verbal and written and behaviors, which can be gestures of self-harm without causing actual harm to the individual (Silverman et al., 2007). SI is self-initiated in the presence or absence of intent to die or in the presence or absence of physical injury being sustained (Van Orden et al., 2010). This is particularly relevant to the target group, adults with AA. While the group has not been extensively studied, related research has found that people with chronic pain conditions are at risk for SI (Calati et al., 2015; Fishbain et al., 2014; Racine, 2014, 2017; Tang & Crane, 2006).

## Research Design

I chose the qualitative research tradition of IPA for its phenomenological thinking as a means to pursue a deep understanding of a phenomenon from the philosophical lens of phenomenology (Smith, et al., 2022). The purpose of this approach is to return to the “things themselves,” (Husserl, 2011) In research, the thing is the lived experience, in terms of what is shared between the researcher and the participants.

IPA is informed by concepts and debates from three key areas. The philosophy of knowledge: phenomenology, hermeneutics, and idiography (Smith et al., 2022). IPA has its roots in psychology and recognizes the role of the researcher in making sense of the personal experiences of the participants (Pringle, et al., 2011) The purpose of this method is to provide a deeper and more interpretative analysis that draws the researcher away from the original meanings while encouraging the researcher to go beyond immediate apparent content. The quotes and metaphors that are used by participants further root the analysis directly in participants' words and can also be used in titles or descriptions going beyond the standard thematic analyses. IPA is particularly useful in understanding experienced chronic and terminal illness and has been used in human and health sciences (Dosanjh, et al., 2021; Peat, et al., 2019; Pringle, et al., 2011; Smith et al., 2000; Smith et al., 2022).

I also considered narrative analysis as a research approach. Narrative research traces its philosophical roots to postmodernism, social constructivism, and feminism. (Patton, 2015). The inter-human relationships, focus on different contexts a basic

assumption, with people's stories (the narrative) and the characters involved emphasized in the research inquiry (Patton, 2015).

Both research methods are strategies to come to a deeper understanding of an issue, event, or population, and to derive meaning from surroundings and experiences (Patton, 2015). Despite these common intentions to find meaning through interviews that take place with participants the two research designs also have distinctive features. Narrative research focuses on storytelling where participants share narratives about themselves, unlike the IPA researcher who gathers material to identify common meanings from individual experiences. Even though both are concerned with direct communication with the participant, I chose IPA for its intent to describe the essence and meaning of this human experience rather than the structure and narrative arc of the illness.

### **Role of the Researcher**

My role as a researcher is an integral part of the research process. As a researcher, it was my task to view the participants as experiential experts. The experiences of the participant cannot simply be revealed but rather occur through a process of rich engagement and interpretation that involves both myself and the participants. The researcher is able to make sense of the participants making sense of their world, as a process known as the double hermeneutic approach (Peat et al., 2019; Smith & Osbourne, 2007). To assist in the meaning-making process, I engaged in a hermeneutic circle, an iterative process that involves moving between smaller units of meaning and larger units of meaning, between the parts and the whole of the investigation of the lived experience of SI in the individual with AA (Peat et al., 2019; Smith & Osbourne, 2007).

One challenge I had to confront was my own experience as a person who lives with AA. In qualitative research, the researcher is the principal actor in data collection, selection, and interpretation, and this increases the risk of bias towards the researchers' experiences (Finlay, 2002). After almost 43 years of suffering from this disease, I know the agonizing pain that this disease inflicts. I understand the SI that comes from the constant pain, and rejection by family and friends who tire of living with someone who is unable to accomplish the smallest of household tasks, and whose moods change constantly and whose life has been upended and looks useless.

To avoid bias or interjecting my own experiences, I focused on the experience of the participants, using a reflective journal to capture my thoughts and concerns and any bias about my own experience concerning them (positionality) (Patton, 2015; Smith et al, 2022). This bracketing of my own experience occurred both before and after each interview. By using the reflective process, I became aware of how I can influence the research process. Reflexivity, defined as the process of 'being aware' and 'bringing to light' how the researcher influences the research process, was employed so as to strengthen the accuracy and ethical quality of my research acknowledging my background and preconception and how those may impact and influence the research process (Smith et al., 2022).

Given the emotional and personal nature of the topic, I included as part of the consent process the resources to refer to anyone who feels the need for further support to 988, the National Suicide Prevention Line. I have trained with and was employed with the Samaritans of Cape Cod & the Islands, a crisis hotline across the United States that

gives support to those experiencing SI. This helped me be aware of the signs of someone becoming overwhelmed or over-sensitive in the telling of their personal story and having feelings regarding the presence now or in the past of SI.

I had no professional or personal relationship with the participants who will be unknown to me until we engage in the study. I have been a contributor to social media, and I belong to groups that discuss arachnoiditis. Often, I have read entries and responses from fellow members who have expressed requests to other members for leads to euthanasia practitioners or expressed their SI, and thoughts about wanting to attempt to end their lives. Seeing these posts has been painful and has been the inspiration for this study. This study represents my contribution to the development of understanding of SI in individuals with AA, the need for literature in this area, and the personal experiences of ideation in a manner that is firmly psychological in orientation and emphasis.

## **Methodology**

### **Participant Selection Logic**

The target population was composed of adults diagnosed with AA, who have had AA for at least 2 years, (Tennant, 2020), and have no other complicating co-morbidity, (i.e. eating disorder, borderline personality disorder, and schizophrenia). Only persons those over the age of 18) could participate. They must also have (a) experienced suicidal thoughts, but not currently experiencing such thoughts, (b) have previously disclosed suicidal thoughts to a member of the faith community or a healthcare professional, and (c) informed their primary care provider or mental health professional about their desire to participate in this study to ensure it is appropriate for them to do so.

The invitation to participate did not include requests for individuals with more complex conditions (Van Orden et al., 2010). The invitation will be sent to Dr. Forest Tennant who runs a non-profit foundation specializing in research and practice for treating AA. The Tennant Foundation and staff are experts in pain and related conditions and have dealt specifically with intractable pain and AA. The foundation has also researched ways to mitigate pain and inflammation, which are the most prevalent symptoms experienced by patients with this condition.

### **Sampling Strategy and Criteria**

I used a purposeful sampling strategy in the selection process. Homogeneous sampling (Patton, 2015) is the recommended choice for IPA so that all participants have similar experiences, and all are experiencing the hardship that having AA presents, maximizing the potential for sharing meaning within a small group of participants. Participants were chosen from those responding to the flyer, distributed through my key informant, and who emailed me expressing interest. The participants came from different locations in the United States, specifically California, Texas, Florida, Ohio, Montana, and Massachusetts. The study sought out six to ten participants so that experience will be varied and provide rich data, which to draw from. A detailed account of the lived experience of the individual is what IPA is primarily concerned with, the issue is not the quantity but the quality (Smith, et al., 2022). Given the complexity of human phenomena, IPA studies usually benefit from a small number of cases (Smith, et al., 2022). The invitation flyer was sent to Dr. Tennant, who planned to distribute the invitation through

his mailing list. Self-report was used to verify that individuals who reach out to me to learn more about the study met the criteria for inclusion.

Saturation is an important part of trustworthy qualitative work (Fusch & Ness, 2015; Guest, et al., 2006). Thematic saturation is approached when there are no new concepts emerge from existing interviews, and data saturation occurs when the addition of new data produces no new concepts (Guest, et al., 2006; Nascimento et al., 2017). I ongoingly evaluated the approach to saturation using the concepts from the framework and literature and planned to interview more participants if necessary.

### **Instrumentation**

Semi-structured interviews using open-ended questions were conducted, guided by concepts identified in the literature review and theoretical framework (Rubin & Rubin, 2012). The interview questions were pre-tested on colleagues for flow, clarity, and timing of the interview. I planned to conduct interviews via Zoom and audio record last approximately 1.5 hours, with the participants encouraged to take breaks as needed. Extended interviews were available to be separated into shorter segments to be mindful of participant's energy and pain.

### **Table 1**

#### *Interview Guide Questions*

Interview Guide Questions	Citations (Author, date)
I am wondering if you could help me better understand your specific situation by sharing your disease, diagnosis, and your experience with SI,	
1. Background	Tennant, F. & Hollis, I
a. So, tell me about your experience with AA.	(2019); Tennant, F.
b. How did you develop your condition?	(2022).
c. How were you diagnosed?	

Interview Guide Questions	Citations (Author, date)
d. How long have you been living in this condition?	
2. Tell me about a typical day. (to get a sense of what it means to live with this disease)	Charmaz, K. (1983)
a. Probe: What is the best part of a typical day?	
b. Probe: What is the worst part?	
The aspect of your experience that I am especially interested in is your experience with SI. I understand this could be triggering so if you do not want to talk about SI, we can end the interview at any time.	
3. I am going to ask you some questions about what happens when you have thoughts about suicide. (We can stop any time)	Joiner, T. (2005); Van Orden, et al., (2010)
a. Remembering a recent time when you had suicidal thoughts, what was happening at that time?	
b. What comes up for you when you think about suicide? 1. Can you give me an example? 2. What goes through your mind? 3. How does this make you feel?	
4. Burdensomeness- Tell me about the relationship you have with your family or caregivers.	Joiner, T. (2010); Joiner, T. (2005); Van Orden, et al., (2010)
5. Tell me about when you felt you were a burden to others.	
a. Was there another time when you felt this way?	
b. Can you give me an example?	
6. Could you tell me a story about your experiences with SI?	Charmaz, K. (1983)
7. What keeps you from acting out your thoughts?	
a. What is the most important reason for you to keep going?	Joiner, T. (2005); Joiner, T. (2010); Van Orden, et al., (2010)
b. Are there other reasons?	
8. Tell me about something you are looking forward to.	Charmaz, K. (2006); Charmaz, K. (1983)
9. What is something that makes life worth living?	

Interview Guide Questions	Citations (Author, date)
<p>10. What would you like people to know/learn about people like yourself and what you experience every day?</p> <p>Thank you for talking to me and sharing some personal and painful experiences. As you continue your journey through life, living with this devastating disease, I commend you for your courage and honoring me by sharing these painful aspects of your life.</p>	<p>Charmaz, K. (2006); Charmaz, K. (1983)</p>

I used a debriefing protocol throughout the interview, as described by Pinto, et al. (2022). This is represented as an outline of the steps and measures available that can be taken to reduce stress and create space: (a) regular check-ins with the participants if they need a break or wish to discontinue the interview; (b) flexibility in the order and depth of questions; and (c) giving the participant the control of pace, timing, and length of the interview. Being flexible was necessary when working with a vulnerable population, offering support, and offering breaks giving participants the opportunity the time they need to share their experiences (Pinto, et al., 2022).

### **Procedures for Data Collection**

Once a potential participant contacted me by email or phone, I explained the criteria for inclusion in the study. I explained the procedure for moving forward, then I asked a series of questions in the interview, and they were allowed to answer questions about their experiences with AA and SI. I let them know how the interview will take place—via Zoom and audio recorded and that the interview will last approximately 90 minutes (about 1 and a half hours) with breaks allowed. The participants were also told they will receive a summary of the interview after it has been transcribed to review to

ensure that there are no misstatements, and that the summary correctly states what they said throughout the interview.

I explained the consent form and emailed it to them, and they were required to respond by email with:” I consent” after thoroughly reading the informed consent after I send it to them. Once they responded to the email, I scheduled an interview with each of the participants, reminding them that the interview will be recorded and will not be shared with others except my committee. I also let the participants know they are allowed to withdraw at any time during the study, even during the interview without penalty. I encouraged the participants to find a quiet, private place to talk where they will not be interrupted, have water available so they have something to drink during the interview and anything else they need so that we will not be interrupted. When the interview was complete, I reviewed the questions with the participants to see if there is anything else they want to add and remind them they will receive a summary of the interview after it is transcribed for them to review with accuracy.

### **Data Analysis Plan**

Data analysis in IPA involves several steps not used in other methods. The essence of IPA, according to Smith et al., (2022) lies in the analytic focus. This focus directs the analyst's attention toward the participant, who is attempting to make sense of their experience. The IPA researcher commits to understanding the participant's point of view with a psychological focus on personal meaning-making in contexts that are particular to the participant, applied according to the analytic task, flexibly.

The process is a joint process – between the participant and researcher, the double hermeneutic, the researcher making sense of how the participant makes sense of their lived experience (Smith et al., 2022), making the process multi-dimensional. The analytic process is step-by-step in IPA in an attempt to make the process more manageable, moving from one interview to the next, honoring IPA's idiographic commitment.

1. Reading and re-reading: immersing oneself in the data; this was done by listening to each audio recording while reading the accompanying transcript.
2. Exploratory: The aim of which was to produce a comprehensive and detailed set of notes and comments on the data (Smith et al., 2022).
3. Constructing Experiential Statements: this is an important stage for consolidating and crystalizing my thoughts as I created exploratory notes from the transcripts as the basis for creating these statements.
4. Searching for Connections Across Experiential Statements: I charted the connections within each participant's statements to construct the themes.
5. Naming the Personal Experiential Themes (PETS): Once the themes within each transcript were determined, I named them and organized them into a table.
6. Continuing the individual analysis of other cases: I moved to the next participant's transcript and started the process over.
7. Work with PETS to develop group experiential themes: I looked for patterns of similarity and differences across the individual PETS to create group PETS.

### **Issues of Trustworthiness**

Trustworthiness is an important criterion for qualitative research (Patton, 2015; Shenton, 2004). Unlike quantitative research which results in probabilities and confidence levels based on statistical assumptions, qualitative analysis must describe how implementing strategies and plans laid out throughout the methodology, I planned to show that the data collection, analysis process, and results are consistent with IPA methodology, including the systematic and conscientious search for alternative themes, divergent patterns, and rival explanations (Patton, 2015; Rodham & Doran, 2013). These dimensions of credibility are discussed in terms of the strategies I plan to employ (Lincoln & Guba, 1995; Shenton, 2004).

#### **Credibility**

In this study, I planned to use well-regarded qualitative strategies to accurately capture how the participants see their world and construct their reality, which is essential in this type of study (Shenton, 2004; Rodham & Doran, 2013). This includes the use of established IPA research strategies for collecting thick descriptions of the phenomenon of SI and its context. I have familiarity with the disease process and the culture of chronic pain medical care, and therefore my questions and analysis of responses are fully informed. Using my training in suicide hotline work and my study of qualitative interviewing, I planned to establish a rapport and trust so that participants can feel comfortable disclosing, and debrief participants during and at the end of the interview and send participants summaries for member checking so that they are “heard”, and that they are free to discontinue if there is any discomfort. I planned to spend a considerable

amount of time listening to and reading transcripts to immerse myself in the voices of my participants (Bloomberg & Volpe, 2008; Rodham & Doran, 2013).

### **Transferability**

The goal in transferability is to be transparent with my analysis and trustworthiness will provide a vivid picture that informs and resonates with other readers. (Connelly, 2016). The extent to which my findings are useful in other settings will be achieved by providing sufficient detail of the data collection, analysis, and interpretation so that the reader can determine how applicable the findings are to their situation (Lincoln & Guba, 1995; Shenton, 2004). I focused on the participants and their stories, and explained the process of “bracketing” my own experiences throughout (Rodham & Doran, 2004; Smith & Osbourne, 2022).

### **Dependability**

This refers to the stability of my data over time despite the conditions of the study. It is similar to the reliability in the quantitative research study, but not really as the dependability of the qualitative study depends on the conditions of the study (Connelly, 2016). As described in Shenton (2004), I planned to address dependability by describing the methods (the data gathering as well as the data analysis process) sufficiently so that they can be replicated. I also planned to reflect on the dependability of the effort once it is completed (Connelly, 2016).

### **Confirmability**

This refers to the degree to which the findings are consistent and can be replicated. Analogous to objectivity in quantitative research, the methods for

dependability include creating an audit trail for the data analysis process that will be summarized and reported in Chapter 4 (Lincoln & Guba, 1985; Shenton, 2004). My detailed notes included records of all decisions, and these were reviewed by members of the committee.

### **Ethical Procedures**

In any research study, the protection of the participants is vitally important. Planning for any ethical issues that may compromise the integrity of the study is an important aspect of the study. To ensure that participants can give informed consent, they must be of the age to do so, all participants of this study must be 18 years old. I described this process in the application to the Institutional Review Board to affirm participant protection from recruitment through debriefing and representation in the final study.

In asking participants to share their lives and experiences with the researcher they need to feel their lives matter. Therefore, the focus of the ethical process of qualitative study is to plan for any conditions that might arise while conducting the study. Informed consent is outlined in the *Belmont Report*, as a method for ensuring that ethical principles are followed for research participants (Biros, 2018). The Institutional Review Board sets forth the guidelines with which I am mandated as a researcher to adhere to. Key ethical issues that must be resolved are:

- Genuine and competent research. The research study needs to be conducted honestly. This means being truthful about how the study is conducted and how the data is presented. It also must be conducted competently without making

crucial mistakes that lead to untrustful findings, wasting the time of the participants, or causing them harm (Sullivan and Riley, 2014).

- **Informed consent.** I have articulated the important steps to attain informed consent so that participants are aware of what they agree to (Sullivan & Riley, 2014). This is particularly important in this case, as I am asking participants to describe sensitive experiences.
- **Confidentiality.** While the results of the study will be made public, participants' confidentiality will be maintained. This includes assigning a number to each participant rather than using their real name; and explaining to the participants what will be done with the study data, including how it will be identified and stored in password-protected files (Sullivan & Riley, 2014). I will also communicate to participants that words, phrases, and sentences may be used in reporting the results. If a participant reveals the likelihood of self-harm I will stop the interview, provide the participant resources for treatment, and encourage them to contact their primary care provider, or mental health professional to discuss the thoughts of harming themselves (Cornell University Office of Research Integrity and Assurance, 2017; Sullivan & Riley, 2014).
- **Harm and distress.** As described above, protocols are in place and are explained in the Informed Consent. I will discuss with my chairperson and colleagues' ways to identify sources where harm might inadvertently occur, and how participants might respond. I have gone through training with the Samaritans and worked as an employee for over two years. I worked 327hours in 2023, and over

2000 hours before I left in 2025. This has given me insight into how to mitigate issues for a participant if they reveal intentions to self-harm. Areas where harm might occur are by embarrassing or personally offending the participant without planning to, or where trauma events are triggered, psychological distress, or a strong emotion is elicited. Participants will be made aware upon volunteering and signing the consent form that SI is the study focus and if they are uncomfortable, they can opt-out or they may wish to proceed, I planned to encourage them to call 988, the National Suicide Prevention Line, SAMHSA's National Helpline for treatment referrals and the Samaritans of Cape Cod and the Islands should they need support as prevention of harm should be a focus (Sullivan & Riley, 2014).

- Deception. The design of the study does not include a deceptive condition. All questions and the interview process will be explained and repeated if necessary.
- Debriefing. This occurs during and at the end of data collection. A written debrief in the form of a written summary was provided to participants to modify and rescind any disclosures if they choose. If recording the interview is uncomfortable, I offered to interview without being recorded (Shenton, 2004).
- Right to withdraw. Participants were told they may withdraw without penalty at any point in the study, including at the interview itself. This was communicated before giving their consent (Sullivan & Riley, 2014).

### **Summary**

The overall goal of this chapter was to outline the IPA design, the role of the researcher, and the research methodology. This included defining the target group and the criteria for selection, the researcher's role, and the methodological procedures. I listed the interview questions and literature sources to substantiate the content validity of the questions. I described the procedures I planned to use to enhance the trustworthiness and confirm the ethics of the study methodology.

## Chapter 4: Results

### **Introduction**

The purpose of this study was to explore the experience of SI (SI) in individuals with AA. I explored explore SI and also how people with this condition chose not to end their lives. The following research questions guided the inquiry.

RQ1: How do individuals with AA experience SI?

RQ2: How do individuals with AA Experiencing SI abstain from acting on their suicidal thoughts?

In this chapter, I review the data collection methods, including the number of participants, duration and how the data was collected, variations in data collection, and any unusual circumstances encountered during the data collection. Then, I describe Smith et al.'s (2022) procedures for IPA. I describe the efforts to improve trustworthiness, and the explain the results of the thematic analysis to address the two research questions. I conclude with a summary of the chapter.

### **Setting**

As described in Chapter 3, four interviews were conducted using Zoom, and four were conducted over the telephone using the Zoom link. One person was in the car using her phone. The participants did not report any personal or organizational conditions that influenced their ability to complete the interview. Although the participants were all asked to ensure they had privacy and the interview should take place in a separate room from others, some participants did otherwise. P6 for instance, requested being interviewed during a time when she was being driven to a doctor's appointment because

it would take at least an hour and a half to get there. She checked with her friend who was not opposed to the idea.

### **Demographics**

The participants were a variety of ages and reported experiencing from AA between 2 and 34 years. There were seven female participants and one male participant. They came from diverse parts of the United States, including Ohio, California, Massachusetts, and Montana.

Participant 1's interview took place while the participant was relaxing in their living room. Relaxed and self-assured, this participant described how they had an injection for typhoid fever before deployment with the Disaster Medical Assistant Team from Ohio to Haiti in 2010. P1 never made it to Haiti as they contracted typhoid fever from the live vaccine becoming hospitalized and very sick. After their recovery, P1 suffered from a weakened immune system, and extreme pain, and in 2013, P1 was diagnosed with AA. Unlike most cases of AA, P1 has never had any surgical procedures, which stumped the medical community. This interview was completed in 90 minutes and was conducted over Zoom with the audio saved to the cloud.

The interview with Participant 2 was mixed with laughter and tears and took approximately 2 hours. P2 injured their back in a roll-over car crash; however, it was the steroid injection mistakenly injected into their spinal cord that eventually led to the diagnosis of AA in 2020. Despite P2's condition, she still finds joy in her garden and has an attitude that despite AA in both her back and neck, she believes there are others both better and worse than her.

Participant 3 experienced an autoimmune disorder that resulted in a degenerative disc disorder. P3 was diagnosed approximately in 2017, after a second back surgery, and has had nine surgeries in total. P3 sees this disease as torment and stated that it robbed her of a great deal. At the same time, she prays at night for all the things she's grateful for, which are many.

Participant 4 was the longest survivor of AA to be interviewed. The interview lasted an hour and told the story of a survivor in every sense of the word. Diagnosed almost 35 years ago, P4 has found pain control that meets their needs and allows them to lead a normal life. P4 was reluctant to share much information about themselves. They had testified at a government hearing in which they spoke against the FDA's policy on opioid medication for individuals such as themselves, who suffer from an incurable disease and how that leads to suicide in those who experience intractable pain.

Participant 5 was the most challenging. P5 had great difficulty connecting via Zoom and was in a frail condition. P5 declined to be visually identified for the study and only an audio footprint was obtained, which was saved to the cloud as were the data from all the other participants. Like another participant, P5 had a fear of government retaliation, and that their pain control protocol would be targeted. P5's interview took a little over an hour given the participant's frail condition.

Before being diagnosed 2 years ago with AA, Participant 6, was diagnosed with hypermobile Ehlers-Danlos disease, a connective tissue disease often found in individuals with AA. P6, was diagnosed with AA after surgery for Tarlov Cyst surgery and has numerous co-morbid disorders. P6 related her and her husband have gone into financial

debt, due to the high cost of medical care and medications, The interview with P6 was accomplished while they were being driven to a medical appointment by a friend.

Participant 7 was first told she was either depressed because “she was a single mother,” or it’s “because I am crazy and it’s all in my mind and they can fix that,” by the same doctor who did the procedure that resulted in the AA diagnosis. P7 was told repeatedly by other medical practices they would not take her on as a patient, again, because the doctor who did the procedure was already her doctor. P7 considered going to Columbia where euthanasia is legal. She sees herself as her son’s role model and must show him “no matter what situation we go through in life, no matter if you literally fall to the floor, we get up and keep on fighting.”

Participant 8, like all the participants, fears losing their physician and access to pain medications. In an email from P8 while the data analysis was taking place, the participants revealed their greatest fear had come true, their pain doctor was going to be leaving the area, and this participant had no idea what she should or could do. She also no longer has her boyfriend to do many of the everyday tasks.

### **Data Collection**

Data collection was carried out as described in Chapter 3, with some variations ranging from time to collect data to how data was collected. I conducted each Zoom interview in a private area of my home office and each participant confirmed they were able to speak freely. Each participant was provided with a review of the interview process, and the purpose of the study. Before the interview started, I sought permission to begin the study and reminded the participant that only the audio recording would be

saved. Some interviews were longer than others and the physical condition of participants varied depending upon the stage of AA they were currently in, and other co-morbid conditions caused by the AA were present.

At the end of each interview, I inquired if the participant was suffering from any distress that they wished to talk about which was answered by each participant that they were fine, and they were provided the opportunity to ask questions or express any concerns they might have. I concluded by thanking each participant and revealing to them that I also suffer from AA. All participants were sent a summary of their interview and were asked for feedback. Three provided additional comments, and all approved the summaries.

### **Data Analysis**

As described in Chapter 3, I used the Smith et al. (2022) procedures for IPA. In the first step, I read and re-read the transcripts and listened and re-listened to the audio to immerse myself in the data. For the second step (exploration), I summarized all eight interviews and added to the notes I took during the interview to audit my reactions and thoughts about the participant's responses and producing a comprehensive and detailed set of notes and comments. The coding process consisted of listening to the audio transcripts and re-reading the transcripts. I began coding using Atlasti.com and switched to manual coding with MSWord, creating tables and highlighting text.

The next step was to construct experiential statements, which is an important stage for consolidating and crystalizing my thoughts as I worked from the transcripts, exploratory notes and summaries, and identified potential themes. This was repeated for

all eight interviews. Table 2 provides an example using Participant 1. This participant was particularly evocative in her description of the intense pain she had to manage, and what she would do to stop it: “If someone told me to stand on my head, 2 crackers with peanut butter in my mouth and whistle, I would do it if it was going to fix my pain”. She also expressed actions of self-harm (cutting), as well as her reason to live (Korey, her granddaughter).

**Table 2**

*Example of PES, Potential Themes, and Quotes, Participant 001*

Experiential Statements	Potential Themes	Quote
AA Not from Surgery, Symptoms of AA, Result of AA, Dr. Tennant	Background	“Having that typhoid ruined my immune system, and that’s how I got AA.”
Pain Relief, Heat relieves Pain, Pain Management, Drugs as Lifeline, Ready for day after morning meds, Planning for the future	Living with AA	“If someone told me to stand on my head, 2 crackers with peanut butter in my mouth and whistle, I would do it if it was going to fix my pain.”
Not Drug Addict	Living with AA – Social Perception	“I have chronic pain. I take methadone. He thinks I am a drug addict. He thinks I am a dope head.”
Burden to others	S.I Precursor	“I know I am just a burden, you know. I’m in healthcare and I know you get caregiver burnout. So, I just knew my husband is, he’ll get caregiver burnout one of these days.”
Self-harm	Suicidal Attempt but no harm	“I was ready to be done, it, I started cutting my arms. You know I am an adult who knows better but I was in so much pain I had to release the pain somehow.”
SI, Caregiver Burnout	SI	“That is what I would have probably done would have gone to the garage with the car, with the carbon monoxide, and drink a lot of alcohol, I was drinking a lot, too, I was drinking a lot of alcohol and mixing it with my painkillers because was in so much pain.”
Korey: Her Reason for being and living.	SI - why not do it	“I could never do anything because of her [granddaughter]. What would that do? To what legacy would that leave for her [Granddaughter]? So, I just can’t do it.”

For Step 3, I sorted all the PES, potential themes and quotes by potential theme and examined the statements for common elements. After generating my own list of common and discrepant elements, I entered the statements into an Artificial Intelligence application (Anthropic, 2025). I first prepared a statement defining the search parameters:

This is a proprietary dataset of interview data statements stated by people with AA. Do not use any other inputs, just this data. Please identify 7 common elements among these statements that summarize how these individuals were diagnosed with this condition, and the circumstances around the process of getting properly diagnosed. Also identify the statements that don't seem to go with other statements (i.e., the statement is unique to others).

I reviewed the AI output, looking for similarities between my own generated elements, and discrepancies and hallucinations generated by the AI. Table 2 depicts an example of this intermediate stage. For the potential theme SI Precursor, I noted where there was commonality between the elements I identified and those identified by the AI. I also noted where my considerations for elements were discrepant with those generated by AI. I refined my findings using the AI generated content as suggestions, rather than final content statements. An example of this is represented in Table 3.

**Table 3***SI Precursor: Common and Discrepant Elements of Potential Themes*

Potential Theme	Elements Common Between Researcher and AI	Researcher Discrepant Elements
SI Precursor	Burden to others. Leaving people behind is tough but the unbearable pain and life no longer meaning is worse. The wish is to be free of pain rather than just die. Fears loss of pain doctor would force him to commit suicide like others he has known. Way out End of struggle. Ruminating on how they did not deserve this All their accomplishments are gone. Caregiver burnout. Not how they wanted to live. Thinks about consumption of all their meds. Will know when enough is enough and be ready when that day comes. Self-harm SI Frequent thoughts during the first year. End of the struggle.	Would go to Columbia where euthanasia is legal. Son told her to go ahead to Columbia if she needed to, as he did not to see her suffer anymore. Not ready to curl up and die. Permanent sleep means no more pain. SI when have a lack of sleep. Leave letters to those left behind-overwhelms her so continues to live. No one would know they were doing it intentionally. Not brave enough.
SI Precursor: "Why Not"	Korey [granddaughter] is their reason for being and living.	Would devastate his wife.

I further refined my findings using the AI generated content as suggestions, rather than final content statements. I reviewed the results of this process again, moving experiential statements from one theme to another to create homogeneity of meaning within each theme. I also clarified that P6 was a discrepant case, as most of her interview

statements were very different than the other participants, as will be described below. I also identified discrepant statements within themes that participants voiced as unique and compelling. The final themes and experiential statements are presented in the Results section, with accompanying tables and exemplary quotes.

### **Discrepant Case: P6**

P6 is considered a discrepant case because by the age of 56 she was being actively treated for 59 medical conditions, including AA, Hypermobile Ehlers Danos Syndrome (HEDS) and Rheumatoid Arthritis. She has been seeing a variety of specialists weekly; however, P6 continues to blame AA for her pain. She stated she is not treated with any pain medication because of the other conditions but had a series of Ketamine infusions for AA that made her sick. To P6, “treating symptoms when they come up” is tantamount to not treating her AA. P6 also stated that she needs tethered cord surgery (when the spinal cord attaches to the spinal canal during fetal development, and as an adult the cord stretches and restricts the blood flow to spinal nerves leading to numbness, weakness and loss of motor control).

She reported experiencing periods of SI, stating that taking all these medications together is incredibly inviting as she believes she will “just fall asleep” forever.” P6 described “relief” and “control” as the thoughts that come up when she was asked about suicide. P6 also felt she was a burden to her husband: “I have ruined us... it’s the financial burden that is so bad.” They doubt they will ever get from under it.

Her future is much bleaker than the other participants because of all the complications of her other conditions. Her rheumatologist says the reason her fingers (and perhaps her

legs) are hard to move is the RA. Should a wheelchair become a necessity a “care facility” becomes more of a reality because her small house could not be made accessible. P6 described how she makes key chains out of beads as an occupational therapy for her fingers. Last year, a local newspaper did a story on her and how a television program was using a keychain as a prop on the show. Asked how she survives given the weight of the financial burden, P6 replied “pure grit”; “I don’t take no for an answer”; I am surviving on pure spite.”

### **Evidence of Trustworthiness**

#### **Credibility**

During the data collection process, I acquainted myself with the culture of the participants who were recruited for my research study. Being already familiar with the phenomenon, my goal was to become familiar with each participant, establishing trust between myself, and each participant (Shenton, 2004). To further establish credibility for this study, I read and re-read the written transcript gleaned from the audio recordings to become familiar with each participant. I achieved persistent observation by becoming familiar through reading and rereading the data which I then analyzed and edited the codes. I further categorized them before finalizing the themes that provided in-depth insight into the phenomena (Korstjens & Moser 2018).

#### **Transferability**

The purpose of this qualitative study is not to obtain generalizability but rather to contribute to the understanding of SI and document the existence of a major medical phenomena, namely SI in adults who have AA. I utilized thick description and added

contextual elements for each participant's experience. Further, I attempted to make transparent the data collection and analytical process so that others could replicate the study (Nowell et al., 2017; Shenton, 2004).

### **Dependability**

Dependability was sought by the attention to details, especially to verbal communication, paying close attention to the interview guide. I reported on these details. A reflective journal was utilized as another strategy, with an audit trail to ensure the study's dependability and guide the data analysis process (Nowell et al., 2017; Shenton, 2004). These strategies were consistent with Chapter 3 and contributed to the study's dependability of process and findings. A study on SI in adults with AA has not been done before and or previously reported. It is anticipated that detail to be provided by this study for future applications is anticipated

### **Confirmability**

In order that my own experiences would not obscure the process of data-gathering and the analytic process, ZOOM interviews were conducted and recorded with the Zoom platform. Using the audio recording I attempted to quote verbatim in order to capture interviews and prevent me from including or excluding any data. I strove to maintain accountability given there is a close relationship between myself and the phenomena. To minimize the bias of my own experiences with AA, I took several steps to ensure that my data collection and analysis of the data would not be compromised. Journaling helped achieve ethical reflexivity for the purpose of acknowledging and confronting biased thoughts or comments on data that might have arisen during the data collection process

where my worldviews and personal experiences could have influenced the analysis process. Openness and honesty describing my own experiences of living with AA with each of the participants was done after all the interviews were completed. My own experiences enabled me to be empathic and allow the participants the opportunity to speak as freely as possible regarding their lives with an AA diagnosis.

By describing the procedures used to reach findings, confirmability was enhanced. The use of the interview guide reviewed and approved by Walden University's Internal Research Reviewer and subject matter expert prior to the approval of the study (Shenton, 2004; Smith et al., 2022). In Chapter 3 any potential influences were listed that might potentially impact the interpretation of data to were identified in the Role of the Researcher section of this study.

## **Results**

The results of IPA produced four themes, and 17 sub-themes. These are listed here (the subthemes are presented in parentheses). These include:

1. Background (the context)
2. Living with AA (waking up/ managing medications, "I'm not a drug addict", social support, daily suffering/severe pain, contentment/acceptance, gratitude, psychological, coping and adaptation, and loss of independence and function)
3. SI ("What Comes up for Me?", experience of being a burden, thoughts and ideations, what are the deterrents, as an escape from pain, loss of identity and purpose, planning and control over death, and outlier statements)

4. What I want People to Know (the meaning of this theme, supported by direct quotes from participants).

### **Background**

The theme, background, contextualizes the experience of SI in persons with AA, revealing the many similarities and some differences in how they developed this condition. The common and discrepant elements of this theme are presented in Table 3. Most common was participants sharing the symptoms of AA appearing (and then being diagnosed) consequently or coinciding with a surgical procedure, or administration of an epidural. For example, P3 described being diagnosed after 2<sup>nd</sup> surgery. P7 described how she developed AA:

...and they were putting the needle in my spine, I felt it like bone or something really, like hard, like it was, you know, trying to force something in. And it was not budging. And I told him he was hurting me. And he told me to sit still that he's almost done...and then when he puts the medicine in, I feel a burning sensation that goes into my spine and down my legs. Within 15 minutes I was in pain. And ever since I have been in pain.

What was also common was the experience of seeking a diagnosis and being sent from doctor to doctor without a clear answer; and being told that it's "all in your head" (P7) or "you don't want to know." (P8) P5 was told that "it's psychological." Dr. Tennant was mentioned numerous times as the physician ("I sent my MRIs to Dr. Tennant, and he diagnosed me with AA") who correctly diagnosed their case and gave them directions for treatment and management. What made the process of diagnosis more complicated was

participants' financial ability to seek proper diagnosis and treatment protocols. For example, P5 could get expensive stem cell treatments, while P6 stated "We have used all our savings and travel fund on medical expenses and maxed out our credit cards on my medications." What also made the diagnosis complex for some patients was the presence or emergence of co-morbid conditions. Particularly in the case of P6, whose discrepant experience was composed of a plethora of medical conditions such as a tethered cord syndrome and Hypermobile Ehlers-Danlos Syndrome (HEDS), a connective tissue disease and AA are common in these patients (Tennant, 2024).

### **Living with AA**

The theme, living with AA, reveals the physical, contextual, social, and emotional experiences of what it is like to live with an "on-goingly" painful chronic condition, described as "pure torture." "I think now if somebody tortured me, I'd be okay with it because I feel like I've been through it." (P3) The participants revealed living with AA as a struggle to find access to the things of normal life that most people take for granted. P2 described how she manages her garden:

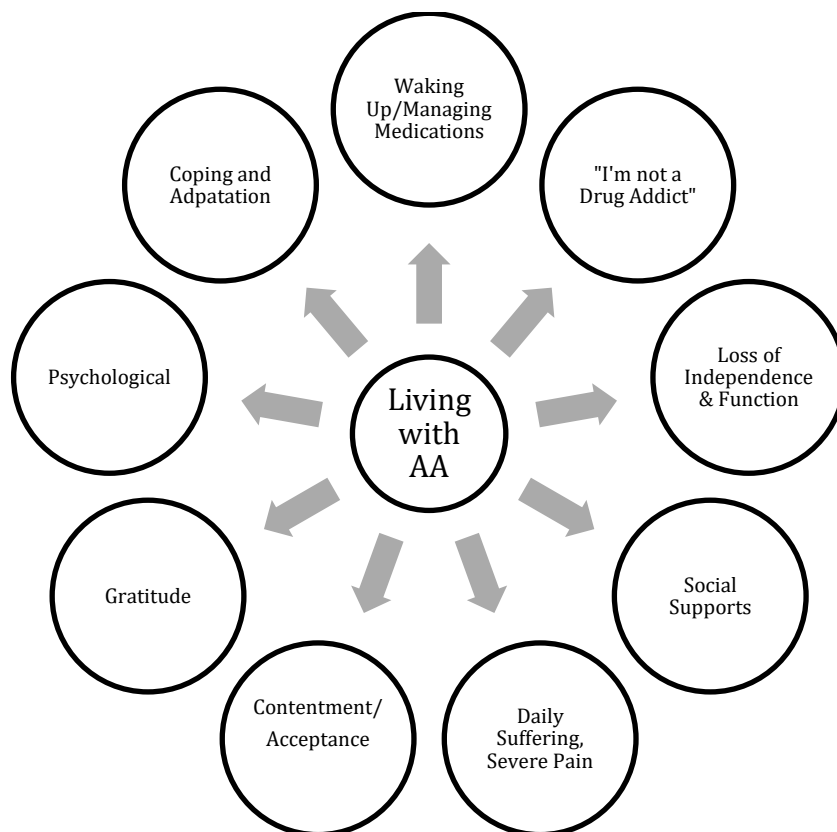
I have a special chair outside that I lay back, and I can go and water for a minute, lay down in my zero gravity chair, water a minute, lay down on my chair, And I get a lot of enjoyment out of that but I can't go to a friend's house unless I know they have a couch I can lay on while we are talking, and that they understand that. I can't understand, I can't walk around and stand for very long.

This theme emerged as a complex representation of this lived experience, touching on daily regimens, relationships, pain, and emotions. To fully explore this

theme, I identified nine sub-themes. These are presented in Figure 4 and are described below.

**Figure 4**

*Living with AA: Themes and Subthemes*



***Waking Up/Managing Medications***

This sub-theme is composed of the things participants do, and the experiences they have upon waking every morning. Most common is waking up to a “cocktail” of medication and then waiting for them to take effect before rising. For example, P2 is ready for the day after taking her multiple meds and finds the best part of her day happens when the “meds kick-in.” Waking up also means being re-confronted with pain

and pain management. P8 stated (and P4 affirmed) that “being without pain control is a constant fear.”

When I wake up in the morning, the first thing I do is take my adrenal gland meds because my adrenals were damaged because I tried to tough out the pain for so long. And then I take my pain meds first thing also, it either takes me longer to absorb the opioid and get it into our system, and I don't process it fast enough. So it takes two hours for a dose to sink in...and so basically I lay in bed for two hours until that has happened before I can get out of bed or I have immense pain in the soles of my feet...and so if I get out of bed before the opioid has soaked in, it puts my body into a fight or flight mode for the day and I have less ability to deal with stress. So, I lay in bed for two hours. I usually watch something on my Kindle...and when I get up the day is basically spent (P2).

Other participants have similar routines. P3 is able to do errands once her body has been properly medicated, she describes her routine as first taking Lyrica an anti-inflammatory drug, then she has an injection of a combination of methylprednisolone and Toradol. To add to her routine, she has been also getting ketamine injections. It is only then that she able to walk and accomplish her errands and by the end of the day, barely able to stand. She sleeps and the next day, the same medication.

### **I'm Not a Drug Addict**

This sub-theme is composed of statements that support their core belief that their disease necessitates the use of narcotic medication. P4 stated: “Patients with AA are useful members of society when their pain is managed.” Their direct experiences

contradict the beliefs and training of some medical practitioners who see participants' requests for medication as "pain-seeking behavior", rather than authentic requests for managing acute pain.

They have to really understand that most doctors are not equipped to diagnose this disease. Most doctors are taught to look for pain-seeking behavior, which AA can often look like because it's hard to diagnose... (P2).

P1 described their experience with a doctor: "I am on methadone. He thinks I am a drug addict. He thinks I am a dope head." On the other hand, P5 noted she has a network of awesome doctors: "they provide necessary pain relief." Drugs are a lifeline, although P4 noted his pain needs have changed over time. Participants seem to agree that life can be good as long as, their pain is managed.

...see the person. Don't look at us of, I don't know, a chart of somebody my age and say sorry they are in line to be addicts. I've proven that through the years I am not addicted. I've been off pain meds, on pain meds, and I've done it without help. I get off as soon as I can and if I need it, I think a person should have all they need for a decent life. Isn't that what medicine is all about, right? Try to make people's lives livable. I don't think they are doing that with people...and they won't listen to the research and the things that are being found that help. They (medical community) need to listen (P3).

The participants did not only have to maneuver through the medical field for the proper medication for their pain, but filling the prescription can also come at a cost. For

P8, her local pharmacist has suddenly refused to fill her pain prescriptions causing her to travel 80 miles round trip to get those specific prescriptions:

What do you mean you can't fill them? I'm just not going to fill narcotics for anybody. I said, "Well, I don't think you can do that. He said, yeah, I can.

So, I wrote an 11-page complaint letter to the local pharmacy board, now I have to drive 80-miles round trip to get my prescriptions, and you can think it was fair and all the reasons why and different things and they wrote back a graph letter back and said, yep, he can do that.

There is no law that says a physician must dispense narcotics to an individual for any reason, and it is not required that a duly licensed pharmacist fill a narcotics prescription, unless the narcotic is specifically for the treatment of cancer.

### **Social Supports**

Although the ability to maintain social contacts changed considerably because of the pain, this sub-theme describes the experience of the different types of social support utilized by the participants: social support systems; what it means to be supported/to support; and social contacts. Social support systems include family and friends. P7 described talking on the phone with family every day, and does video chats when her family travels:

... they take me on a trip with them. We do video chat, and they show me, you know, where they are at. So, I kind of visualize myself that I am there with them and just, you know, enjoying the food...

What it means to be supported/to support was represented by participants' feelings about support. P6 noted "we are all meant to love, support, and uplift one another."

...especially my boyfriend because he does everything for me, everything. He cooks, he mows my lawn, he takes out the garbage, he does everything. Takes care of my dog, did take care of my dog. Oh, yeah, I'm not sure why he sticks around. Yeah definitely, he does everything for me (P8).

Social contacts refer to some participants for whom there is no family or expression of the feelings of support. For example, P8, because of life's experiences, "has no local family so she depends on her medical team for support"; as does P7 who "now has a personal care attendant (PCA) who does everything for her," despite family support.

### **Daily Suffering/Severe Pain**

This sub-theme represents how life with chronic pain provides a lower quality of life. "The pain is killing me. My husband was putting on my socks, putting on my shoes, sometimes wiping my behind because I cannot bend over" (P1); "It's severe, intractable, continuous pain" (P5); "I'm unable to walk, my feet feel like burning embers and glass shards are piercing my feet." (P2) P7 had an evocative description:

Pain is like an electric current that runs within your spine, and it's like, it extends out, wraps around the whole hips, down the legs, under my ribcage, through my private areas and my left leg cramps up...It is the worst pain ever. You want to disappear. You want to jump out of your body and not feel it or have them amputate your legs.

### **Contentment/Acceptance**

Despite living with AA, participants described how they maintained a positive outlook on life and learned to appreciate others. “Some people have worse hardships; some people have less hardships, which are less hard. But regardless, anyone who has a hardship, they feel overwhelmed”, P2 explained.

Participant 2 finds that listening to music, especially NuMetal brings joy and relaxation. “With this music I am part of a community, and my struggles are like others, and they are reflected in the lyrics of the songs...Music does not create restrictions like AA does.”

I like a very specific genre of music, and it’s the only thing that makes me feel part of a community and the music itself often sings about the same emotional struggles I have...and not only does the music help me to forget my pain and my anger and my loss...it helps me to not feel so different, it brings me joy and helps me focus on the positive to stay alive.

P8 described how traveling and short trips make her relax and enjoy life despite her severe pain. For P4, “...as long as pain is managed life is good.” Contentment came in numerous ways for the participants. While expressing how severe pain has changed their lives for the worse, they have found ways, however minute, to find joy, and a degree of acceptance and contentment for the changes in their lives.

### **Gratitude**

Gratitude was a unique subtheme, consisting of acknowledging someone or something in the participants’ lives that helped make their lives easier and even joyful.

P2 said, “I try to find something that I am grateful for in the moment”. P8's boyfriend consistently handles yard work, cooking, cleaning, and other household chores without complaint. This generosity, however, also comes with a significant amount of stress, which is another element they consider when expressing gratitude. P8 recognizes “her gratitude for his help, but at the same time I feel sadness and a sense of despair, which ultimately creates more stress, because I am unable to do the chores myself.”

Somehow, despite excruciating pain other participants find gratitude, even in the mundane. P3 stated:

My faith is very strong, and I work hard every day to be joyful. I write down things that I am grateful for at night and when I wake, I pray about things I have written down and am grateful for. I appreciate everyone and everything that touches her life: walking outside seeing the birds sing-zooming in on all the little things...”

### **Psychological**

This sub-theme represents the psychological aspects of living with AA. The common psychological experience was depression, expressed in a variety of ways. Participants P7 and P8, were told by some doctors that their condition was “psychological.” “The doctor told me ‘You have something really bad, and you don’t want to know what it is’” (P8); “...and that doctor that did it told me I was either depressed because I was a single mom, or I am crazy, and it is all in my mind and they can fix that,” (P7). For P5, described not having any emotional reserves left to deal with stress, because she is already maxed out managing her pain. This led to stress and

eventually depression, and her psychological state became somewhat tenuous. “When I was suicidal, I focused on the losses and got depressed about what I had lost and the quality of life I had before this.” P5 and P4 know each other, and they have other acquaintances that have AA. They help each other get through the bad days, providing each other with support, as they understand exactly what it is like to live with the physical and psychological pain.

### **Coping and Adaptation**

For the participants, finding a way to function day-to-day is a priority. P2 described her zero-gravity chair that allows her to rest as she gives her garden the care she lovingly provides. P7 explained how she adapts to the situation.

Sunday, I went to the pond, and I had to wear a loose dress and sneakers because I can't wear sandals. Because my feet cramp up and I get bruises on the bottom of my feet. I had to bring ice packs, like basically a cooler full of ice packs filled with ice. My walker, my wheelchair...

P7's ability to put together the ice packs, walker, and wheelchair was a testament to her desire to be with others and to cope and adapt to the situation. The other participants adapted to their situation as well. P5 described:

I'm increasing my steroids to deal with the inflammation, increasing the opioids, plus Ibuprofen, wearing my back brace, and then I am using my hot tub every morning before I go to work, I sit in the hot tub and that helps a lot...so these are my tools so I can still function.

P2 finds planning everything in advance helps her cope with her surroundings and her pain. She explained, “yeah. Okay, um, so, um, Yeah, so things like being extra fatigued and then getting extra frustrated with something unexpected happening. I have to plan everything I do.”

P4 developed skepticism toward the benefits of any procedure after his surgical experience, as a way to cope, with the multitude of doctors who he believes have tried to push different procedures to him, for a problem they created. “I was so mad at my doctors that gave me this disease that I was really skeptical of any procedures, and I kept out of the operating room.” P4 believes that is what saved his life. “I watched a lot of my friends. Every time they got a surgery, they were a little more disabled, and pretty soon they killed themselves, you know.”

### **Loss of Independence and Function**

This sub-theme brings out the sense of loss all the participants feel.

... then my thought was, I never get around, I can never ski again, I can't do this, I can't do that. It's just all my losses. And then when things get bad...you know my health, I don't have reserve to deal with stress, you know, it comes in many forms, and I don't have the reserve to handle that anymore because I am already maxed out managing my pain... (P5).

The essence of this experience is not just the loss of everyday activities; there comes a point where the body fails. For P1, her right foot literally froze. “If you touch it, it's frozen. So, I wear it's called ‘hot hands. I buy them by the case from Amazon, and I put one in the bottom of my shoe.” (P1)

...because of the sympathetic damage I've done to my foot, when I shave my leg, my right leg, you can't feel it. I see the razor on my leg, I feel nothing. I also have numbness in my perineal area...every time we move, we put bidets on the toilets, because I can't tell. The bidet water comes from the tank water so it's ice cold. I can't tell that; it doesn't feel ice cold to me. I don't feel a thing (P1).

Loss was also felt in the experience of relationships. As P1 described, "So, it took a lot away. It really did. I was engaged at the time, and I broke it off. Because I thought this is not going to get any better." P3 speaks for all the participants and the lived experience of AA:

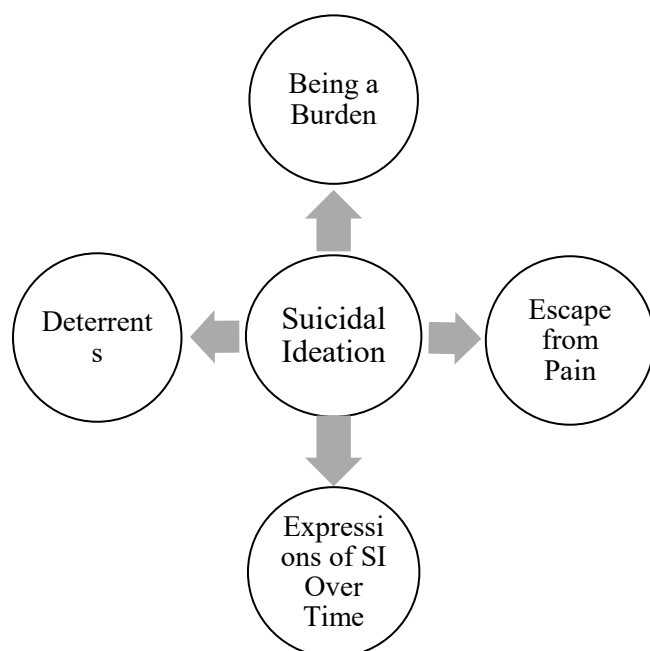
...try to imagine. I think the best picture for me is, I think, most people understand the fear of being tortured. And I think you understand that if somebody was being tortured every day, constantly, you would do whatever you could to help them. I don't think doctors, friends and family, they don't grasp that...

### **Lived Experience of SI**

This theme describes the dynamic essence of SI as it is present in persons living with AA. Common to all participants was the experience of being a burden, although this was expressed in different ways and at different points of their lives. Four sub-themes emerged from the data: being a burden, escape from pain, expressions of pain over time, and deterrents. These are described below and illustrated in Figure 5

**Figure 5**

*Living Experience of SI: Themes and Subthemes*



### **Expressions of SI Over Time**

This sub-theme describes in a non-apologetic detail the unique SI the eight participants experienced as they varied in terms of time and expression. First, all participants expressed some kind of underlying thought process about suicide as the final ultimate control over their bodies and pain. For some, it was the thought of not waking up (“...some days the thought is so inviting...to fall asleep and not wake up again” - P6). For others, it was the relief from burdening others with their care (“My family would be financially set. They wouldn’t have to deal with my crap” - P1). For others, it was the loss of quality of life (Uh-huh, loss. Just focusing on my losses and getting depressed about what I have lost and the quality of life I had before this.”) (P5). They all described

the possibility of suicide as having control over their bodies and not having to be in pain any longer.

I have really mixed emotions. Part of me feels really relieved because it gives me a way out and then the other side is I won't have to struggle every day...I don't need to be in pain anymore; I have control of my life (P2).

Second, the expression of SI occurred at different points in time, depending on where participants were in their disease process.

I would say that first year, I was writhing in pain. Yeah, there were no answers. And it was like, honestly, I think now if somebody tortured me. I'd be okay with it because I feel like I've been through it. So. Putting that on my family. I just didn't want to do it. ...I couldn't do anything, and I remember one time in the shower, and it felt like water running down my legs and it's pulsing and spazzing and then I realized the shower isn't on and I thought I cannot do this anymore.

For some participants, these thoughts come and go. P4 described his suicidal ideation to be a thing of the past,

...I had some really big plans to kill myself. I like plans. And so, I live on a little lake, right here. One of my plans was to get my fishing pole and ice auger and walk out there to a spot where I knew the ice would break. And do it at night so everybody would be in bed, no one would see me, and I just would walk out there and fall through the ice.

Now, Participant 4 has different thoughts, in part, because he can't leave his wife "I love her. She would be devastated...so I will never do that." Participant 1 never thought of a plan specifically, but described for me what she imagines...

What I probably would have done would have been to go out to the garage with the car and the carbon dioxide and drink lots of alcohol and mixing it with my painkillers because of the pain. You know physical, mental...

P4 has worked hard to eliminate his pain and as such, he testified before the FDA in defense of pain control for patients with relentless, severe and debilitating iatrogenic pain. As one conference publication noted: "His contribution to this effort is unsurmountable and the number of lives he saved from suffering the same fate as his is incalculable" (EDMS, 2019). P4 went on to say:

The thought I have toward now, is, is, I'm, uh, if the FDA kills my doctor... and I lose control of pain. It's going to be hard for me to find a new doctor, because I'm on a high dose, you know because of being a rapid metabolizer. And there's not a doctor in the country, I think, that would take me as a patient. And my pain would force me into suicide.

### **Being a Burden**

The sub-theme Being a Burden tells of the experiences of those with AA and their relationship with their families and caregivers.

So, I know my husband will get caregiver burnout one of these days. I know one of these days you'd be like, you know—here...here's the keys to the car. I take, which I told you about, you know overdosing on Elavil is fatal. So, you know,

here's your bottle of Elavil, (P1), just keep taking them until you can't swallow anymore. I just know one of these days, he's going to say that (P1).

Being a burden is the experience those with AA because their pain is unrelenting and intractable. Participant 6 (who has AA and co-morbidities) must manage extremely expensive care, and describes with exasperation:

...holy crap, you know would my husband be better off if I hadn't cost him, us, all our savings and our travel fund? You know, he has friends right now that are retired, he should be retired, but he can't. I need the Blue Cross from his employer. That's a huge impact of guilt because our entire life has changed from what we thought the future was going to be like with traveling, with financial security. It's made it a complex nightmare of a burden.

For Participant 2, being a burden is something she feels all the time.

Even though I have worked through a lot of the emotional things with this disease, I still really feel like a burden because, so nicknamed myself the 'money pit' in my family, because I always have some, there's always a big expensive test that needs to happen or a treatment protocol that might help me I want to try...

Besides feeling like a burden, Participant 7 felt she should never have had the procedure that led to her AA. She questioned: "you know, why did I do this? Why'd you go to the doctors? Why didn't you stop him...But I've, I've learned, you know, that my family, they're still there".

### **An Escape from Pain**

Escape from Pain is a sub-theme that looks at what ways participants utilize their SI to escape from the pain and the circumstances that may exacerbate pain.

...I can't put my shoes and socks on by myself anymore. You know, never. I can't. I was a burden to my family, and I was ready to be done. I started cutting my arms. You know I am an adult who knows better, but I was in so much pain I had to release the pain some way. So, I've got scars on...I'm right-handed so I've got scars on my left arm, where I was cutting...

The circumstances may be unique, and you can't imagine that anyone has ever done or experienced the degree of suffering that the eight individuals in this study feel.

I will be driving my car, and I will have the radio on extremely loud because one of the ways I have learned to help manage the pain is through distraction and the louder the music is it will distract. I wonder what would happen if I hit that tree. That would end the pain...so draining to be in pain 24/7 with nothing making it better...

Thoughts and ideations can occur at almost any time. P6 says a lack of sleep can lead her to SI and thought. Participant 3, her SI was mostly during her first year with AA when she felt "tortured." P5 described how extreme a road her pain has taken her, traveling as far as Europe and many places in the United States to find relief. After her visit to Germany, she attempted suicide. She stated her experience of SI in her attempts to find treatment to relieve the pain: "Here I go again, it's like *déjà vu* all over again... and

that's the part when I think about that [i.e., travels for other treatments], I can get in this endless loop of 'here I go again'..."

Participant 8 described her experience of having suicidal thoughts and she believes it is not because people want to die, it is just that you just want the pain to quit. "Thinking about it not that long ago, not that you, you want to die, it's that you want the pain and agony to stop." For Participant 4 who describes his life:

My life is pretty good right now because I have pain control, and, um, you know, when you're it doesn't matter how bad your pain is...when you know it's going to get better...you can endure any amount of pain if you know there's an end to it.

### **What are the Deterrents?**

For the eight participants in this study finding life, with a body wracked with pain, is a compromise. P6 said: "... and I think no, my luck is so horrible, [if I tried to kill myself in a car crash] I will survive this crash, and it will make my situation worse." For P8, her doctor asked her "...have you ever thought of...? And how you actually would do it? If you ever get to that point, you better call somebody'. But I've never gotten that far."

Participant 1 talked often about Korey, her granddaughter:

I got no motherly love. My grandmas were all old and dead by the time I came along, so I didn't really have a grandma relationship. So, I want Korey's relationship with her BG (*Best Grandma*), to be nothing but fun memories. My grandma taught me this. Me and my grandma would do this. That's what I want her to be able to say. I survived Covid...you know. So, obviously, it isn't my

time. There is something here for me to do, and I think it has to do with that little girl...I could never do anything because of her. What would that do. What kind of legacy would that leave for her.

Participant 2 has a unique perspective:

I've also feel I've told myself that is I ever do actually do that, which I have felt like I was actually going to do it before, I want to write letters to the people that I care about to let them that I love them and you know that I just can't take the suffering anymore. But that's a lot of work to write letters and I get overwhelmed...and sometimes that in itself saves my life because by the time I've gotten through some of the letters, I start to remember I have reasons to live...and I don't want to end it if I haven't finished the letters.

P5 reflected on her final acceptance of her diagnosis of AA.

I'm always going to be in pain. And I just didn't want to do it anymore. And there are actually there's a couple of times I actually attempted suicide...But when I focus, I have to accept it, you know, and I have, otherwise still, I wouldn't be here. I've come to accept this is my new life, but when I feel lost and sad, I can get into depression and not want to do anything. That's not going to help me...Oh, I am looking forward to when I retire.

“Quit operating on us!”, Participant 4 exclaimed:

...you know, and I am fortunate because I avoided, you know, I was so mad at my doctor that gave me this disease that I was just really skeptical of any procedures, and I kept out of the operating room.

Not everyone is convinced that they could die at their own hands. Participant 7 described her thought process and how she would not be able to do it, "...I can't do it myself."

I've considered going to Columbia for euthanasia...I remember, my son was 15 years old, and I was watching the news, the Spanish news, and this lady...she couldn't take the pain anymore and they passed a law in Columbia where you can be euthanized because of a medical condition. And my son saw that, and he asked me, he told me, if you want to do that, it's ok. I don't want to see you suffer anymore, but I am going to miss you...

### **What You Want Others to Know**

This last question asked the participants to describe what they want others to know about them and about AA in general. This was an open-ended question and their responses varied from what people should know about their disease: "I just wish they understood it more (AA), like my physical therapist. I thought she'd know (P8)"; and to wish that people would look at them and realize they were suffering, in most cases silently. Participant 3 stated: "Don't look at the surface. Try to imagine that someone was being tortured every day constantly." And P6 related to an additional sentiment:

But what I'd really like them to learn and see is, I am trying to do this with grace. I'm trying to do this to the best of my ability. That's what I want to be remembered for, not the person who has spent years in their life (like this).

Other responses were more generalized. "It is not easy trying to be a normal person against a point where we don't know what normal is anymore." (P7). Some were

more optimistic about what they can and cannot do with AA as a diagnosis: “I can’t have seven horses in my field I can rotate riding, but I can have 20 plants that I can keep alive.” (P2). Seeing life beyond AA does not negate the pain and constant feelings of being considered less than due to their degree of disability is disheartening.

I wish people would just say it’s a horrible, horrible condition. Sometimes I can’t get out of bed for two or three days, and because I am on disability, they think I’m just out here retired, or I just don’t want to work. (P8)

Still, there is a desire to be like others who do not suffer from disease, “I want to live life. To be able to walk out in the air, even with a walker” (P7). Another participant spoke for herself and others with AA when she said: “Focus on things that bring you joy and keep focused on those and keep reminding yourself of those things and find things you can do.” (P2)

More than anything, these eight participants want their doctors to be accountable. P4 stated quite bluntly: “Quit operating on us, you know, I was so mad at my doctor that gave me this disease that I was just skeptical of any procedure.” (P4) Besides accountability these participants do not want to be considered ignorant, “And a lot of times when you mention it to a doctor, they look at you like you are stupid.” (P3). P2 described how “...most doctors are taught to look for pain-seeking behavior, they are not equipped to deal with this disease.” P4 re-iterated the sentiment of all the participant to anyone who cares to listen: “we are not drug addicts; we can be productive members of society if our pain is treated.” P6 expressed her philosophy: “you are not the label ‘disability’—there’s more you can give and provide.”

P7 reflected on their lives compared to others: “You know some people are lucky. They can walk without pain, the easiest thing that comes naturally. Imagine trying to get up and you’re stuck. And that pain is a test” The eight participants are crying for relief from pain, for understanding, and for empathy, particularly from those that think any of these eight retired early, or they do not like working, and are faking it. P3 expressed: “Deep down we are crying—we’re in pain. We’re miserable.” P7 said: “It’s not easy trying to be normal against a point where we don’t even know what normal is anymore.”

### **Summary**

In this chapter I described the data collection and analysis process for exploring the experience of SI (SI) in individuals with AA. The intent was to explore SI and how people with this condition chose not to end their lives. Using IPA (Smith et al., 2022), the eight participants revealed the complexities of their day-to-day lives balancing the management of relentless pain with daily activities of normal life. Their heroic efforts and challenges were represented in four major themes (background, living with AA, SI, and what I want people to know); and numerous sub-themes. Trustworthiness was demonstrated in detail in describing the data analysis process, and steps I took to minimize bias and authentically express their experiences. The meaning of these results, and the relationship of the findings to published literature and framework are presented in Chapter 5.

## Chapter 5

### **Introduction**

The purpose of this qualitative study is to explore the experience of SISI in individuals with AA. The results of this study may contribute to a better understanding of the subject and some of the processes involved in the complex relationship between chronic pain and SI. This area needs research as there is no previous research that explores this topic.

Perhaps the most powerful finding of the study is the courage and determination expressed by the participants in their efforts to balance the management of relentless pain in the most mundane of daily life with efforts to find joy and contentment. Their heroic efforts and challenges were represented in four major themes: Background, living with aa, SI, and what I want people to know. The findings are summarized for each theme and interpreted in terms of the published literature and the conceptual framework described in Chapter 2.

### **Interpretation of Findings**

#### **Findings Relevant to the Literature**

The importance of the theme, background, was to contextualize the experiences of the participants by understanding how their condition presented, how they were diagnosed, and the struggles of finding competent and compassionate care. For most, the symptoms of AA appeared after surgery or related to a surgical procedure, or the administration of an epidural. What was also common was seeking a diagnosis and being sent from doctor to doctor without a clear answer and being told that “it's all in your

head” (P1). Differences in financial ability influenced the ability to seek a proper diagnosis and explore alternative treatment protocols.

The findings in this study regarding background are similar to the literature on other chronic conditions. Studies have affirmed that individuals with chronic pain conditions, such as Rheumatoid arthritis, fibromyalgia, and migraines have been implicated in increasing the risk of suicidality because of ongoing physical and emotional suffering (e, g, anxiety, depression, and loneliness; Dahlhamer, et al., 2018; Racine, 2014). The emotional and financial toll are high, in chronic pain, as well, due to the loss of employment and the skyrocketing costs associated with medical treatment and medicine (Stubhaug et al, 2023; Yong et al., 2022).

The theme, living with AA, reveals the physical, contextual, social, and emotional experiences of what it's like to live with an on-going, painful chronic condition. This theme emerged as a complex representation of the lived experience, touching on daily regimens, relationships, pain, and emotions. The results of this theme included nine subthemes (waking up/managing medications, i'm not a drug addict, social supports, daily suffering/severe pain, contentment/acceptance, gratitude, psychological coping and adaption, loss of independence and functions). This is consistent with current published research documenting the complexities and daily life demands of living with chronic pain, including getting access to medications (Atkins & Mukhida, 2022; Baker et al., 2024.) However, the participants in this study reported unique experiences associated with living with AA (Tennant, 2019). For example, two of the participants found substantive differences in their ability to live with AA that varied according to the

region's climate. As described in Chapter 2, AA comes with many complex side effects (bowel, bladder, and sexual dysfunction) and short term and long-term complications. Many of the participants, in addition to AA, were also dealing with other complex, painful conditions (adrenal failure, HEDS, migraines), and loss of function (neurological, cognitive and sleep dysfunction).

The theme, suicidal ideation was the primary focus of this study. The findings revealed that SI exists in the lived experience of relentless chronic pain. The emergence of SIs leads to efforts to make sense of the consequences of chronic pain, and communicating this experience to healthcare professionals, work colleagues, families and friends so that they understand what their pain is like. Jobes and Joiner (2018) noted that the prevalence of SI-related behaviors outpaced SI. For example, 13, 200,000 adults in America and 3, 400,000 teens in 2022 reported having serious thoughts of suicide, a prevalence rate of 300 times greater than suicide (Jobes et al., 2024). SI was represented by the following subthemes: Expression of SI over time, perceived burdensomeness, desire to escape from pain, and deterrents). These results showed that all eight participants shared several beliefs about suicide. First, the participants saw suicide as the final ultimate control over their bodies and pain. Second, they saw suicide as releasing their families from the burden of care because of their condition. Third, the SI was described as “just wanting to go to sleep and not wake up,” making suicide a passive experience. All these beliefs went hand-in-hand with the amount of pain and discomfort being experienced.

Some participants have little thoughts about suicide at this part of their journey but know that their days would be numbered should they lose their pain control. For a few of the participants they have teams of medical professionals who will make sure they are comfortable. Should they lose those professionals and their access to necessary medications, they feel they would be forced to commit suicide, like friends before them.

One participant made an attempt, while another, while she has not attempted, stated “I cannot guarantee I won’t” (P2). Each participant, in this study, has a different circumstance leading to their condition, but all have a condition that no one without this disease can imagine the suffering they endure. Jobes, et al., (2024) noted that the purpose of SI may be to alleviate some form of misery through a sense of control or empowerment. This study confirmed that, when considering suicide, they want to feel control over their life when they have so little control over what is happening to their bodies and continue to wreak havoc in their lives.

The last theme, what i want people to know, was the last question asked of all the participants. More than anything else, participants want recognition from the medical community (i.e., the providers and staff who they seek out for help) that AA exists and displays a constellation of physical and psychological symptoms that need to be respected and addressed, particularly when the condition arises after a surgical procedure or epidural. Participants reported struggles with getting correct diagnoses and being told “it’s all in your head.” There is some literature emerging that identifies the challenges of diagnosing and treating post-surgical pain that has pointed out the issues of misdiagnose

and inappropriate care, but patient-perspectives on this issue have not been studied (Wooden, 2024).

Participants also want to be understood regarding their need for pain medication in order to attend to activities and quality of daily life. These participants are “not drug addicts” but have a genuine need for narcotics. They are not merely retiring early and not interested in financially supporting themselves. At the same time, the participants emphatically want to be known as more than their disease or disability. With appropriate medication and support, they can enjoy the beauty in their garden, to be able to soak in a hot tub, and to be a role model for their child. This has been recognized in current literature as the stigma associated with chronic pain. (Declercq, 2025; Leese, et al., 2024). This will be discussed further in research recommendations and implications for social change.

### **Findings Relevant to the Framework**

The ITS uses the term suicidal behaviors as those that involve some degree of intent to die; and explains why individuals engage in suicidal behavior while identifying those who may be at risk (Van Orden, et al., 2010). The ITS is used as the theoretical framework to develop the interview questions and interpret the results. The risk of suicide occurs more than double in individuals with chronic pain than without, however, no such studies have been done for individuals with AA, with enough studies on conditions that cause chronic pain using the ITS framework.

This theory was consistent with participants’ reporting on their ideations and near lethal attempt. They described their thoughts, communications (both written and verbal),

and behaviors gestures of self-harm. For example, while P2 had thoughts of suicide, she also said that felt she needed to write letters to family and friends to explain her need to take her own life. This is consistent with the framework's description of how SI varies in intent and the presence of co-occurring risk factors. There are three components recognized by the theory that are necessary for the desire to turn deadly: thwarted belongingness ), perceived burdensomeness , and acquired capability . These were clearly represented in participants' words:

*(Thwarted Belongingness)* I have a tenuous relationship with them [my family]. Everyone says they care about me; everyone says they love me, but nobody really wants to hear about my problems. And, and that sounds like they don't care. But they do. It's just. It's a really deep subject. It's a deep thing to hear my hardships...It's really hard to hear how much I suffer, how hard things are, especially knowing the kind of life I used to have, how full of life I was. And I think that's why I feel they have abandoned me. (P2).

*(Perceived Burdensomeness)* So, I know my husband will get caregiver burnout one of these days. I know one of these days you'd be like, you know— here...here's the keys to the car. I take Elavil, which I told you about, you know overdosing on Elavil is fatal. So, you know, here's your bottle of Elavil, just keep taking them until you can't swallow anymore. I just know one of these days, he's going to say that (P1).

*(Acquired Capability)* The thought I have toward now, is, is, I'm, uh, if the FDA kills my doctor... and I lose control of pain. It's going to be hard for me to find a

new doctor, because I'm on a high dose, you know because of being a rapid metabolizer. And there's not a doctor in the country, I think, that would take me as a patient. And my pain would force me into suicide (P4).

ITS posits that TB and PB are proximal and sufficient cause for passive SI. The simultaneous presence of TB and PB, when perceived as stable and unchanging (hopelessness regarding these states) is a proximal and sufficient cause of active suicidal desire. Three meta-analyses (Robison al., 2024, Chu et al., 2017 & Ma, et al., 2016) that systematically reviewed the interactions between TB and PB, found that PB was significantly associated with SI. In other words, as TB increases so does severe SI. And the presence of TB and SI produces a greater suicidal risk and continued suicidal attempt history. In this study, all these participants expressed thwarted belongingness, perceived burdensomeness and acquired capability, and yet for the most part, did not translate intent into action. These results suggest that *courage* and *determination*, noted as the most powerful finding, are the qualities that make it possible for life to go on.

The ITS illustrated how important social connections are to the value of life. TB has identified that social connectedness as a fundamental need for psychological health and wellbeing. Distress has been found to be a predictor of SI (Baumeister and Leary, 1995, Gill et al., 2023). perceived burdensomeness, and thwarted belongingness when both moderated, and mediated the relationship between distress and SI is also high. If perceived burdensomeness and thwarted belongingness are high, as well as distress, the more closely linked to SI (Gill et al., 2023). The findings of this study are consistent with the framework recognizing the importance of social connectedness in averting suicide.

The concepts of the framework and the results of this study suggest that an increase in belonging with a reduction in burdensomeness could help in intervening between distress and SI. Further, the lack of belonging constitutes severe deprivation which leads to a variety of physical illnesses, and/or prolongs other disabilities. The basic desire to form attachments exists even under the direst circumstances. This study found this to be true with all 8 participants; where there was belonging with family members there was less SI. When participants felt different or like an outsider the SI was higher. All the participants felt they were burdens, whether financially and/or because of their AA.

### **Limitations of the Study**

As described in Chapter 1, I was concerned about getting a sufficient number of participants. However, I received many phone calls and emails asking to be part of the study. I recognize that IPA does not have stringent sample size requirements, however, the recommendation is 6-8 and homogenous sample, which I successfully completed. The individuals who did not become part of the study were located out of the country (the UK and the Netherlands) or lived in jurisdiction's outside of the IRB approved locations. Those chosen met the requirements and lived in states the IRB approved because they were states without mandatory reporting laws.

In Chapter 3, I noted that interviews might have to extend over a period of time, depending on the well-being of participants. The interviews did not go longer than the time set aside for each specific interview, which was estimated at the onset of an hour - to- an hour and a half. One participant's interview took approximately 45 minutes, while the longest interview was an hour and a half. Participants were so eager to tell their

stories that any discomfort they were physically experiencing was put aside so they could get their story told, to be finally heard.

As the sole researcher, I employed these strategies: member checking, use of recordings for transcription, reading and re-reading transcripts and listening to the audio recording, to enhance the trustworthiness and dependability of the study. I also compared my findings to other studies of people with different chronic pain conditions and found many similarities. However, target group characteristics –such as degree of disability, how they first developed AA, how they were told about their disease and whether it was told or implied AA was “in their heads,” medication necessities, their views on SI, self-harm as a means to escape their pain, were found in this sample and not mentioned in other studies.

Finally, as described in Chapter 4, I was rigorous and transparent in documenting my data collection, analysis, and interpretation. The intent is that others can understand and apply what I did and what I found. It is hoped that this enhances transferability so that other researchers can replicate this study in this population and with individuals with other chronic pain conditions.

### **Recommendations**

The results of this study provide several directions for future research. There is still more to be studied regarding the experience of chronic pain. As this study and others (e.g., Declercq, 2025; Yong et al., 2022) have shown, once indications of traceable, visible tissue damage disappear, the medical community, friends and family do not recognize that terrible pain persists. Therefore, more studies are needed to quantitatively

render this kind of pain as more visible, particularly in medical settings where pharmaceutical decisions are made. The current scale (Kim & Buschmann, 2006) is insufficient for giving people living with AA and other chronic conditions acceptable and documentable ways to describe what they endure.

The results of this study also suggested that SI changes over time as participants with the AA diagnosis got older, and other co-morbidities occurred. Therefore, it is recommended that the future studies include longitudinal quantitative assessments of changes in SI over time, particularly burdensomeness and belongingness. In addition, psychological variables like hopelessness, depression and anxiety can be included to better understand the mental health implications of dealing with SI over time.

This study also showed that qualities of resilience, determination and courage exist in this population. More qualitative research on these themes could contribute to how unique these findings are to people with AA. Qualitative case study methods are suggested comparing these qualities found in persons with AA to others who suffer with invisible chronic pain.

Finally, one of the unsung heroes in participants' stories was the physician, Dr Forest Tennant, who recognized and validated their pain experiences, and translated this knowledge into actionable, life-enhancing care. Qualitative studies on the meaning of the invisible chronic pain patient-doctor relationship would provide insights to both patients and physicians regarding how to care for and respect individuals with AA and other invisible chronic pain.

### **Implications for Social Change**

Pain is not simply an uncomfortable sensation that comes and goes (van Rysewyk et al., 2023.) Rather it devastates a person's health, quality of life, and often ends in suicide. The participants highlighted the need for doctors to understand their disease. Therefore, the first recommendation is to improve the knowledge transmission and training to diagnose and treat AA for all medical school students, particularly those in pain management and radiology. In addition, basic training for all primary care doctors in the detection of conditions like AA is imperative, as detecting this condition early on may improve the options for treatment and quality of life.

The results of this study also reveal the complexity of the relationship between pain management by opioids and the risk of moving from SI to suicide. The medical community sees opioids as an addictive and suicidal tool. The person with AA needs pain management medication and understands how it could be used as a tool for suicide. Both patients and doctors need frank conversations and education to recognize the need for opioid medication is not indicative of addiction or the risk of intentional overdosing. Patients with AA become overwhelmed with pain and are not simply exhibiting "pain seeking behavior"; rather, they are suffering and need narcotic medication to help alleviate their pain. As this study has shown, those receiving adequate medication are still productive members in society. Those who are marginalized with very limited medication regimens cannot work and are too disabled to do more than get themselves off the couch.

## Conclusion

Understanding the experience and meaning of SI before it leads to suicide attempts and lethal suicide in adults living with AA was the intention of the study. AA is a misunderstood disease, and the general practicing physician is often unaware of the disease and the etiology that this disease presents. Patients coming in with undiagnosed AA are often told to “suck it up,” given a referral for psychological evaluation, or are simply written off as malingerers (Vittucci, 2019).

I have been living with this condition since 1974. The stories of struggles, pain, perceived burdensomeness and thwarted belongingness as expressed by the resilient and brave participants in this study mirror my own experiences. I want people with AA to know that life is possible after the AA diagnosis, and I want the larger community to know that this condition exists. People with this condition and other invisible chronic pain conditions are not freeloading, lazy, “druggie”, malingerers. We feel joy, appreciate relationships, and know that life with us is not easy.

Personally, after many years in and out of psychiatric hospitals, the connection to the AA was never explored. It was just assumed my suicidality was just a mental health problem, even as I begged for medication to dull the back pain. I finally concluded that without medication I was doomed. I lobbied my primary care doctors’ staff, and they presented my ordeal to her, and miraculously she agreed to finally prescribe opioids. Soon after I started this online doctoral program. The admissions counselor often said to me, “you have an AA degree, why another.”

I was eventually talked into pursuing my master's degree, and I settled on Higher Education because it would allow me to teach online. I then enrolled at Walden in 2010, bound and determined to get my master's degree. In the beginning it was about me and just continuing after graduating with my BA in 1980. The difference was, I was now in my 50's. Soon along the process, I became convinced that anyone with a disability could continue or even begin higher education and succeed. I was convinced that if I, with my background, could succeed almost anyone had an equal if not better chance of success, but it wasn't going to be easy.

It was told to me, back in 2010, that I should consider following through and go for a terminal degree. I remember saying no, it would take too long and I was not up to it. Thirteen years later, I am writing the conclusion, and my message of resilience and hope for those with AA, comes from someone who was stricken with AA in 1974, and had to fight all along for the workman's compensation that included my diagnosis of AA. I succeeded in 2023 to finally receive full workman's compensation that included the AA diagnosis, rather than just degenerative disc disease.

It is hoped that the results of this study will meaningfully contribute to a better understanding of this condition and its consequences in the medical community. Furthermore, this personal journey has been long effortful, and I hope my experience is a testament to the elderly and the physical suffering that you can set your heart and mind to a challenging journey like a doctoral degree. Here I am, at 72 writing the final touches to my study, a labor of love and determination.

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## Appendix A: Permissions

10/3/22, 9:38 AM

Mail - Kathleen Haynes - Outlook

### Article Permission

#### To Whom it may Concern:

I wanted to use a figure from the article in the journal: *Suicide and life-threatening behavior* 3(3) 264-276. June of 2007. The article is titled Rebuilding the tower of Babel: A revised nomenclature for the study of suicide and suicidal behaviors: Part 2: Suicide-related ideations, communications, and behaviors.

The authors are Silverman, et al. I am interested in including Figure 3: Nomenclature for Suicide-Related Behaviors, in my dissertation.

The article notes, The American Association for Suicidology as having the copyright to the article, and I was hoping you would grant me permission to use the one figure from the article.

Thank you,  
Kathleen J. Haynes  
Walden University Dissertation Student

## Appendix B: Permission to Use Diagram from Article

Tue 1/10/2023 1:52 PM

To:

•

Dear

Thank you for your inquiry. As far as I am concerned this is fine. But I do not think I am the holder of the copyright for this figure because it now belongs to the journal. You might need to look at their policies about reprinting figures. Because you are not reprinting the figure for a commercial purpose it may well be fine with them if you use the figure. But it might be a good idea to check.

Sorry not to be able to help more.

Best wishes,

Dr.

**From:**

**Sent:** Tuesday, January 10, 2023, 1:41 PM

**To:**

**Subject:** Permission to use diagram from Article

Dear

My name is and I am a dissertation student at Walden University. I am about to complete my proposal and would like to use the figure from your article "Chronic pain and suicide: Understanding the association." published in *Current Pain and Headache Reports*, 18(8). My dissertation, which is on AA and suicidal ideation, would benefit greatly from the inclusion of this figure. As there is no research available on AA and suicidal ideation, the figure helps depict the relationship between all the constructs, from the Interpersonal Theory of Suicide and suicidality. I would really appreciate your approving my use of it in my proposal.

Sincerely,

Walden University

## Appendix C: Permission to Use Figure

10/3/22, 9:31 AM

kathleen.haynes1@verizon.net - AOL Mail

Re: [EXT] The Interpersonal Theory of Suicide

Thanks for reaching out and sharing about your work.

Publishers actually hold copyright to figures that appear in journals, so I can't grant permission to use it. What I usually suggest is that researchers create their own figures based off the figure they are interested in, especially since doing so allows them to highlight parts of the figure most relevant to their work. Alternatively, the publisher may allow use of figures for things such as dissertations, but I am not sure and you would need to check the publisher, the American Psychological Association.

Best wishes,  
Kim

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**Subject:** [EXT] The Interpersonal Theory of Suicide

Dear Dr. Van Orden,

My name is Kathleen Haynes and I am a dissertation student at Walden University. I am writing seeking your permission to use Figure 1: Assumptions of the Interpersonal Theory of Suicide., from the author's manuscript available on NIH Public Access. I was also wondering, how to go about getting permission to use a chart from Silverman, et al., 2007. Rebuilding the Tower of Babel: Part 2; Suicide-related ideations, communications, and behaviors. The correspondence email address for Dr. Silverman no longer exists.

My dissertation title is The Lived Experience of Suicidal Ideation in Individuals With Adhesive Arachnoiditis, and the conceptual framework is based on your work on the Interpersonal Theory of Suicide. My dissertations gap is there is a great deal of work on the relationship between chronic pain and suicidal ideation. However, chronic adhesive arachnoiditis is one of the most painful diseases found related to chronic pain, yet there are no studies, I have found in my literature search, that describe the phenomenon.

I might add I have CAA and know the pain that is a result of the disease. I also know what it was like living with suicidal ideation and have worked my way through that stage in my life, so I understand firsthand what people suffering from this disease go through. I have read so many individual posts in the groups I belong to on social media, begging for someone to give them a lead to someone who will euthanize them and other's posting and wanting to be able to post with people because they have had suicidal ideation for so long and have moved to where they are afraid they will act on their impulses. This is frightening and yet doctors still deny the disease even exists.

I hope you will honor me with your permission to use Figure 1. I believe it will have a great impact in my dissertation.

## Appendix D: Interview Guide

Interview Guide Questions	Citations (Author, date)
I am wondering if you could help me better understand your specific situation by sharing your disease, diagnosis, and your experience with suicidal ideation,	
10. Background <ul style="list-style-type: none"> <li>e. So, tell me about your experience with AA.</li> <li>f. How did you develop your condition?</li> <li>g. How were you diagnosed?</li> <li>h. How long have you been living in this condition?</li> </ul>	Tennant, F. & Hollis, I (2019); Tennant, F. (2022).
11. Tell me about a typical day. (to get a sense of what it means to live with this disease) <ul style="list-style-type: none"> <li>a. Probe: What is the best part of a typical day?</li> <li>b. Probe: What is the worst part?</li> </ul>	Charmaz, K. (1983)
The aspect of your experience that I am especially interested in is your experience with suicidal ideation. I understand this could be triggering so if you do not want to talk about suicidal ideation, we can end the interview at any time.	
12. I am going to ask you some questions about what happens when you have thoughts about suicide. (We can stop any time) <ul style="list-style-type: none"> <li>c. Remembering a recent time when you had suicidal thoughts, what was happening at that time?</li> <li>d. What comes up for you when you think about suicide?               <ul style="list-style-type: none"> <li>1. Can you give me an example?</li> <li>2. What goes through your mind?</li> <li>3. How does this make you feel?</li> </ul> </li> </ul>	Joiner, T. (2005); Van Orden, et al., (2010)
13. Burdensomeness- Tell me about the relationship you have with your family or caregivers.  14. Tell me about when you felt you were a burden to others.	

<p>a. Was there another time when you felt this way?</p> <p>b. Can you give me an example?</p>	<p>Joiner, T. (2010); Joiner, T. (2005); Van Orden, et al., (2010)</p>
<p>15. Could you tell me a story about your experiences with suicidal ideation?</p>	<p>Charmaz, K. (1983)</p>
<p>16. What keeps you from acting out your thoughts?</p> <p>c. What is the most important reason for you to keep going?</p> <p>d. Are there other reasons?</p>	<p>Joiner, T. (2005); Joiner, T. (2010); Van Orden, et al., (2010)</p>
<p>17. Tell me about something you are looking forward to.</p> <p>18. What is something that makes life worth living?</p>	<p>Charmaz, K. (2006); Charmaz, K. (1983)</p>
<p>11. What would you like people to know/learn about people like yourself and what you experience every day?</p>	<p>Charmaz, K. (2006); Charmaz, K. (1983)</p>
<p>Thank you for talking to me and sharing some personal and painful experiences. As you continue your journey through life, living with this devastating disease, I commend you for your courage and honoring me by sharing these painful aspects of your life.</p>	

Appendix E: Participant Self-Portraits (Participant 7)



