

2017

# Alexithymia and comparison of alternative treatments to talk therapy for people who have a mental health diagnosis

Rebekah Milhoan

Follow this and additional works at: <https://scholarworks.smith.edu/theses>

 Part of the [Social Work Commons](#)

---

## Recommended Citation

Milhoan, Rebekah, "Alexithymia and comparison of alternative treatments to talk therapy for people who have a mental health diagnosis" (2017). *Theses, Dissertations, and Projects*. 1905.  
<https://scholarworks.smith.edu/theses/1905>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact [scholarworks@smith.edu](mailto:scholarworks@smith.edu).

Rebekah Milhoan  
Alexithymia and  
comparison of alternative  
treatments to talk therapy  
for people who have a  
mental health diagnosis

### **ABSTRACT**

This research study was a quantitative, descriptive investigation of the relationship between the rate of alexithymia in the mental health population and exploring the helpfulness of alternative treatments compared to traditional talk therapy.

An online based questionnaire, using the Toronto Alexithymia Scale (TAS-20), a Likert scale used to measure the presence of alexithymia, and an open-ended comment section, was administer anonymously to fifty-four people with a mental health diagnosis. The major areas of interest were levels of alexithymia in the mental health population and finding out about the helpfulness of alternative treatments.

Participants had higher than average scores on the TAS-20. Though several participants found alternative treatments helpful for their mental health, a majority of the participants have never tried alternative treatments described in the study.

**ALEXITHYMIA AND COMPARISON OF ALTERNATIVE TREATMENTS TO  
TALK THERAPY FOR PEOPLE WHO HAVE A MENTAL HEALTH DIAGNOSIS**

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Masters of Social Work

Rebekah Milhoan  
Smith College School for Social Work  
Northampton, Massachusetts 01063  
2017

## ACKNOWLEDGEMENT

Thank you for all of those who have walked by me, side by side, even if for a moment. You will forever be aligned with me in my thoughts and intentions as I move into my career as a social worker and researcher.

*Aligned*

*I will see you in heaven, my friend*

*Paths separate but aligned*

*Hold on to both forces in you*

*To one does feed the other*

*You are precious to me, though*

*We walked aligned but separate.*

*Hold firm to what grows light and release*

*All*

*May the almighty show us our truths*

*And calm only the storm within*

*As we wait aligned but separate.*

*How far people walk, side by side is UNKNOWN, but*

*Forever align is in a single thought.*

To my parents and family, I am forever in your debt for the millions of small selfless acts.

To Joshua Woods, who at times had to literally pick me up and carry me through to the next step.

To my close friends, who listened and cried with me: Marvin Berman and Gina DeCesari.

To my mentors at Highlands Hospital in Oakland, CA, and Bay State Franklyn Partial Hospitalization Program, thank you for showing me how to be passionate and efficient.

Special thanks, specifically for this project goes to Elaine Kersten, my thesis advisor who walked me through this project with me step by step, email after email and Peter Sapira from the writing center who was ever so patient with me.

Last, but not least thank you to everyone in my life past and present, who believed in me, even when I couldn't fathom continuing.

## Table of Contents

ACKNOWLEDGEMENTS .....	ii
TABLE OF CONTENTS .....	iii
LIST OF TABLES .....	iv
CHAPTER	
I INTRODUCTION .....	1
II LITERATURE REVIEW .....	3
III METHODOLOGY .....	13
IV FINDINGS .....	17
V DISCUSSION.....	27
REFERENCES .....	32
APPENDICES	
Appendix A: Human Subjects Review Approval.....	35
Appendix B: Informed Consent .....	36
Appendix C: Message to Director .....	42
Appendix D: Recruitment Message .....	44
Appendix E: Message to Individuals.....	46
Appendix F: Permission to Use the TAS-20.....	48
Appendix G: Survey Layout.....	49

## LIST OF TABLES

### Table

1.	Age Distribution .....	18
2.	Gender .....	19
3.	Level of Education Completed .....	20
4.	Mental Illness Diagnosis .....	21
5.	Treatment Modalities.....	23

## **CHAPTER I**

### **INTRODUCTION**

People who are in treatment for mental health issues and challenges often seek therapy to address problems. The most common mental health treatment approach in the United States is talk therapy, during which the therapist and patient explore the issues through verbal exchange. This modality of treatment assumes patient's ability to express themselves verbally. However, as research has shown, the ability to verbally identify, explore and express feelings is not an inherent capacity in all human beings.

According to the description offered by Taylor and Bagby (2013), researchers from the University of Toronto, Alexithymia is a cluster of characteristics, including difficulties identifying and describing feelings, a restricted ability to think in the abstract and an externalized thinking style. Alexithymia is a personality construct characterized by the subclinical inability to identify and describe emotions in the self. The core characteristics of alexithymia are marked dysfunction in emotional awareness, social attachment, and interpersonal relating. Alexithymia is prevalent in approximately 10% of the general population and is known to be comorbid with several psychiatric conditions" (Taylor, 2013). Furthermore, people with depression, eating disorders, substance abuse, brain injuries or PTSD are at a higher risk for having an acute or chronic condition associated with alexithymia (Weiss, 2016). Given the prevalence of this verbal communication challenge and the fact that so many of these people also find themselves in therapy situations, it is clear that talk therapies may be challenging when this condition is present.

The purpose of the proposed study is to investigate to what extent people with mental health diagnoses of depression, eating disorders, substance abuse, brain injuries, PTSD and

developmental challenges may be at risk of having Alexithymia traits. Further, I am also interested in learning from the client's perspective what treatments seemed to be effective for them, including alternative treatments such as yoga, meditation, play therapy, etc.

Thus, the research question is two-fold. The first part of my proposed study is to learn about the prevalence of Alexithymia in a sample of individuals who have a mental health diagnosis. Secondly, for those individuals who appear to have some level of alexithymia, I am interested in learning what types of treatment they received and especially if they received alternative treatments to talk therapy if those alternative treatments felt supportive/effective for their treatment.

The overarching research question is: What is the level of alexithymia in a sample of individuals who have mental health diagnosis; and, for individuals within the sample who have the condition of alexithymia, what are their impressions about therapy they received, including alternative therapies. To explore this question, a descriptive research design is contemplated in which I will use a survey format for data collection. The survey will include a set of questions taken from a tool used to measure the presence of alexithymia for which I have permission to use, and will also include a set of questions designed to learn about their impressions about treatment approaches they have had. I choose this design partly because of the sensitivity of the questions asked and that an anonymous survey will be less intrusive than interview questions.



## **CHAPTER II**

### **LITERATURE REVIEW**

In my study, I explored the prevalence of alexithymia amongst people who have a mental health diagnosis; treatment approaches for alexithymia; and clinical approaches employed by clinicians working with patients who have alexithymia that maintain positive treatment outcomes. This review presents contributions made by a set of authors about the concept and characteristics of alexithymia across the general as well as mental health populations and how it could manifest across individuals. Common treatments and challenges faced by clinicians who work with alexithymia patients are presented. This review incorporates studies that reflect both clinicians and, though less available, client perspectives about how to address alexithymia during the therapy experience.

#### **Alexithymia Overview**

In this section, I focus on the basic concepts and characteristics of alexithymia. As described by Taylor and Bagby (2013) in a brief history of alexithymia, the concept of alexithymia was first identified as a clinical construct starting in the 1970's by Nemiah and Sifneos. They noted that alexithymia at the time was defined as a "psychosomatic symptom or medically unexplained body sensation", but Sifneos coined the term alexithymia and linked the alexithymia to the psychological distress patients were having by experiencing these psychosomatic symptoms (Taylor & Bagby, 2013). As Taylor describes in his work, this link between the psyche and the body was researched by Nemiah, Freyberger and Sifneos in 1976 and they concluded that alexithymia was a "multi-faceted construct that was

characterized by a constricted emotional functioning, poverty of fantasy life and difficulty these patients have in finding words to describe their emotions.” (p. 193).

In 1988, Henry Krystal wrote about the links between affect, trauma, and alexithymia that added to the multi-faceted construct posed by Nemiah, Freyberger and Sifneos. Krystal concluded that individuals with high levels of alexithymia have difficulty tolerating emotional states, in part because they have a limited capacity to be self-reflective or introspective (Krystal, 1988). In Taylor and Bagby's own research, they also concluded that alexithymia was both an affective and cognitive deficit. His research was key to the emerging understanding of alexithymia as a personality trait, seen on a spectrum versus a pathology, meaning that most people have some alexithymia traits (2013).

In Taylor and Bagby's study they gave the TAS-20 (Toronto Alexithymia Scale) and the Five-Factor Model of Personality Scale to 221 Italian College Students and found that students with high levels of alexithymia "correlated significantly and negatively with the emotional stability factor (which corresponds to neuroticism, but with reverse scoring;  $r = -.42$ ), the Energy factor (which corresponds to extraversion) ( $r = -.28$ ), the openness to experience factor ( $r = -.36$ ), and the friendliness factor (which corresponds to agreeableness;  $r = -.20$ ) but was not significantly correlated with conscientiousness ( $r = -.04$ ) (Taylor & Bagby, 2013)." These results were redone with four other independent colleges two from Canada, one from the United Kingdom, and one from Switzerland. Though these studies were done with a limited age sample, due to the college campus locations, Taylor concluded that alexithymia was significantly correlated with four out of five of the major personality traits.

### **Multiple Code Theory**

Along the same time of Taylor and Bagby's research on alexithymia and personality, a developmental aspect of alexithymia was being looked at by Dr. Wilma Bucci (2007), who

was working with her multiple code theory to "broaden our understanding of dissociative processes". The multiple code theory establishes how as humans we process emotions and the way we express them. In this theory, there are three stages of emotional processing the first is the sub-symbolic mode (sensory input and motor activity); the second is the nonverbal symbolic mode (images) and lastly verbal symbolic mode (words). These three modes sum up to the modern idea of schemas or the process of our brains to make patterns/ connections between the vast amounts of sub-symbolic input we receive.

According to Bucci's theory, a person is born with sub-symbolic information, but through development and experience this information becomes defined in symbolic forms of first mental images and then language gets attached to these images to allow the person to use information not only for their internal processing but among other people. Bucci explains, "We are not accustomed to thinking of processes, including somatic and sensory processes that cannot be verbalized or symbolized as systematic and organized thought; the new understanding of sub-symbolic processing opens the door to this reformulation. It changes our entire perspective of pathology and treatment when we are able to make this shift." Some alexithymia traits are part of the normal development of a complicated and imperfect language acquisition system.

Being a personality trait meant that alexithymia was on a continuum in each person from low to high characteristics. In his meta-analysis about conducted by Professor Samur, Mattie Tops, Caroline Schlinkert, Markus Quirn, Pim Cuijers and Sander Koole of the University of Amsterdam estimated that 10% of the general population may be characterized by levels of alexithymia that are high enough to be considered pathological (Samur et. al, 2013). Minimally alexithymia is seen in the general population after the personality is developed. This notion that alexithymia is present in some manner with many of his/her clients is of great importance to social workers. And of considerable importance to social

workers is that people with mental health diagnosis are at much higher risk to have alexithymia traits at a level that may be disruptive to treatment.

As earlier discussed, Taylor and Bagby found in their research that alexithymia is on a continuum with normal functioning, but they also found that there are two factors that most commonly were found in patients with pathological levels of alexithymia: minimal self-awareness and less ability to empathize with others. Specifically, Taylor and Bagby suggest that there are links between high levels of alexithymia and concepts such as trouble with mentalization, use of primitive ego defenses, trouble with empathy and insecure attachment styles (2013). Clearly, an understanding of issues related to alexithymia is of considerable importance to social workers.

### **Correlation to Mental Health Diagnosis**

In this section, I discuss how high levels of alexithymia traits manifest differ in patients greatly, but trouble with mentalization, use of primitive ego defenses, trouble with empathy and insecure attachment styles often intertwine between mental health diagnosis symptoms. Such in the case reflected in the work by Spritzer et.al (2007). In their research, they conclude that post traumatic syndrome disorder (PTSD) is often co-morbid with alexithymia and severe mental illness he stated, "People with PTSD and alexithymia are at a much higher risk for a severe mental illness (SMI) and more psychological distress". In the Yalug et.al (2010) study, they made similar correlates between depression, anxiety, pain (somatic symptoms) and alexithymia as Spritzer did with PTSD. In addition to these links between diagnoses, they found that there were positive correlations between patient experiences of physical pain such as chronic migraines that also have higher levels of depression, anxiety, and alexithymia. From this, the authors conclude that alexithymia may not only be co-morbid to depression and anxiety but contribute to the etiology of the disorders.

Many of the articles found spoke of the positive correlation between severe mental illness and alexithymia, but even more so there was often a stronger correlation between mood disorders and alexithymia. For example, in the Leweke (2012) study, they took information from over a thousand behavioral health outpatients clinics about patients with a diagnosis of depression, adjustment, somatoform disorders, and eating disorders and found that overall there was a significant link between alexithymia and these disorders. A third of the patients with depressive disorders had alexithymia at a psychologically distressful level.

When this link between mood disorders and alexithymia was discussed often authors would emphasize the distress that lack of empathy and an externalized thinking style, key traits of alexithymia, affect a person's interpersonal skill: their ability to connect with others. Williams and Wood (2010) research suggests that 60% of traumatic brain injury patients have high alexithymia traits. These patients also reported high levels of distress in their relationships and when assessed showed significant limitations in their abilities to empathize. Neumann, Zupan, Malec and Hammond (2014) expanded our current understanding about alexithymia because of their examination of the correlation between traumatic brain injury patients and externalized thinking style. They found that patients with traumatic brain injuries who also had an externalized thinking style had a much higher risk for high levels of alexithymia. Implications of this study are that this externalized thinking style linked to alexithymia appears to be a core element for alexithymia as a severity factor in mental illness. In their conclusions, the authors noted that, "Results suggest that people who tend to avoid thinking about emotions (externally-oriented thinking) are more likely to have problems recognizing others' emotions and assuming others' points of view."

Therefore, in the literature alexithymia is often co-morbid with mood disorders, PTSD and somatic symptoms this link is thought to be based on the patients' inability to empathize

or mentalize, thus suffering significant distress in connecting with their own feelings and others.

The tendency to avoid thinking about emotions has been reflected in research about the use of substances by people with high levels of alexithymia. In his work about substance abuse patients, Hamidi (2010) noted the tendency to avoid thinking about difficult emotions by using substances. In his research, Hamidi studied people with substance use disorders vs. non-substance users and found that people who used substances were much more likely to have high levels of alexithymia and be far less comfortable in expressing their emotions and inner feelings

This correlation is found in many articles that research substance use and alexithymia, but there is also research on this correlation differing on the age of the patients. For example, in the Bonnet, Brejard and Pardinielli (2013) study they looked at young adults, students and their use of substances, specifically alcohol. They found that alexithymia was a mediation factor for the use of substances. They found that young adults who are still developing these emotional processes may be using substances to mediate their urge to avoid emotions and this tendency to avoid a normal part of development.

On the other hand, in Barth's (2016) study with young adults, he explored the unique relationship between eating disorders and alexithymia. They found that many patients with eating disorders were highly verbal, able to talk about their emotions, but also were high in alexithymia. He concluded that these patients' verbal cognitive strengths may disguise their inability to use these strengths to manage their emotional states. Eating disorders, particularly anoxia, maybe more of a way to mediate this contention between the ability to verbalized emotions, but not being able to manage the emotions. Therefore, it is unclear if alexithymia traits are just a normal part of developing or if these traits could be a warning sign for the development of severe mental illness as adults.

Another aspect of alexithymia research that appears to diverge from studies noted above is how culture plays into the development of alexithymia as a severity factor for mental illness. Many of the studies reviewed were not from the United States but were conducted in other countries, so the difference in cultures and lack of research conducted in other countries is a gap in the development of this personality characteristic. The lack of research in the United States could be a reason that very few mental health practitioners assess for alexithymia.

### **Clinical Approaches that Address Alexithymia in Treatment**

Though there appears to be very little clinical alexithymia research done in the United States there are even less clinical assessments on alexithymia available for practitioners to use with patients. However, in the late nineties, Taylor, Bagby, Keefer, Parker and Inslegers from Universities in Canada and Belgium worked on researching the TAS-20 (Toronto Alexithymia Scale), which Taylor and Bagby created specifically to assess presence and level of alexithymia. In the development of this assessment tool, they paid attention to its reliability across language, gender, and clinical status. This assessment was developed along with the adaptive structured interview version called the TSIA (Toronto Structured Interview for Alexithymia, 2015). The TAS-20 is a Likert scale with 20 questions assessing for the four identified personality defects including cognitive, affect, externalizing thinking style and fantasizing. The associated TSIA is a structured interview that allows for open exploration of these four parts.

The authors suggest using the TAS-20 first to assess the presence of distressing alexithymia traits and then if needed using the TSIA to clarify for the patient which aspects of the traits are distressing; cognitive, emotionality, fantasizing or externalized thinking style. The authors note that using both the TAS-20 and TSIA together were shown to have better validity and reliability for assessing for specific traits that maybe causing distress in patients with high levels of alexithymia (Keefer, 2015)

Although, a few authors disagree that practitioners need to assess for alexithymia based on the intricate connection between negative effects (symptom of psychiatric disorders) and distressing levels of alexithymia (Marchesi, 2014), more authors are finding the differences in high alexithymia psychiatric patients versus low alexithymia psychiatric patients greatly affects treatment outcomes (Samur, 2013)

In their review examining the last four decades of research on alexithymia, Dalya Samur (2013) and colleagues, from the Clinical Psychology department at the University of Amsterdam, discuss how, "many existing forms of psychotherapy may be less than optimal for helping high-alexithymia individuals, given that they typically achieve poorer outcomes in psychotherapy than low-alexithymia individuals (p.1)."

The authors urge researchers to use research on alexithymia as a basis to develop clinical interventions that address the presence of alexithymia in their work with patients. As noted by Samur et, there appears to be very few recommended clinical interventions that identify this assessment step in the current research. It is interesting to note that the recent focus on assessment of alexithymia seems to be gaining importance a full twenty years after Henry Krystal (1982), known best for his work in trauma psychotherapy stated, "Alexithymia is possibly the most important single factor diminishing the success of psychoanalysis and psychoanalytic psychotherapy." (p.364).

In addition to the focus on assessment, treatment approaches that address the presence of alexithymia have shown through some studies the effectiveness of group therapy with patients who have high alexithymia traits. A study conducted by Joyce in 2015 from the University of Alberta and British Columbia on the effects of partial hospitalization program and alexithymia showed that the multi-modalities and group process maybe more effective with high alexithymia traits than talk therapy alone, especially if they are currently having trouble in traditional self-directed talk therapy (Joyce, Nordhagen, Ogrodniczuk, Stovel &



Bjorge, 2015). In their study, they discussed a case study on a patient with high alexithymia traits; who went through a partial hospitalization program. The patients were noted to have high alexithymia rates and difficulty expressing themselves. The results found that from the patient's perspective, the program was more helpful in terms of expression of internal feelings because they experienced different ways to engage in the treatment process and were able to learn to express themselves more clearly.

In another study with sixty-eight patients assessed to be at high alexithymia levels, the authors found that the patients in outpatient group therapy appeared to benefit from the fact that there was a co-occurring effect for patients. When patients were engaged in group therapy they were strengthening internal personal communication skills through the group process, which made the treatment itself more accessible to them in the moment and led to longer sustained treatment outcomes because of the interpersonal skills gained (Ogrodniczuk, 2012)

These findings have potential to help one-on-one practitioners currently treating patients with high levels of alexithymia to first be able to identify alexithymia through the assessment process, then if possible to refer to group therapy or if not possible to use a variety of modalities beyond talk therapy to support the patient effectively. The best type of modalities to use in individual therapy is not well researched beyond using those that are less self-directed and less dependent on a verbal exchange (Terock, 2015).

## **Summary**

To expand the clinical understanding about the presence of alexithymia in clients in therapy, I initiated my study. Further, because there has been a huge void in learning about how alexithymia affects the verbal treatment process from the patient's perspective, I designed my study to also learn about which different modalities maybe helpful from the patient perspective given their level of alexithymia traits. In my study, in addition to asking subjects

about their perspectives about therapy, I also asked about treatments that are less self-directed and more non-verbal focused, since the research I found showed the difficulty engaging could be linked to the lack of self-directness and difficulty with verbal expression.

In the next chapter, I present my methodology.

## **CHAPTER III**

### **METHODOLOGY**

The overarching research question was: What is the level of alexithymia in a sample of individuals who have mental health diagnosis; and, for individuals within the sample who have the condition of alexithymia, what are their impressions about therapy they received, including alternative therapies. Thus, the research question was two-fold. The first part of my proposed study was to learn about the prevalence of Alexithymia in a sample of individuals who have a mental health diagnosis. Secondly, for those individuals who appear to have some level of alexithymia, I was interested in learning what types of treatment they received and especially, if they received alternative treatments to talk therapy if those alternative treatments felt supportive/effective for their treatment

To explore this question, a quantitative, descriptive research design was contemplated in which I used a survey format for data collection. The survey included a set of questions taken from a tool used to measure the presence of alexithymia for which I received permission to use, and I also included a set of questions designed to learn about their impressions about treatment approaches they have experienced. I choose this design partly because of the sensitivity of the questions asked and that an anonymous survey will be less intrusive than interview questions.

#### **Sample**

All participants were 18 years or older who self-identified as having received a mental health diagnosis at some point in their lives; engaged in any type of therapy related to that diagnosis; had access to the internet, and were able to speak and understand English.

Individuals who were currently in treatment for psychosis or acute detox within 30 days of taking this survey were excluded from the study.

The recruitment process began with contact to an individual who had offered to distribute recruitment materials; namely the Director of Universal Access program for Western Massachusetts. Appendix C (Message to Director) is the e-mail I sent to him that included guidance about how to distribute the survey to the member organizations, including a request that they pass it on to other organizations. He had the capacity to distribute this information, including research participation opportunities to member organizations that then sent out the information to their specific members. Appendix D: Recruitment message was sent to the following organizations: All out Adventures, Access Outdoors, Spaulding Adaptive Sports Center, Waypoint, Holyoke Rows, Northeast Passage, Community Boating, other Universal Access Programs in Massachusetts. Appendix E: Message to Individuals. This email (Appendix E) was sent out by the aforementioned organizations to individual members; and contained a description of the study, inclusion/exclusion criteria, and a link to the survey for individuals who were interested in learning more about the study and, if they wished, take the survey.

Due to the accessibility, the Universal Access program had to many participants, feasibility to receive the required number of participants was likely and I achieved the required minimum within a few days, ending with a total of a hundred and eight who looked at the survey, fifty-four participants who meet the inclusion criteria, thirty-nine who finished the survey and fifteen who only finished the demographics questions.

## **Ethics and Safeguards**

The participation in this study was anonymous and no personal or identifying information such as name or contact information was gathered. Survey Monkey tool allowed a set up that eliminates access to individuals. The participants were reminded before the open-end section to not provide any identifying information and to disguise any names. When data was analyzed no identifying information was found that needed to be deleted.

All research materials including recordings, analyses, and consent/assent documents are being stored in a secure location for three years according to federal regulations. If materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data is password protected during the storage period.

## **Data Collection**

This was a quantitative, survey-based study in which anonymous participants completed an internet survey that was designed using the Survey Monkey internet survey tool. The survey was designed to gather data for two major areas of interest. Firstly, the initial part of the survey included a set of 20 questions to assess presence and magnitude of alexithymia. This scale is called the Toronto Alexithymia Scale; its reliability and validity were established by series of articles done by Michael Bagby. (See Appendix F: PERMISSION TO USE THE TAS-20). The last part of the survey was a set of questions designed to learn about client perceptives about treatment approaches they have received, including alternative treatments such as yoga, play therapy, theater; etc. The last page, the participant saw was the Thank You and references page, which instructed them that the survey was over (See Appendix G: Survey Layout).

## **Data Analysis**

For this study, I worked with statistician Marjorie Postal from the Smith School of Social Work, Massachusetts. Using primarily descriptive statistics to describe the sample we compared groups within the sample to investigate the presence of alexithymia and helpfulness of the treatment modalities. T-tests and frequencies were utilized to determine if there was a difference in TAS score by disorder, run to determine if there was a difference between the disorders and to code the helpfulness of the treatments.

The study results are fully presented in the Findings Chapter.

## **CHAPTER IV**

### **FINDINGS**

This study was designed to learn about how individuals who have alexithymia experience mental health therapies. Alexithymia is defined as difficulty expressing or describing emotions. A quantitative survey with optional open-ended questions was administered using Survey Monkey.com. Fifty-four (54) participants completed the demographics section after meeting eligibility criteria and signing the Informed Consent. Of this initial subject pool, a total of thirty-nine (39) participants completed the Toronto Alexithymia Scale (TAS), used in this study to determine the severity of alexithymia traits for this cohort of participants. The thirty-nine participants who completed the TAS also completed a set of treatment modality questions designed to learn about mental health treatments they have received and how helpful or not helpful these were. Finally, these same individuals completed a survey designed to elicit further information about their experience with mental health treatment, given their verbal challenges.

This findings chapter is presented in the following five sections: 1) Description of the Sample Surveyed 2) Examination of the TAS scores 3) Comparison of the Treatment Modalities Analyzed 4) Reflection of the comments made on the treatment modalities 5) Summary of the additional comments given by

#### **Description of the Sample Surveyed**

The fifty-four participants were adults who have been diagnosed with a mental illness and have experienced mental health treatment. Although there were fifty-four participants,

fifteen were excluded from the TAS examination because they left the survey before they completed the scale.

**Age.** The majority (78%) of the valid percent were between the ages of 30-64 (n=39). The least represented age bracket was between the ages of 18-29 (n=3).

Table 1: Age Distribution

		Frequency	Percent	Valid Percent
Valid	18-29	3	5.6	6.0
	30-49	22	40.7	44.0
	50-64	17	31.5	34.0
	65 or older	7	13.0	14.0
	prefer not to answer	1	1.9	2.0
	Total	50	92.6	100.0
Missing	System	4	7.4	
Total		54	100.0	

**Gender.** The majority (66%) of the valid percent self-identified as female. A strong minority (34%) self-identified as male. Of note an option to fill in gender was offered, none of the participants choose this option, though four participants chose to skip this question.



Table 2: Gender

		Frequency	Percent	Valid Percent
Valid	Woman	33	61.1	66.0
	Man	17	31.5	34.0
	Total	50	92.6	100.0
Missing	System	4	7.4	
Total		54	100.0	

**Race and Ethnicity.** The largest racial/ethnic group identified as White or Caucasian (92%, n=46). Four participants skipped this question. Two participants preferred to not answer. One participant selected other.

**Highest Level of Education Completed:** Almost three-fourths (73.4%, n=36) of the complete training or education post high school. One participant didn't complete high school. Seven participants preferred not to answer or skipped the question.

Table 3: Level of Education Completed

		Frequency	Percent	Valid Percent
Men	Masters or higher	5	9.3	10.2
	some HS completed	1	1.9	2.0
	HS graduate	1	1.9	2.0
	some college	9	16.7	18.4
	4-year degree	30	55.6	61.2
	graduate			
	trade/technical training	1	1.9	2.0
	prefer not to answer	2	3.7	4.1
	Total	49	90.7	100.0
Missing	System	5	9.3	
Total		54	100.0	

**Religious Preference.** One-third of the participants (32%, n=16) choice no preference in religious preference. Forty percent of the participants preferred to not answer the question. Twelve percent used the fill in the blank option. Four participants skipped the question.

**Mental Illness Diagnosis:** Of important note was that participants were able to click “all that apply”, but 54 participants were surveyed and 54 single responses were documented. Almost forty percent (n=21) were diagnosed with a mood disorder, with PTSD being the second highest surveyed diagnosis (n=10). Traumatic Brain Injury and Autism Spectrum Disorder were the least represented group with an accumulative 7.4% (4).

Table 4: Mental Illness Diagnosis

		Frequency	Percent
Valid	Mood Disorder (depression or bipolar)	21	38.9
	PTSD	10	18.5
	Eating Disorder	4	7.4
	Substance Use disorder	3	5.6
	Traumatic Brain Injury	2	3.7
	Autism Spectrum Disorder	2	3.7
	Other	8	14.8
	Total	50	92.6
	Missing	System	4
Total		54	100.0

### Toronto Alexithymia Scale

The Toronto Alexithymia Scale is a twenty-question scale that rates the amount of alexithymia traits on a low, moderate to high amount of alexithymia traits with moderate to high traits being seen as clinically significant for patients to experience distress from these traits. Out of the thirty-nine participants surveyed 25.6% (n=10) scored High, 15.4% (n=6) scored moderate, and 59% (n=23) scored low.

The TAS is a twenty questions scale that is broken up into three factors of the alexithymia trait. The first factor assesses difficulty identifying feelings, in the survey the highest possible score was thirty-five for this factor. The mean score for the first factor of participants surveyed was thirteen. The second factor assesses difficulty describing feelings, in the survey the highest possible score was twenty-five for this factor. The mean for the second factor of participants surveyed was eighteen. The third factor assesses if the participant has an externalize thinking style, which makes it hard to be aware of the internal feelings, in the survey the highest possible score was forty for this factor. The mean for the third factor of the participants surveyed was eighteen.

### **Therapy Modalities**

In this section, different therapy modalities were assessed by the participant on a six-point Likert scale from does not apply, very unhelpful to the most helpful. The first modality that was assessed was talk therapy a traditional therapy in which a person would verbally express their thoughts and feelings to a therapist. The second modality that was assessed was play therapy with children, the child is given toys or activities to play with during the session, while the therapist observes and gives verbal promptings to direct the play, The third modality that was assessed was play therapy with adults, this can be done as an individual or as a group, The adult is given promptings around playing with toys or activities during the session, while the therapist observes and gives verbal promptings to direct the play and experience. The fourth modality that was assessed was peer support groups, for people who have a similar diagnosis that are led by a peer or other individual without a mental health license. The fifth modality that was assessed was support groups for people who have similar harmful behaviors or diagnosis that are led by a licensed mental health worker. The sixth modality that was assessed was somatic awareness a type of therapy that focuses on understanding body feelings, instead of talking about thoughts, moods or behaviors. The final

modality that was assessed was mindfulness and recreation, a group that seeks to enhance the quality of life through recreational activities such as yoga, meditation, skiing, boating, or hiking.

Table: 5 Treatment Modalities (only valid percent are shown)

<b>Likert Scale</b>	<b>Talk Therapy</b>	<b>Play Therapy as a Child</b>	<b>Play Therapy as an adult</b>
	N=36	N= 35	N=35
does not apply	2.8	91.4	85.7
not helpful at all	11.1	2.9	2.9
somewhat helpful	13.9	0	0
Helpful	16.7	2.9	5.7
very helpful	36.1	2.9	5.7
the most helpful	19.4	0	0

<b>Likert Scale</b>	<b>Peer Support Groups</b>	<b>Support Groups</b>	<b>Somatic Awareness</b>
	N= 35	N=35	N=35
does not apply	34.3	54.3	71.4
not helpful at all	5.7	0	2.9
somewhat helpful	20	20	5.7
Helpful	8.6	11.4	8.6
very helpful	14.3	2.9	0

the most helpful	17.1	11.4	11.4
------------------	------	------	------

Likert Scale	Recreation/Mindfulness
	N=35
does not apply	25.7
not helpful at all	0
somewhat helpful	5.7
Helpful	14.3
very helpful	34.3
the most helpful	20

A total of thirty-five participants, (97%) of the participants noted that they have been to talk therapy and twenty-six participants (86%) found it at least somewhat helpful, with seven participants (19%) nineteen percent, noting that talk therapy was it the most helpful. A total of three participants (9%) noted that they have tried play therapy as a child and of those who tried it, two participants (6%) found it helpful or above. Of the sample, five participants, (14%) noted that they tried play therapy as an adult and of those who tried it, four participants (12%) found it helpful or above. Of the respondents, twenty-three participants (66%) noted that they have tried peer support groups and of those who tried it, twenty-one participants (60%) finding it to be at least somewhat helpful, with six participants (17%) noting it the most helpful. Sixteen participants (46%) noted that they have tried support groups, run by a licensed mental health worker and of those who tried it all found it at least somewhat helpful, with four of the participants (11%) noting it to be the most helpful. Of the respondents, ten (29%) noted that they have tried somatic awareness treatment and nine (26%) found it at least

somewhat helpful, with four (11%) noting that it the most helpful. Of the participants in the study, twenty-six (74%) noted that they have tried recreation or mindfulness as a treatment and all of them finding it to be at least somewhat helpful, with seven (20%) finding it the most helpful.

### **Treatment Modality- Open Ended Section**

In this section, participants had the option of discussing other alternative treatment modalities that were not listed, that they found to be helpful. Four participants reported that specific types of meditation were helpful for treatment. Three participants reported two-three day workshops on specific topics such as leadership or reliance was helpful. Two participants reported Eye Movement Desensitization and reprocessing (EMDR) was helpful. Individual participants reported some of the following were helpful acupuncture, light therapy, prayer and life coaching.

### **Additional Comments**

In the last section of the survey, participants were given the option to make any additional comments. Five participants commented that all therapy modalities are helpful as one participant said, "Any treatment that forces me to think about my feelings I find helpful. I am not one who naturally does so." Four participants talked about peer support groups and support groups; here are some of their responses:

One participant said about being in a peer support group, "In peer support groups, I lost the feeling that I was "alone" in this struggle. Getting and giving support, especially the giving, has done wonders for my wellness and helped rebuild my self-esteem and feelings of being valued." Another participant said about being in a support group with a therapist versus a peer support group, "Anything that genuinely tried to elicit feelings was helpful, especially in a group, because there is no sense of shame. Three participants reported the different types

of recreation they found most helpful included were yoga, hiking and getting in touch with the body through nature.

The implications and limitations of these findings will be explored in the Discussion Chapter.



## **CHAPTER V**

### **DISCUSSION**

In this section, I discuss the findings of this study; exploring the two major questions of the study, limitations and address potential for future research and clinical implications. This study was focused on two major questions 1) Do people with mental health diagnoses, have higher levels of alexithymia? 2) Would alternative treatment modalities, that don't require verbal expression or describing of feelings, be helpful for people with a mental diagnosis?

#### **Do people with mental health diagnoses, have higher levels of alexithymia?**

Out of the 39 participants who took the Toronto Alexithymia scale (TAS-20) 25.6% (n=10) scored High, 15.4% (n=6) scored moderate, and 59% (n=23) scored low. That means that 41% of people who self-identified having a mental health diagnosis had clinically significant alexithymia traits, whereas the general population has been estimated to only have about 10% of the population with clinically significant alexithymia (Taylor,2013).

The TAS is broken up into three factors of the alexithymia trait. The first factor assesses difficulty identifying feelings, the second factor assesses difficulty describing feelings and the third factor assesses the propensity to have an externalized thinking style. The second factor assesses difficulty describing feelings, in the survey the highest possible score was twenty-five for this factor and participants surveyed scored a mean of eighteen. This means that over 70% of the participants assessed reported that they have a moderate to high difficulty describing their emotions. Out of the three factors, this was the highest mean. The third factor assesses if the participant has an externalized thinking style, which makes it

hard to be aware of the internal feelings. In the survey, the highest possible score is forty for this factor. The mean for the third factor of the participants surveyed was eighteen. In the study findings, externalized thinking style factor was by far the lowest mean. Therefore, this was analyzed to suggest that most of the participants weren't engaging in externalized thinking styles and were aware of their emotions, but couldn't describe them to others.

Higher amounts of alexithymia in the mental health population was an expected result from the research, but the lower capacity for subjects to describe their emotions was unexpected. Another finding of interest is that many of the study respondents (over 90%) have gone on to higher education, suggesting that intelligence level and difficulty describing emotions doesn't seem to have a positive correlation, though mental illness and alexithymia does. Thus, it appears that people with a mental illness diagnosis, regardless of their education level, are more likely to have the alexithymia condition, and appear to have real challenges in expressing emotions. This is of great interest to the clinical treatment world of a therapist.

**Would alternative treatment modalities, that don't require verbal expression or describing of feelings, be helpful for people with a mental diagnosis?**

It is not surprising that talk therapy was the most popular form of treatment that participants have tried because talk therapy been the most traditional type of therapy in the United States. Further, talk therapy is one of the only types of therapy insurance will pay for, thus limiting choices for alternative treatments. In my study, 97% of the participants had tried talk therapy as a treatment for their therapy needs; while not surprisingly, very few of the participants reported having ever even trying to utilize alternative treatments. The few respondents who reported having utilized alternative treatments noted that these were at least somewhat helpful. In fact, some sixty percent of participants who utilized alternative treatments found them to be the most helpful treatments for their therapy needs. Though

much more research needs to be done to verify this feedback, this could mean that alternative treatments may be better suited to treat people with mental illness, especially those who have difficulty describing their emotions verbally or who have clinically significant amounts of alexithymia.

Though I did receive enough responses to conduct my analysis of the key study questions, the diversity of the sample was another matter. My main recruitment source, The Universal Access program, is located in Western Massachusetts. Diversity is limited in this region in general. Due to this fact and the anonymity of the survey, racial and social economic status diversity of the participants was skewed based on geographic proximity. The snowball sampling may have helped to include surrounding areas, but the end result was not as diverse as initially projected. The survey did receive a diverse mix of people with differing mental health diagnosis, who completed the survey.

This diversity in diagnosis among the participants was important for the feedback received about alternative treatments. Currently, people who are in treatment for mental health issues and challenges often seek therapy as a way to address problems, but the most available mental health treatment approach in the United States is talk therapy, in the course of which the therapist and patient explore the issues through verbal exchange. This modality of treatment assumes patient's ability to express themselves verbally. However, as this study and other research strived to show, the ability to verbally identify, explore and express feelings is not an inherent capacity in all human beings.

## **Conclusions**

### **Limitations/Recommendations for Further Study**

**Race and Ethnicity.** The biggest limitation to this study is the lack of racial diversity: ninety-two percent of the group identified as White or Caucasian. Though the study originated in Western Massachusetts, the hope was that through snowball sampling the racial

diversity would have been more even, if this study was done in the future I would start in an area with more racial diversity.

**Religious Preference.** Forty percent of the study participant pool preferred not to answer this question with another thirty percent who said that they don't have a religious preference. This could be another study on religious affiliation and alexithymia.

**Specific Mental Health Diagnosis.** Another limitation of this study is that three of the Mental Health Diagnosis that were found in the literature review to be correlated with high levels of alexithymia were the least represented in the study sample Traumatic Brain Injury and Autism Spectrum Disorder were the least represented group with an accumulative seven percent and substance use disorders were the second to least group represented with six percent. More study in this area is indicated.

### **Implications for Social work practice**

This study had several limitations, including a low sample size, but the future implications of this study are far-reaching for social work. This study supported the literature that alexithymia is in higher rates with people who have a mental health diagnosis and by doing so pointed the light on the need for research on alternative treatment methods and types of assessment in clinical encounters. There are thousands of patients that are deemed treatment resistant in the United States (Hamidi,2010), but what if these clients have high levels of alexithymia and are struggling to describe or express their emotions in a treatment modality that only allows verbal communication to be exchanged. In the National Social Work code of ethics, a social workers primary mission is to support the vulnerable and to empower them. This study found a group of patients that are struggling to get treatment and don't understand why they can't get the help they deserve. We need to have treatment modalities that support people who express themselves in different ways, not just the people who are good at articulating their situations in a verbal way. We need to be open to

alternative treatments that could support our clients better than the modalities we are comfortable using. Critically, we need to advocate for insurance to cover alternative treatments, especially for vulnerable people who require alternative treatments. We need to assess for alexithymia and other possibilities before deeming client's treatment resistant and giving up the hope for their recovery. We can add these perceptives to our clinical encounters and continue research to support alternative treatment modalities.

## REFERENCES

- Barth, F. (2016). Listening to words, hearing feelings: Links between eating disorders and alexithymia. *Clinical Social Work Journal, 44*(1), 38-46.
- Bonnet, A., Brejard, V., & Pardinielli, J. (2013). Emotional dispositions and substance use: Mediating effect of alexithymia. *Psychological Reports, 112*(1), 289-302.
- Hamidi, S., Rostami, R., Farhoodi, F., & Abdolmanafi, A. (2010). WCPCG-2010: A study and comparison of alexithymia among patients with substance use disorder and normal people. *Procedia - Social and Behavioral Sciences, 5*, 1367-1370.
- Joyce, A. S., Nordhagen, A., Ogrodniczuk, J. S., Stovel, L. E., & Bjorge, A. (2015). Partial hospitalization treatment of the alexithymic patient: A case study. *Journal of Clinical Psychology, 71*(2), 167-177.
- Keefer, K. V., Taylor, G. J., Parker, J. D. A., Inslegers, R., & Michael Bagby, R. (2015). Measurement equivalence of the Toronto structured interview for alexithymia across language, gender, and clinical status. *Psychiatry Research, 228*, 760-764.
- Krystal, H. (1988). *Integration and self-healing: Affect, trauma, and alexithymia*. Hillsdale, NJ: *Analytic Press*.
- Leweke, F., Leichsenring, F., Kruse, J., & Hermes, S. (2012). Is alexithymia associated with specific mental disorders? *Psychopathology, 45*(1), 22-28.
- Marchesi, C., Ossola, P., Tonna, M., & De Panfilis, C. (2014). The TAS-20 more likely measures negative affects rather than alexithymia itself in patients with major depression, panic disorder, eating disorders and substance use disorders. *Comprehensive Psychiatry, 55*, 972-978.
- Neumann, D., Zupan, B., Malec, J. F., & Hammond, F. (2014). Relationships between alexithymia, affect recognition, and empathy after traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 29*(1), E18-E27.

- Ogrodniczuk, J. S., Piper, W. E., & Joyce, A. S. (2011). Effect of alexithymia on the process and outcome of psychotherapy: A programmatic review. *Psychiatry Research, 190*, 43-48.
- Ogrodniczuk, J. S., Sochting, I., Piper, W. E., & Joyce, A. S. (2012). A naturalistic study of alexithymia among psychiatric outpatients treated in an integrated group therapy program. *Psychology & Psychotherapy: Theory, Research & Practice, 85*(3), 278-291.
- Samur, D., Tops, M., Schlinkert, C., Quirin, M., Cuijpers, P., & Koole, S. L. (2013). Four decades of research on alexithymia: Moving toward clinical applications. *frontiers in psychology, 4*.
- Spitzer, C., Vogel, M., Barnow, S., Freyberger, H. J., & Grabe, H. J. (2007). Psychopathology and alexithymia in severe mental illness: The impact of trauma and posttraumatic stress symptoms. *European Archives of Psychiatry & Clinical Neuroscience, 257*(4), 191.
- Taylor, G. J., & Bagby, R. M. (2013). Alexithymia and the five-factor model of personality. In T. A. Widiger, P. T. J. Costa, T. A. Widiger (Ed) & P. T. J. Costa (Ed) (Eds.), (pp. 193-207). Washington, DC, US: American Psychological Association.
- Taylor, G. J., & Bagby, R. M. (2013). Psychoanalysis and empirical research: The example of alexithymia. *Journal of the American Psychoanalytic Association, 61*(1), 99-133.
- Terock, J., Janowitz, D., Spitzer, C., Miertsch, M., Freyberger, H. J., & Grabe, H. J. (2015). Alexithymia and self-directedness as predictors of psychopathology and psychotherapeutic treatment outcome. *Comprehensive Psychiatry, 62*, 34-41.
- Williams, C., & Wood, R. L. (2010). Alexithymia and emotional empathy following traumatic brain injury. *Journal of Clinical & Experimental Neuropsychology, 32*(3), 259-267.

Yalug, I., Selekler, M., Erdogan, A., Kutlu, A., Dundar, G., Ankarali, H., et al. (2010).

Correlations between alexithymia and pain severity, depression, and anxiety among patients with chronic and episodic migraine. *Psychiatry and Clinical Neurosciences*, 64(3), 231-238.



## APPENDIX A: Human Subjects Review Approval



---

School for Social Work

Smith College

Northampton, Massachusetts 01063

January 3, 2017

Rebekah Milhoan

Dear Rebekah,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,  
Michael Murphy, PhD  
Member, Human Subjects Review Committee

CC: Elaine Kersten, Research Advisor

APPENDIX B: Informed Consent



2016-2017

**Consent to Participate in a Research Study**

Smith College School for Social Work • Northampton, MA

.....

**Title of Study:** Exploring the prevalence of Alexithymia in differential diagnosis and evaluating alternative treatment modalities, from the participants perceptive.

**Investigator(s):**

Milhoan, Rebekah

rmilhoan@smith.edu

.....

**Introduction**

- You are being asked to participate in a research study designed to gather information from people diagnosed with a mental health diagnosis about how they express and identify their emotions, which treatments they have tried, and which of those treatments were helpful or not helpful.

- You were selected as a possible participant for the following reasons/because you meet the following criteria: you are 18 years or older; self-identify as having received a mental health diagnosis;; have access to the internet; are able to read and understand English; and have not been in treatment for psychosis or acute detox within the last thirty days.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

### **Purpose of Study**

The purpose of this research study is to gather information from people who have a mental health diagnosis, may have difficulty expressing themselves verbally and who have experience with different mental health treatments about how different treatments were helpful or un-helpful in expressing or identifying their emotions. **Having trouble expressing your feelings through words is a term known to researchers as alexithymia.**

- This study is being conducted as a research requirement for my master's level social work degree.
- Ultimately, this research may be published or presented at professional conferences.

### **Description of the Study Procedures**

- If you agree to be in this study, you will be asked to do the following: First, confirm that you meet the inclusion criteria for the survey. Second, read the Informed Consent and agreement to participate in the survey. Third, you will complete a survey.

### **Risks/Discomforts of Being in this Study**

- There is a minimal potential for some discomfort when taking this survey, due to reflection on previous treatments experienced.

- If while taking the survey you have any discomfort and would like to speak with a mental health provider please see below for free mental health referral services.
- For participants in the Western Massachusetts area by county:

Find a health care provider to speak with:

Berkshire County

413.236.5656

Hampshire County

413.582.0471

Hampden County

413.737.9544

Franklin County

413.774.1000

North Quabbin

978.249.9490

Worcester County

978.632.9400

---

FOR CRISIS SERVICES CALL:

Franklin County

413.774.5411

800.562.0112

140 High Street

Greenfield, MA 01301

Fax: 413.773.8429

Hampshire County

413.586.5555

844.788.6470

29 N. Main Street

Florence, MA 01062

Fax: 413.586.2723

North Quabbin

978.249.3141

800.562.0112

491 Main St.,

Athol, MA 01331

Fax: 978.249.3139

- ***National Suicide Prevention Lifeline*** – 1-800-273-TALK (8255) or [Live Online Chat](#)

If you or someone you know is suicidal or in emotional distress, contact the [National Suicide Prevention Lifeline](#)<sup>®</sup>. Trained crisis workers are available to talk **24 hours a day, 7 days a week**.

Your confidential and toll-free call goes to the nearest crisis center in the Lifeline national network.

These centers provide crisis counseling and mental health referrals.

- ***SAMHSA Treatment Referral Helpline*** – 1-877-SAMHSA7 (1-877-726-4727)

Get general information on mental health and locate treatment services in your area. Speak to a live person, Monday through Friday from 8 a.m. to 8 p.m. EST.

### **Benefits of Being in the Study**

- Participants may benefit from having an opportunity to reflect on treatments they received.
- The benefits to social work/society are: to verify research of the presence of alexithymia and to identify treatments that are helpful to people who have trouble expressing themselves verbally.

### **Confidentiality**

- This study is anonymous. We will not be collecting or retaining any information about your identity.

### **Payments/gift**

- You will not receive any financial payment for your participation.

### **Right to Refuse or Withdraw**

- The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the survey at any time. As an anonymous survey, simply exit at any point by clicking on 'escape' at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in my study.

### **Right to Ask Questions and Report Concerns**

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about

the study, at any time feel free to contact me, Rebekah Milhoan at [rmilhoan@smith.edu](mailto:rmilhoan@smith.edu). If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

### **Consent**

- By clicking the box below you are electronically signing this informed consent, which indicates that you have decided to volunteer as a research participant for this study and that you have read and understood the information provided above. Print or save a screen shot this consent form for your records.

## **APPENDIX C: Message to the Director**

Dear Tom McCarthy-Director of the Universal Assess Program,

Attached is the recruitment letter that I ask you to send to your member organizations, asking them to send it to their members for consideration to participate in my survey, with the survey link.

Please forward this attachment as an email to the following organizations:

All Out Adventures, Inc. Northampton, MA

Access Outdoors, Amherst, MA

Spaulding Adaptive Sports Centers, Boston, and Cape Cod

Waypoint Adventures, Lexington, MA

Holyoke Rows, Holyoke, MA

Northeast Passage, Durham, NH

Community Boating, Boston, MA

The survey takes approximately twenty minutes to complete.

As a reminder, the participants may be eligible for this study if they are 18 years or older and have received a mental health diagnosis during the course of treatment and have engaged in any type of therapy, including alternative self-directed therapy activities such as yoga, meditation, and mindfulness. People who are in active treatment for psychosis or acute detox within the last 30 days should not participate in this survey. Participants must also have access to the internet and be able to read and understand English.

Please include the following to the message to your member organizations:



This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC).

Thank you for your support!

Sincerely,

**Rebekah Milhoan**

MSW Student

School of Social Work

Smith college

Northampton, Ma

On November 15<sup>th</sup>, 2016, I discussed with Tom McCarthy, Director of Universal Access Programs for Western Massachusetts, my thesis proposal and he agreed to distribute to the organizations listed below and he would encourage those organizations to “send the survey forward” to their partnering organizations.

All out Adventures, Access Outdoors, Spaulding Adaptive Sports Center, Waypoint, Holyoke Rows, Northeast Passage, Community Boating, and other Universal Access Programs in Massachusetts.

## **APPENDIX D:Recruitment Message**

Thank you for taking a moment to learn about my study.

My name is Rebekah Milhoan. I am a graduate student from the school of Social Work at Smith College. I am writing to tell you about a study I am conducting to gather information from people who have a mental health diagnosis and may also have the condition known as 'alexithymia', and have experience with mental health treatments.

Alexithymia is a personality construct that affects an individual's capacity to express themselves verbally. I am interested in learning about the presence of/level of alexithymia in a sample of individuals who have a mental health diagnosis, and also to gain their perspective on the treatment they received including alternative treatment methods (such as yoga, wilderness therapy, meditation, play therapy, etc).

The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC)

Attached, please find a message that I ask you to send to your members to consider participating in my study.

Thank you for your help!

Sincerely,

**Rebekah Milhoan**

MSW Student

School of Social Work

Smith college

Northampton, Ma

## **APPENDIX E: Message to Individuals**

Thank you for taking a moment to learn about my study.

My name is Rebekah Milhoan. I am a graduate student from the school of Social Work at Smith College. I am writing to tell you about a study I am doing to gather information from people who have experience with mental health treatments to gain their perspective on alternative treatment methods.

**The purpose of this research study is to gather information from people who have a mental health diagnosis, may have difficulty expressing themselves verbally and who have experience with different mental health treatments about how different treatments were helpful or unhelpful in expressing or identifying their emotions. Having trouble expressing your feelings through words is a term known to researchers as alexithymia.**

You may be eligible for this study if you are 18 years or older, have received a mental health diagnosis at any time, and have engaged in any type of therapy, including alternative self-directed therapy activities such as yoga, meditation or mindfulness. Participants must also have access to the internet and be able to read and understand English.

You are not eligible to take this study if within the last 30 days you were in active treatment for psychosis or acute detox.

**The survey takes approximately twenty minutes to complete. If you are interested, please follow the link below before 3/1/2016. Participation is anonymous and voluntary. Whether or not you participate in this study will have no effect on your relationship with any Universal Access programs.**

If you have any questions about the survey or the study you can contact me at [rmilhoan@smith.edu](mailto:rmilhoan@smith.edu)

.

The data collected from this study will be used to complete my Master's in Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

This study protocol has been reviewed and approved by the Smith College School for Social Work Human Subjects Review Committee (HSRC).

Thank you for your time and consideration.

Sincerely,

**Rebekah Milhoan**

MSW Student

School of Social Work

Smith college

**APPENDIX F: Permission to Use the TAS-20**

*Toronto Alexithymia Scale*

2016 Thesis x



**Graeme Taylor**

Nov 15,  
2016

Dear Rebekah:

Thank you for payment of the US\$40 copyright fee for use of the TAS-20.

The scale is attached as a pdf file. Also, a list of related references in a Word file.

All the best with your research study.

Best regards,

Graeme Taylor, MD

Professor of Psychiatry

University of Toronto

Email: [graeme.taylor@utoronto.ca](mailto:graeme.taylor@utoronto.ca)

[www.gtaylorpsychiatry.org](http://www.gtaylorpsychiatry.org)

## APPENDIX G: Survey Layout

Welcome to the survey!

**The purpose of this research study is to gather information from people who have a mental health diagnosis, may have difficulty expressing themselves verbally and who have experience with different mental health treatments about how different treatments were helpful or unhelpful in expressing or identifying their emotions. Having trouble expressing your feelings through words is a term known to researchers as alexithymia.**

In this survey, you will find:

1. Pre-screening page to confirm that you meet criteria to take the survey.
2. Informed consent page, confirming that you understand the study's purpose and uses and agree to participate in the study.
3. A survey that includes information about you, and questions about how you think about the therapy you received.

The survey takes approximately twenty minutes to complete.

**Reminder:** The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the survey at any time. As an anonymous survey, simply exit at any point by clicking on 'escape' at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in my study

Attachment E: Pre-Screening Criteria

You may be eligible for this study if you:

- Are 18 years or older
- Have received a mental health diagnosis at any time and have engaged in any type of therapy, including alternative self-directed therapy activities such as yoga, meditation or mindfulness.
- Are able to read and understand English

- AND have access to the internet.

You are NOT eligible for this study if within the last 30 days you:

- Were in treatment for psychosis or acute detox.

By clicking this box you are confirming that you meet all the inclusion criteria to take this survey and would like to be taken to the informed consent page.

By clicking this box you are confirming that you DO NOT meet all the inclusion criteria and would like to exit this survey.



**There are three parts to this survey as described below:**

1. A set of questions about the basic demographic information.
2. A set of questions about how you identify and express your emotions
3. A set of questions that ask you about types of treatments you have received for your diagnosed condition, including asking you to rate treatments in terms of how these were helpful or not helpful.

**Reminder:** The decision to participate in this study is entirely up to you. You may refuse to answer any question or withdraw from the survey at any time. As an anonymous survey, simply exit at any point by clicking on 'escape' at the top of the screen if you wish to do so. Answers to questions prior to exiting will remain in the survey up to that point, but I will have no way to know who you are, and the survey will be discarded as I will not use incomplete surveys in this study.

### **Section 1: Basic Demographic/Identity Information**

**Please check the box next to the answer you most identify with OR check other and fill in the blank**

#### **1. Age:**

18-29

30-49

50-64

65- Older

Prefer not to answer

#### **2. Gender:**

Woman

Man

Transgender

Other (please specify)

Prefer not to answer

**3.Race and Ethnicity:**

American Indian or Alaska Native

Asian

Black or African American

Hispanic or Latino

Pacific Islander

White

Other not listed:

Prefer not to answer

**4. Highest Education Level Completed:**

No high school completed

Some high school completed

High school Graduate

Some college

4- Year degree graduate

Trade/technical training

Other:

Prefer not to answer

**5. Religion Preference:**

Fill in the blank

No preference

Prefer not to answer

**Section 2: Questionnaire about how you express and identify your feelings.**

Using the scale provided as a guide, indicate how much you agree or disagree with each of the following statements by checking the corresponding number. Give only one answer for each statement.

Check 1 if you **STRONGLY DISAGREE**

Check 2 if you **MODERATELY DISAGREE**

Check 3 if you **NEITHER DISAGREE NOR AGREE**

Check 4 if you **MODERATELY AGREE**

Check 5 if you **STRONGLY AGREE**

1      2      3      4      5

1. I am often confused about what emotion I am feeling.
2. It is difficult for me to find the right words for my feelings
3. I have physical sensations that even doctors don't understand.
4. I am able to describe my feelings easily.
5. I prefer to analyze problems rather than just describe them.
6. When I am upset, I don't know if I am sad, frightened, or angry.
7. I am often puzzled by sensations in my body.
8. I prefer to just let things happen rather than to understand why they turned out that way.
9. I have feelings that I can't quite identify.
10. Being in touch with emotions is essential.
11. I find it hard to describe how I feel about people.
12. People tell me to describe my feelings more.
13. I don't know what's going on inside me.
14. I often don't know why I am angry
15. I prefer talking to people about their daily activities rather than their feelings.

16. I prefer to watch “light” entertainment shows rather than psychological dramas.
17. It is difficult for me to reveal my innermost feelings, even to close friends.
18. I can feel close to someone, even in moments of silence.
19. I find examination of my feelings useful in solving personal problems.
20. Looking for hidden meanings in movies or plays distracts from their enjoyment.

**Section 3: Feedback questions about mental health treatments and self-care practices you have found helpful or not helpful. Please check the box(s) next to the diagnosis that you have received:**

Mood disorder (Depression or Bipolar)

PTSD

Eating Disorder

Substance Abuse Disorder

Traumatic Brain Injury

Autism Spectrum Disorder

Other:

**Please check the box next to the treatments below that you have received and rate how helpful they were on a scale of 1 being not helpful at all to 5 being the most helpful. There is space available after each response if you care to expand on your response.**

21a. Talk Therapy – Traditional therapy in which a person would verbally express their thoughts and feelings to a therapist.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

21b Optional Question: Why did you find this model of treatment helpful or not helpful?

22a. Play Therapy (as a child) – The child is given toys or activities to play with during the session, while the therapist observes and gives verbal promptings to direct the play.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

22b. Optional Question: Why did you find this model of treatment helpful or not helpful?

23a. Play Therapy (as an adult) – This can be done as an individual or as a group. The adult is given promptings around playing with toys or activities during the session, while the therapist observes and gives verbal promptings to direct the play and explore the feelings around the action.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

23b. Optional Question: Why did you find this model of treatment helpful or not helpful?

24a. Peer Support Groups – Groups for people who have similar diagnosis that are led by a peer or other individual without a mental health license.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

24b. Optional Question: Why did you find this model of treatment helpful or not helpful?

25a. Support Groups- Groups for people who have similar harmful behaviors or diagnosis that are led by a licensed mental health worker.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

25b. Optional Question: Why did you find this model of treatment helpful or not helpful?

26a Somatic Awareness- A type of therapy that focuses on understanding body feelings , instead of talking about thoughts, moods, or behaviors.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

26b. Optional Question: Why did you find this model of treatment helpful or not helpful?

27a Mindfulness or Recreation- A group that seeks to enhance quality of life through recreational activities such as yoga, meditation, skiing, boating, or hiking.

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

27b. Optional Question: Why did you find this model of treatment helpful or not helpful?

28a. In the space provided, please add other Treatment Models or Alternative Self-Care Activities you may have received that are not mentioned above:

1 Not Helpful at all 2 Somewhat Helpful 3. Helpful 4. Very Helpful 5. The most helpful

28b. Optional Question: Why did you find this model of treatment helpful or not helpful?

29. Any Additional Comments:

This is the end of the survey. Thank you for your time and valued input.

Attachment H: Thank you and resource page

Thank you for your time.

- If you wish to learn more about the personality construct known as alexithymia follow the link to the US national Library of Medicine article.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2931418/>

- If while taking the survey you have any discomfort and would like to speak with a mental health provider please see below for free mental health referral services.
- For participants in the Western Massachusetts area by county:

Find a health care provider to speak with:

Berkshire County

413.236.5656

Hampshire County

413.582.0471

Hampden County

413.737.9544

Franklin County

413.774.1000

North Quabbin

978.249.9490

Worcester County

978.632.9400

---

**FOR CRISIS SERVICES CALL:**

Franklin County

413.774.5411

800.562.0112

140 High Street

Greenfield, MA 01301

Fax: 413.773.8429

Hampshire County

413.586.5555

844.788.6470

29 N. Main Street

Florence, MA 01062

Fax: 413.586.2723

North Quabbin

978.249.3141

800.562.0112

491 Main St.,

Athol, MA 01331

Fax: 978.249.3139

- ***National Suicide Prevention Lifeline*** – 1-800-273-TALK (8255) or [Live Online Chat](#)

If you or someone you know is suicidal or in emotional distress, contact the [National Suicide Prevention Lifeline](#)<sup>®</sup>. Trained crisis workers are available to talk **24 hours a day, 7 days a week**.

Your confidential and toll-free call goes to the nearest crisis center in the Lifeline national network.

These centers provide crisis counseling and mental health referrals.

- ***SAMHSA Treatment Referral Helpline*** – 1-877-SAMHSA7 (1-877-726-4727)

Get general information on mental health and locate treatment services in your area. Speak to a live person, Monday through Friday from 8 a.m. to 8 p.m. EST.