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The ethics of dying: an exploration of the right to suicide and clinician response to self-determination and suicidal ideation among adults who struggle with mental illness

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ABSTRACT

This paper explores the question: *What beliefs, values and assumptions do social workers hold when assessing whether or not a person who is a mental health client has the right to suicide?* The current literature reveals that individuals struggling with physical disorders deemed extreme and untreatable are likely to be accepted as rational grounds for suicide. Underrepresented in extant research is the critical examination of the desire to die as a rational versus pathological and treatable response to mental health concerns. The study question is examined, in part, through the lens of the Code of Ethics presented by the National Association of Social Workers.

In answering this question, a qualitative, exploratory study was conducted to examine clinicians’ beliefs on a person’s right to suicide and the potential impact of clinician subjectivity in work with client suicidality. The study included 10 individual, semi-structured interviews with current social workers. The findings of this study include the following: the majority perspective of clinicians interviewed revealed that persons who are mental health clients have a right to suicide; an overlap exists between physical and mental health, but reactions to physical and mental health continue to differ; person-centered therapy yields most successful results. The literature reviewed and data collected from this study reveal a clear need to rethink responses to suicidal ideation amongst persons who are mental health clients. Significant findings of this study echoed much of the existing literature on the subject of suicidal ideation amongst mental
health clients: a person’s ethical right to suicide remains questioned, but the need for improved clinical response to suicidality proves imperative.
THE ETHICS OF DYING: AN EXPLORATION OF THE RIGHT TO SUICIDE AND
CLINICIAN RESPONSE TO SELF-DETERMINATION AND SUICIDAL IDEATION
AMONG ADULTS WHO STRUGGLE WITH MENTAL ILLNESS

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

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Chapter I

Introduction

The purpose of this study is to explore the question: *What beliefs, values and assumptions do social workers hold when assessing whether or not a person who is a mental health client has the right to suicide?* In answering this question, I will conduct a qualitative, exploratory study to examine clinicians’ beliefs on a person’s right to suicide and the potential impact of clinician subjectivity in work with client suicidality.

In 2012, over 1.3 million adults living in the United States reported that they attempted suicide in the past year, and 39,426 adults died by suicide (Bianco, Compton, Han, et al, 2016). While such numbers show the prevalence of suicide, further research is needed to explore how the field of social work can most ethically respond to a person’s want to die. The current literature reveals that individuals struggling with physical disorders deemed extreme and untreatable are likely to be accepted as rational grounds for suicide. Rational suicide is considered to be a presumably reasonable, informed choice to end one’s life (Hewitt, 2013). Underrepresented in extant research is the critical examination of the desire to die as a rational versus pathological and treatable response to mental health concerns.

The Code of Ethics presented by the National Association of Social Workers (NASW) obligates social workers to protect their clients from harm of self or others (NASW, 2017). The required response to suicidal ideation is thus suicide prevention. The NASW (2017) further obligates clinicians to promote client self-determination. The study question aims to investigate the overlap of these two ethical guidelines. I will interview social workers who work with persons who are mental health clients using qualitative research methods. This research holds the potential to encourage clinicians’ use of diverse and innovative therapeutic responses to
suicidality, and consequently improve the quality of client care and clinicians’ upholding of the NASW Code of Ethics.

The following chapters discuss the theoretical and empirical basis for this study, the methodology used to explore the research question, the demographic and qualitative findings, and a discussion section that attempts to interpret and make meaning of the findings.
Chapter II

Literature Review

The following review of the literature focuses on previous research pertaining to the study question: What beliefs, values and assumptions do social workers hold when assessing whether or not a person who is a mental health client has the right to suicide? The first section, determining capacity, will explore the legality and definition of rational suicide amongst individuals with terminal physical illnesses and use findings to assess rational suicide amongst adults with mental health concerns. A section on ethical guidelines will follow to demonstrate the connectedness of the NASW Code of Ethics and social workers’ responses to clients with suicidal ideation. Finally, social workers’ subjectivity in determining rational suicide will be discussed. The current study will explore the ways in which, if at all, subjective views of suicide affect the practice of social workers who work with clients who have/had suicidal ideation.

Determining Capacity

In 1997, the Supreme Court decided two precedent-setting cases, Washington v. Glucksberg and Vacco v. Quill (Mariner, 1998). The Supreme Court overruled the notion that physician assisted suicide is a right under the 14th Amendment, and permitted instead the right for individual states to define their own statutes and for the Court to revisit the issue and make changes if needed at a future time (Mariner, 1998). The bordering states of Vermont and Massachusetts, where much of the independent research for the current study is expected to take place, can highlight such differences in law. In 2013, Vermont became the first state to pass the Death with Dignity law through legislation, and the third state to enact the law in the United States (Death with Dignity, 2017). The Death with Dignity law offers end-of-life options to individuals who are terminally ill, which includes physician-assisted suicide. This law was

The aforementioned legal advocacies largely encompass somatic illness and do not directly speak to the right to die resultant of mental health illnesses. In review of literature regarding the legality of suicide, it is important to consider that comparing attitudes toward the right to die for individuals who are terminally ill and individuals who are mentally ill “does not provide an apt basis for understanding the unique implications of patient psychopathology in the process of determining one’s right to suicide. A common theme in debates of assisted suicide, regardless of precipitating factors, is the examination of autonomy. Schermer (2002) defines autonomy as the ability to hold one’s own self-selected values and goals and arrange one’s life in accordance to them. If a person does indeed have autonomy⁴, then it is problematic for a physician to justify compulsory care⁵. If a person is deemed incapable of autonomous decision making due to the severity of their illness, then compulsory care is justified (Hewitt & Edwards, 2006). Such an argument leaves the question unanswered: How does one determine a person no longer has the right to autonomous decision making? Much of the available literature that
explores rational suicide exists in relation to somatic health and terminal illness; this literature can help to evolve an understanding of what constitutes rational suicide. In the literature around terminal illness and suicide, it is revealed that having a physical disorder deemed extreme and untreatable is likely to be accepted as rational grounds for suicide (Hewitt, 2013). Psychiatrists are called upon to determine a patient’s capacity when an appeal for euthanasia is requested due to terminal somatic illness (Azar, Bergman-Levy, Huberfeld, Siegel, & Strous, 2013). Such may suggest that despite the written law’s effort for hard science to justify rational suicide, an evaluation of the mind is still a crucial component to determine a person’s ability to gain access to assisted suicide.

Hewitt (2013) explains that suicides of those with serious mental illness are often regarded as non-voluntary due to constituted irrationality. In exploration of the idea that suicide is a fundamentally irrational choice, Héctor Wittwer (2013) reports that there can be good reasons for someone to want to end her or his life” (Witter, 2013). In review of empirical data from his study, “The problem of the possible rationality of suicide and the ethics of physician-assisted suicide”, Wittwer concludes that overwhelmingly, healthcare professionals link suicidal ideation with mental health. Must then a struggle with mental health be coupled with a somatic illness to be considered rational? The American Medical Association’s (2013) Code of Medical Ethics posits that “even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis” (p. 1038).

“Serious mental illness is typically conceived of as a coercive pressure which prevents rational deliberation and as such, the suicides of those with serious mental illness are considered to be substantially non-voluntary acts arising from constitutive irrationality” (Hewitt, 2013).
Insight is one aspect observed in a mental status examination conducted to determine a person’s ability to make an informed decision about their care. Markova and Berrios (1992) offer a broad understanding of insight that is defined not only by people's understanding of their illness, but also in terms of understanding how the illness affects individuals' interactions with the world. “The term 'insight' encompasses a complex concept which should not be considered as an isolated symptom which is present or absent. Instead, it may be more appropriate to think of insight as a continuum of thinking and feeling, affected by numerous internal and external variables” (Markova & Berrios, 1992, p. 855). Such a definition calls for accurate clinical assessment of insight that is specific to the individuals being served; the care received should mirror such diversity through person-centered approaches.

Hewitt (2010) further draws attention to the need of greater research that explores how to most accurately determine mental capacity in work with psychiatric patients. The little research that does exist, Hewitt (2010) explains, has a particular focus on people with schizophrenia, and reveals that individuals with such a diagnosis are more likely to experience isolated, rather than constitutive, irrationality and are therefore not necessarily globally incapacitated. Hewitt (2010) challenges the idea of global irrationality conferred by a diagnosis of schizophrenia and argues that, “where delusional beliefs are unifocal, schizophrenia does not necessarily lead to a state of mental incapacity” (p. 63). Hewitt (2010) further asserts that people diagnosed with schizophrenia can be capable of a realistic assessment of their psychological suffering, and thusly make rational decisions in regards to suicide.

**Ethical Guidelines:**

An additional factor of great importance in the discussion of a person’s right to suicide is the consideration of moral action. James Werth (1996) argues that both the ethical and legal
standards of care should be changed to allow mental health workers the option to not coercively interfere with clients who choose to die. Under the value of dignity and worth of the person, the NASW Code of Ethics (2017) state:

Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession (p. 6).

Section 1.02, Self-Determination, of the Code of Ethics (2017) adds:

Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others (p. 8).

The current study aims to further develop the understanding of a person’s right of self-determination as it relates to the NASW Code of Ethics through individual interviews with current social workers. Gordon (1999) argues that ethics are at the heart of psychotherapy, and that “ethics in this sense requires an attitude or position of radical openness towards the other in all his strangeness which avoids reducing the other to what is already known to us” (p. 47). Evans (1996) explains that the task of the clinician is to enable the client’s own unique truth to
emerge in their treatment, a truth which is therefore absolutely different to that of the clinician (p. 39). In section 4.02, Discrimination, the NASW Code of Ethics (2017) state: “Social workers should not practice, condone, facilitate, or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, or mental or physical ability.” These social identities significantly inform each person’s individual truth, and as such one could argue that the NASW Code of Ethics require that a clinician not discriminate against an individual’s truth. Kai Möller (2009) asserts that in order “to be really free we constantly need the assistance of others. To respect autonomy therefore means to offer enabling conditions for services that support people in the pursuit of their individual lives; and this might entail decisions to die (p. 257). Within the ethical principle that social workers will challenge social injustice, the NASW Code of Ethics (2017) advocate that social workers will ensure the “quality of opportunity and meaningful participation in decision making for all people.”

Brandt (1992) poses the question, “What reasons have been offered for believing that there is a strong moral obligation to avoid suicide, that cannot be superseded by any consideration of personal welfare?” (p. 319). In the United States, suicide has become a term largely viewed as taboo (Moody & Sasser, 2012). As such, even when considered lawful, coded language is often used in the discourse around assisted suicide. For example, in the courts, a medical professional that participates in the deliberate ending of the life of a person suffering from a terminal illness has repeatedly been concluded as not homicide, suicide, or assisted suicide. Courts instead describe such deliberate interventions with phrases such as withdrawing life support and termination of life-sustaining treatment (Moody & Sasser, 2012). Such inconsistencies between language and action offer evidence that in order to begin to address
suicidal ideation, one must be able to first talk about it. Scott Fitzpatrick (2014) argues that “contemporary approaches to the study of suicide tend to examine suicide as a medical or public health problem rather than a moral problem […] but morality entails more than judgement about action or behaviour, and our understanding of suicide can be enhanced by attending to its cultural, social, and linguistic connotations” (p. 223). Fitzpatrick’s argument highlights the need for both further discourse around the topic of suicide and confrontation of coded language in such discourse.

Brandt (1992) argues that if an individual has decided to end her/his/their life based on clear evidence that such a decision would indeed relieve suffering, then there is a moral obligation for caregivers to provide assistance in carrying out such a wish. Given that a person suffering from a mental illness can be in distress ruthless enough to make him/her/them want to die, the position that mental illness can be as relevant in the end-of-life context as other kinds of severe suffering is not without intuitive plausibility. In the exploratory study “Psychotherapists’ attitudes toward suicide”, James Werth and Becky Little (1994) interviewed therapists to gain insight on their thoughts of personal moral obligations in relation to suicidal ideation experienced by their clients. The study’s results revealed that even when it went against their moral beliefs, some therapists felt pressured to maintain a standard of suicide prevention due to their fear of ethical or legal reprisal. The findings of Werth and Liddle (1994) revealed that many respondents in their study believed in and accepted rational suicide, but would be hesitant to allow a client to follow through with such a decision because of their fear of repercussions. Such findings indicate that despite the intentions of legal and ethical frameworks, these standards fail to allow a clinician the ability to truly prevent their clients from harm.
Subjectivity of the Clinician

The healthcare field is built upon a degree of trust that its professionals will act in the interest of the patient, and thusly that physicians will perform their jobs to the expectation that their personal beliefs will not negatively interfere with their practice of equitable care. Hewitt and Edwards (2006) investigated that subjective factors can impact physician involvement with assisted suicide. They found that connectedness and a physician’s sympathetic understanding of the patient are crucial components to develop a more holistic understanding of patient needs (Hewitt & Edwards, 2006). For example, if a patient does not feel safe or able to disclose a sensitive issue with his/her physician, then medical decisions made by the doctor will be based on incomplete evidence. Hewitt and Edwards (2006) report that these subjective parts of understanding are necessary then to explore the role of health professionals working with individuals who have suicidal ideation.

Though the ideal practice trusts that medical professionals withhold their personal bias in the treatment of the individuals they work with, professional decision-making in patient care remains susceptible to the subjective factors influencing assessment. Particularly, as argued by Thomas Schramme (2013), the value of personal life is dependent on a point of view that is relative to subjects, and cannot be determined entirely objectively. Schramme (2013) explores the ambiguity of what measures the quality of one’s life:

There seem to be two options: Either it has to do with the consciously experienced suffering that makes the death wish understandable, or it is related to the objective constraints due to illness. If the former is meant, then quality of life is a purely subjective concept, based on the experiential quality, and it would seem to follow that the death wish of others must generally be comprehensible, because for the suicidal person life is to
some extent unbearable by definition, or else she would not even have the death wish.

[…] If we understand, on the other hand, the quality of life in an objective way as based on the presence of constraints, then we have to ask why we do not find the lack of a death wish incomprehensible if the same conditions of severe illness apply. (p. 480).

Such an exploration of quality of life highlights the central theme of ethical uncertainty in the discussion of self-determination as it relates to suicide. Schramme (2013), with assumption of goodwill on behalf of health professionals, addresses the theme of ethical ambiguity succinctly with reference to “the common legal slogan ‘volenti non fit injuria’, which (roughly) translates to ‘no one is wronged willingly’” (p. 481).

Though decision processes may be lined with good intent, it remains crucial for health professional to remain self-critical and reflective of their decision-making. In the exploratory study “Attitudes towards euthanasia and assisted suicide: A comparison between psychiatrists and other physicians”, Azar et al. (2013) found a significant association between orthodox religion and moral opposition to assisted suicide. The research of Azar et al. (2013) lacks a deeper understanding of the relationship between sociodemographics of the physicians surveyed and of the patient’s they worked with. For example, it is unknown if the responses of physicians surveyed would vary conditional to the social identities of the individuals they serve. Further absent from this research were data of any direct impact such bias had on patient-care; it is unknown if physicians holding moral opposition to assisted suicide did or did not explore the possibility of, and/or assist in suicides as justified by law and patient choice. Dennis Porter (1992) cautions that while health professionals “must not align themselves with society’s morality as this is seen as being pathogenic […] but neither should they advocate that the client adopt a libertine approach to themselves and their problems (p. 314).
Summary

Available research reveals that there is a need to reexamine ethical and legal standards in the care of clients who are suicidal. Through review of the current literature, it is unmistakable that there is not one universal approach to suicidality. A consistent thread, however, can be seen throughout available research that highlights a desire from mental health professionals to uphold their commitment to protect their clients from harm. My research will provide social workers’ perspectives on a client’s right to suicide amongst adult individuals with mental health diagnoses. Such perspectives are timely to explore in the U.S. secondary to an unfolding understanding of accepted rational suicide gained from the example of those countries where mental health disorders are acknowledged as a valid legal basis for euthanasia.
Chapter III
Methodology

Research Purpose and Design

The current study aims to examine social workers’ perspectives on the right to suicide among adults who struggle with mental illness. I aim to investigate this question through exploratory research using qualitative methods and induction, a process whereby data collection and analysis precedes theory. Through interviews, I will gain perspectives from social work clinicians of their ethical responsibility when working with adult individuals who have suicidal ideation. I will create an interview guide containing semi-structured, open-ended questions to gather narrative data from participants. Much of the current research on rational suicide examines perspectives towards individuals with terminal somatic illness; this research will help to develop an understanding of, if any, rational suicide among individuals who struggle with mental health concerns.

This research will be exploratory in an effort to look for new phenomena that is underrepresented in extant literature about rational suicide and suicidal ideation amongst individuals struggling with mental health diagnoses. This research will study clinician perspectives of suicidal ideation and completed suicide amongst their adult clients with mental health diagnoses, and will explore potential possibilities for viewpoints of rational suicide for those clients. Examination of rational suicide among individuals who struggle with mental health can strengthen therapeutic responses to suicidal ideation, and consequently improve social workers’ ability to prevent their clients from harm.
Sample

I will conduct the study by interviewing a sample of twelve social workers that work with individuals who have been impacted by suicidal ideation. I will use convenience and snowballing techniques to recruit participants. I will begin recruitment at the mental health clinic of my field placement, New Alternatives for Children, in New York City. I will also make an announcement of this participation opportunity at the team meeting with outside clinicians who provide trainings at the mental health clinic. When in person communication is not viable, I will utilize email to initiate communication with potential participants. The email distributed will request participants as well as referrals for participants (Appendix B); a copy of the consent form will also be attached to this email (Appendix A). I will then use networking and snowballing to access additional participants. If the individuals I contact know potential participants, they may give them my contact information or get their permission for me to contact them. Upon contact with potential participants, I will describe the study, along with the potential benefits and risks of participation.

Participants will be social work clinicians who currently work with adult clients ages 18 and older who have:

- at least one DSM-V diagnosis;
- reported suicidal ideation or suicide attempt within the past two years;
- completed suicide within the past three years.

Ethics and Safeguards

Participation in this research is voluntary, and participants can revoke their participation in the study up until one month prior to research submission; I will explicitly communicate this to potential participants. I will conduct interviews over the phone, through video chat, or, when
possible for both the participant and myself, in person; participants who wish to participate will be communicated with via phone and/or email to schedule a time and mode of interview. Measures will be made to protect anonymity, though the researcher will know participants’ identities. Sociodemographic information obtained from participants will not be used to describe individuals in my report; rather, I will combine demographic data to describe the subject pool in the aggregate. In this way, study participants will not be identifiable in the final report.

Participants will be audio recorded with QuickTime Player; each participant will be assigned their own file and a corresponding number so labels will be made without the use of names. I will also take notes that include the corresponding participant number. All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period.

Participants will be asked to discuss a potentially difficult topic, and consequently interviews have the potential to cause participants distress. Local resources will be identified and shared with participants should they require support after the interview. Participants will be made aware of the research focus on suicide prior to their agreement to participate, to promote their preparedness to discuss this topic. Participants can stop an interview at any time should they need to.

Data Collection

This study will use semi-structured interviews to explore participants’ experiences with clients who have/had suicidal ideation/suicide attempt(s)/completed suicide. The purpose of the interview is to gain insight into clinician perspectives of suicide prevention and rational suicide.
The use of interviews will offer room for expansive answers to open ended questions and the opportunity for clarifying questions not supported by a survey. Interviews will last between 45 minutes and one hour. The interview will be audio recorded, and permission to do so will be gained prior to the interview. Interviews that are conducted in person will be in a quiet location agreed upon by both this researcher and the participant; potentially this researcher’s office at New Alternatives for Children would be used as a location. For phone and video chat interviews, this researcher will be in a private location and the participant may be in any location they feel comfortable to talk about sensitive material in.

Intensive interviewing will allow for the collection of responses from open-ended questions that aim to elicit clinical perspectives on rational suicide. Interviews will begin with a collection of demographic data, specifically: ability, gender, professional degree, age, spirituality, race, and sexual orientation. Although the twelve-person sample is too small to examine demographic subgroup variation with any systematic confidence, I will look for any trends among subgroups that may indicate further study in the results. Sample questions include:

1. How do you define harm as it relates to the NASW Code of Ethics?

2. The American Psychological Association recently stated: “The American Psychiatric Association, in concert with the American Medical Association’s position on Medical Euthanasia, holds that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death.” (APA, 2016). What is your response to this statement?

3. Do you think suicide can be “rational”? Why?

4. Do you think your beliefs on rational suicide impact the treatment you provide? Are there any particular cases in which this is highlighted for you?
Data Analysis

After interviews, I will transcribe the interviews verbatim from the audio recordings. Grounded theory will be used to explore themes that emerged from the participant interviews. While the small number of participants will impede my ability to study demographic subgroup variation systematically, I will still try to include perspectives from non-dominant identities. Additionally, the study pool of 12 participants will also inform my use of replication logic rather than sampling representativeness for the validity of my conclusions (Anastas, 1999).

It will be important that I remain cognizant of the fact that the answers I am analyzing are only from the perspective of social workers; missing from my research is the client perspective. Though incomplete, critical analysis of clinician responses can begin to offer understanding of who in the therapeutic relationship defines harm as it relates to autonomy and the determination of capacity for decision-making.
CHAPTER IV

Findings

This chapter contains findings that are based on 10 individual, semi-structured interviews conducted with current social workers. All participants answered all interview questions. Two interviews were done in person and eight were completed via phone due to geographic logistics. Interviews were fully transcribed, and then coded using thematic analysis. Throughout the interviews, the participants often vacillated between speaking about their personal experiences and the collective experiences of the social work field, switching from first-person singular to first-person plural. The data from the interviews are presented in the following sequence: demographic data, perspectives of clients’ right to die, responses to clients’ suicidal ideation, and the subjectivity of the clinician and religion/spirituality.

Demographic Data

Participants of this study ranged in age from 27 to 70 years old, with a median age of 45. Most (N=9) participants identified their racial identity as white or Caucasian; one participant’s race was described as European-American. There was a range of religious and spiritual identities of participants. Three participants identified as Atheist; two participants identified as Pagan, one of whom also identified with Native American spiritual practices; two identified as spiritual, one of whom also identified culturally as Jewish; one participant identified as agnostic; one participant identified as Protestant; one participant identified as Jewish. All participants held a Master’s in Social Work. Participants’ work with clients who have experienced suicidal ideation, to include work both pre and post-master’s, ranged from nine to 48 years of practice, with a mean of 20.6 years working with clients who have experienced suicidal ideation.
Perspectives of clients’ right to die

Half (N=5) of participants stated that there are plausible situations in which a person who is a mental health client has an ethical right to end his/her life without intervention from a clinician. Some (N=3) respondents discussed their inability to offer a direct answer to the question, and described the ethics of suicide for persons who are mental health clients as a grey area. Two participants stated that there is never a situation in which a person who is a mental health client has an ethical right to complete suicide without intervention from a clinician.

Participants who described their stance on a person’s right to end his/her life as a grey area (N=3) noted that while they may be able to understand a person’s desire to die, their professional role in upholding that right was complicated. Two respondents discussed their responsibility to uphold the law and protect their clients from harm, and all three of these participants discussed the uncertainty in how to determine capacity. One respondent discussed:

A certain part of me believes that people should have freedom over their own lives, and that part of what we're supposed to do as social workers who are helping people self-actualize and have agency, is give them whatever agency they can have help them have it, and not be this authority in their life. On the other hand, it can be hard to know if when an individual is feeling suicidal, I think it can be hard for them to know whether that's ultimately resolvable or not.

Alternatively, half of the respondents in this study discussed their understanding of a client’s desire to die and identified a lack of competency is not a standard of suicidal ideation. One respondent highlighted the diagnosis of Schizophrenia and challenged normative views that if a disease affects experiences with consensus reality, then that person is likely incompetent to make decisions in his/her best interest. The participant shared:
I think schizophrenic people are highly intelligent people. I mean, if they're highly psychotic and not reality based at all, but there's a lot of schizophrenic people that they know that their mind doesn't work. They don't like feeling like that. That can be competent. I mean, are people who are depressed, does that make them incompetent? No.

All participants (N=5) who reported that persons who are mental health clients have the right to suicide described that age, competency, and exhaustion of available treatment options would be factors in determining a person’s right to suicide. In regards to age, one respondent explained specifically that maturity of brain development would be a consideration in determining a client’s right to suicide. Most (N=7) of the participants discussed that their understanding and support of a client’s right to die was firmer when considering work with older adults. One respondent posited:

Right. So my sense is that it would look much like a situation where we currently determine a person with a cancer diagnosis has a right. So we've explored all treatment options and that the person, and again, so this is a grey area, but as best I can state it is that they seem to be in a frame of mind where they have insight, that their judgment is not poor. Unfortunately, I recognize that one might argue that someone making the decision complete suicide has poor judgment. I don't think that that's necessarily the case. I think that if you're working with somebody sitting across from you who's saying "I have been struggling with, let's say, chronic suicide ideation for the last 10-15 years of my life," maybe a part of that is "I hear voices or I have visual hallucinations that are so intensely disturbing to me that life is not worth living. That I've tried all of the available
treatments to me. I've been engaged in working with my therapist and my psychiatrist or people in my community to address this and I continue to find life untenable."

The two participants who reported that there is never a situation in which a person who is a mental health client has a right to complete suicide noted their legal obligations as outlined in the National Association of Social Workers (NASW) Code of Ethics.

**Responses to clients’ suicidal ideation**

All participants (N=10) discussed situations in which they put in place preventative measures to address client suicidality. Preventative measures utilized were dependent on the location of practice, inpatient or outpatient. Interventions used by participants to prevent clients from completing suicide were described as hospitalization, written and/or verbal safety contracts, police or security forces, and utilization of non-hospital crisis services. One participant explained the importance of offering transparency around mandated reporting when working with clients who are suicidal to support a client’s autonomy. In discussion of response to clients’ suicidal ideation, several (N=4) respondents presented concern around a lack of referral resources that adequately address client needs. A respondent advocated:

> And then specifically, since the advent of managed care, we have a complete lack of mental health residential treatment centers. And in acknowledgement that that level of care is necessary and should be covered. It has to be substance abuse primary or private pay, if that still exists anymore. […] I think the difficulty is that we have a society that's looking at every corner to cut costs. And residential mental health treatment is not cost-saving. It's not about dollars, it's about lives.

Another participant discussed that even those programs that do exist often fail to meet the complex needs of many clients with suicidal ideation.
Most (N=8) participants interviewed had worked with individuals who have completed suicide. The majority of those participants (N=5) could not recall an exact count of the number of clients who completed suicide; participants reported a range of one – 10 clients they have worked with that completed suicide. There was no apparent theme in regards to previous attempts of suicide, or discussion of one’s desire to die among clients who completed suicide. Participants described a range of clinical presentations and diagnoses assigned to those individuals who completed suicide, to include: Schizophrenia, Schizoaffective Disorder, depression, psychosis, personality disorders, Bipolar Disorder, substance dependency, Dissociative Identity Disorder, Post Traumatic Stress Disorder. Two participants interviewed had not worked with individuals who completed suicide, but had worked with clients who both disclosed suicidal ideation or attempted suicide, and described similar variance of diagnoses.

Such variability was also reflected in many interviews, though this impacted respondents differently. Some respondents considered the fluidity of insight to influence their belief that a person, who struggles with chronic mental health issues, can at times make a competent choice to complete suicide, and others considered this an argument to prevent suicide. Participants discussed that psychosocial circumstances in clients’ lives are ever changing, and thus a client who presents with suicidal ideation for a period of time may very well in the future be grateful to be alive.

The two participants who did not support the right to die for persons who are mental health clients also offered in their responses that persons with terminal somatic illnesses have an ethical right to suicide; both further identified that physical and mental health are often interwoven. Such a concept was reflected in all interviews. One respondent explained:
I think it's very difficult, and I think it's actually a drawback to our current model that we so distinctly separate physical illness from mental illness because mental illness is an illness of the brain and a brain is an organ of the body. So I think that mind/body split really is detrimental to the research that we've done and the way that we approach mental illness in our current culture and society.

Another participant explored the relationship of physical and mental health as follows:

If my client is successful in their attempt to suicide, I have not done my job properly. And I think it's really important for us as mental health clinicians and professionals to be more compassionate and be more willing to be less black and white about that because any doctor going into the field, let's say cardiology, he or she, they are presented with, there are a number of cases that will be terminal. There's nothing you can do with our current technology that will save this patient. And certainly you try everything that you can and you do as best as you can to save that live and to give the person the quality of life that you want.

And:

And when we're in the mental health field, the symptoms that we want to make, the decision that I want to kill myself and I no longer want to be alive, those are symptoms of mental illness. So we think, sometimes paternalistically, that we can treat and change someone.

**Subjectivity of the Clinician**

In this study, participants were asked about the impact of their personal beliefs in work with clients to explore clinician subjectivity. All (N=10) respondents in this study discussed the inevitable subjectivity that exists within a therapeutic relationship between two humans. In
review of this study’s data, there was no connection reported between a participant’s self-identified religion and/or spirituality and their standpoint of whether or not a person who is a mental health client has the right to suicide. Many participants, however, discussed the opinion that within the field of social work, a clinician’s religion and/or spirituality would likely impact professional responses to clients who experience suicidality. One participant summarized:

I think it would be really difficult to separate one's personal beliefs from that decision because if you have a belief in eternal life brought upon by believing in a particular deity, then why wouldn't you want everyone to believe in that deity?
And if you believe that suicide in particular eradicates that possibility for everyone, like no matter what, if you commit suicide, you will not have access to this afterlife, you're gonna do everything you possibly can to prevent that. Otherwise you would be a monster. If I believed that when I die, if I did something in particular that would grant me an eternity of bliss, I would want that for everyone. So I can't see how it wouldn't impact one's work and there certainly would be countertransference.

Throughout all interviews (N=10) participants discussed the relationship between their individual beliefs and legal standards that obligate clinicians to utilize interventions that prevent clients from completing suicide. One participant’s personal beliefs were described to align without complication with the NASW Code of Ethics and legal standards. All other (N=9) participants discussed that variances could exist between their personal values and the law. A respondent provided the succinct statement:

Even though I do believe that people have the right to kill themselves, I'm certainly not in the business of helping them with that.
Another participant further explained the internal dilemma that complicates a symbiosis between legal guidelines and human subjectivity:

So I see a lot of people who have truly ungodly, miserable lives, and this one person I'm working with right now, I hate to say this, but there's a part of me, an important part of me that thinks she would be better off if she weren't having to live. So, yes, I come in conflict with that at times. On the other hand, it's ambivalence, because I have worked with some people who are almost, in my subjective point of view, in such misery, and I've seen them to some degree recover. But I'm still not going to take back what I said. I come in conflict with the code at times in terms of my subjective feelings.

Several (N=3) participants explored loose standards of mandated reporting as a way in which, as either an individual or observer of clinicians in the field, they addressed the subjective conflict that can exist between personal beliefs and an obligation to uphold the law.

In consideration to subjectivity, many participants discussed the importance of clinician self-reflection to promote that the clients’ needs remain centered in work together. Such an approach revealed that most participants advocate for person-centered interventions to client suicidality. One participant discussed the impact of subjectivity in work with clients as follows:

Well, I certainly hope it impacts it a lot because I think that, as a clinician, you have to use yourself to be a good clinician, and because the clinical relationship is everything. It's not all about the theories. It's really about your relationship with someone and people feeling that you're listening, that you're safe, that you care.

Regardless of a participant’s standpoint on a client’s right to suicide, all respondents explained that including the client in the process, whether it be a suicide intervention or other therapeutic response, is essential to a successful clinical practice.
Summary

Major findings from 10 interviews with practicing social workers that have worked with adult individuals who have experienced suicidal ideation and/or completed suicide have been presented in this chapter. Significant findings were predominately derived from the following focus areas: perspectives of clients’ right to die, responses to clients’ suicidal ideation, and the subjectivity of the clinician. The next chapter will compare and contrast these findings to existing literature. The following section will explore the interpretations of these findings and discuss the implications this study has on the field of social work. Next, the strengths and limitations of this study will be addressed. Lastly, suggestions for future research will be presented. These findings include the following: the majority perspective of clinicians interviewed revealed that persons who are mental health clients have a right to suicide; an overlap exists between physical and mental health, but reactions to physical and mental health continue to differ; person-centered therapy yields most successful results.
CHAPTER V

Discussion

The purpose of this study is to explore the ethical standpoints among social workers regarding client autonomy and suicidality. This chapter opens with an exploration of the salient findings inducted from the subject narratives in the context of the literature reviewed. These findings include the following: the majority perspective of clinicians interviewed revealed that persons who are mental health clients have a right to suicide; an overlap exists between physical and mental health, but reactions to physical and mental health continue to differ; person-centered therapy yields most successful results. This will be followed by implications for clinical practice and areas of further research. A summary concludes this chapter.

Key Findings: Comparison with the Previous Literature

This section, exploring the results of this study in comparison to the previous literature, is divided into the following sections: perspectives of clients’ right to die with subsections on persons who are mental health clients and overlap of mental and physical health; responses to clients’ suicidal ideation.

Perspectives of Clients’ Right to Die

**Persons who are mental health clients** Consistent with literature reviewed were study participants’ discussion of grey areas that exist within a system of black and white parameters as it relates to suicide prevention. The findings of James Werth and Becky Little (1994) similarly revealed that therapists struggled to find a balance between their moral beliefs in work with clients who are suicidal and their fear of ethical or legal reprisal. Despite efforts made in this study to de-identify participants, many respondents struggled to speak candidly when audio recorded. All interviews ended with an invitation to offer any additional thoughts individuals felt
important to add to the discussion, yet once the interview ended, and it was known that the audio was shut off, most participants revealed expanded thoughts on the subject, which are consequently not reflected in the previous chapter.

Some respondents identified that their more filtered responses during the audio recordings were largely due to the fear that their opinion challenged the legal and ethical status quo of their profession. Such filtered responses from clinicians in regards to their moral standpoint on a client’s right to suicide reiterate the unintentional legal impact explored in most interviews. Additionally, the subject of suicide was observed to impact fluid answers from some participants; a number of transcriptions are riddled with filler language and pauses specific to responses that answer prompts regarding personal rather than generalized viewpoints. This is also conducive to what Moody and Sasser (2012) attribute to the mainstream societal view that the term suicide has become taboo in the United States.

Many respondents in this study discussed their understanding of a client’s desire to die and identified a lack of competency is not a standard of suicidal ideation. One respondent specifically discussed the diagnosis of Schizophrenia and argued that persons who may experience non-consensus reality are not globally incapable of competency. Hewitt (2010) similarly asserts that people diagnosed with Schizophrenia can be capable of a realistic assessment of their psychological suffering, and thusly make rational decisions in regards to suicide. Markova & Berrios (1992) add that determining capacity is influenced by the complexities of insight, which they describe as a non-stagnant concept that exists on a continuum.

Such variability was also reflected in many interviews, though this impacted respondents differently. Some respondents considered the changeability of insight to influence their belief
that a person, who struggles with chronic mental health issues, can at times make a competent choice to complete suicide, others considered this an argument to prevent suicide. Some participants discussed that psychosocial circumstances in clients’ lives are ever changing, and thus a client who presents with suicidal ideation for a period of time may very well in the future be grateful to be alive.

**Overlap of mental and physical health** Overwhelmingly, participants endorsed that mental health symptoms influence physical health symptoms and vice versa, but without the component of terminality, responses varied regarding a person’s right to suicide.

Hewitt (2013) has explored extant literature around terminal illness and suicide, and concluded that having a physical disorder deemed extreme and untreatable is likely to be accepted as rational grounds for suicide. Though the study did not focus on somatic health specifically, many participants discussed terminal physical illness in their interviews. Azar et al (2013) also discuss an overlap between the fields of mental and physical health with note that even in instances of terminal somatic illness, psychiatrists are called upon to determine a patient’s capacity to make such a decision. All respondents who discussed terminal physical illnesses reflected Hewitt’s findings that terminal illness was acceptable grounds for rational suicide.

Wittwer (2013) furthers the discussion of possible rational suicide amongst persons who are mental health clients with the simplified notion that there can be good reasons for someone to want to end his/her life. Participants of this study discussed work with clients who had unwavering symptoms of mental health diseases despite exhaustive measure to alleviate targeted symptoms, chronic suicidal ideation, and an inability to participate in what brings an individual client meaning and joy. Half of the participants of this study found such circumstances to warrant
a client the right to suicide; three participants described this as a grey area of their work they did not yet have a firm standpoint on; two participants reported they have never worked with someone, or could theorize a situation, in which they believed a person who is a mental health client has the right to suicide.

**Responses to Clients’ Suicidal Ideation**

All participants of this study endorsed that often there is a need for clinical intervention to a person’s suicidal ideation, as criteria discussed to a client’s right to suicide is not the norm of participants’ interaction with suicidal ideation. Porter (1992) described the desired balance of a clinician to both challenge societal pathology of a client and also avoid influencing a client to adopt libertine approach to him/her/their self or circumstance. Though participants did not present a uniform response to how they respond to a client’s suicidality, each respondent discussed the importance of informing a client of the intervention process. Transparency regarding the intervention, whether it is a call to mental health crisis, hospitalization, or development of a safety plan, was described as vital to support the continuation of a therapeutic relationship.

Additionally, most respondents discussed an overwhelming lack of appropriate referral resources for clients to receive comprehensive care to address their suicidality. One participant pointed to research done by Lisa Wexler, who has notably studied high-risk suicide populations in Australia and Alaska. Wexler (2015) describes the need to develop culturally appropriate and effective suicide prevention programs, which are largely missing from most utilized mainstream intervention methods. This position is consequently supported by the homogenous clinical interventions described in this study.
Implications for Social Work Practice

The social workers that volunteered to participate in this study did not comprise a representative sample in terms of an all-inclusive study, but data gained may be valuable in application within mental health field.

All respondents in this study discussed the inevitable subjectivity that exists within a therapeutic relationship between two humans. Many participants discussed the importance of clinician self-reflection to promote the clients’ needs remain focal in work together. Evans (1996) echoes that the task of the clinician is to enable the client’s own distinctive truth to emerge in his/her treatment. As such, the study demonstrates that regardless of a clinician’s standpoint on a person’s right to suicide, it is imperative that the therapeutic spaces welcome open discussion of suicidal ideation. Hewitt & Edwards (2006) discuss that when treatment is person-centered, then clinicians can develop a more holistic understanding of client needs, thusly supporting more comprehensive responses to those needs.

Many participants of this study also discussed the lack of attention given to suicidal ideation within both graduate studies and professional development opportunities thereafter. In this way, clinical response to suicidality has largely become standardized. Moreover, several participants discussed that suicide intervention standards are largely influenced by legal protection of the clinician’s license rather than appropriately addressing the protection of the client’s life.

Limitations and Biases of the Study

This study was composed of a small sample size (N=12) and thus the findings of this study cannot be generalized. In addition, the sample was racially homogenous, as participants identified as white, Caucasian, or European-American (which is interpreted by this researcher to
be a privileged racial identity). Of note, this study anticipated participants to work in the geographic areas of Massachusetts or Vermont, but limited responses for participation in those areas led to a geographical widening of respondents to include locations across the United States. Such is not observed to be a limitation of the study’s generalizability, but rather a limitation in gaining participation. Reasons for difficulty in gaining participants in a smaller geographic area were in part due to an unexpected decrease in potential participants who did not work directly with the researcher. It can also be inferred from the previous discussion that participation in this study may have been deterred secondary to risk of exposure of personal viewpoints on suicidality that differ from legal and ethical guidelines.

Another limitation to this research included the semi-structured interview method, which offered broad questions that allowed each participant's interview to vary in length and in the depth of their responses. Despite this inherent methodological limitation, the interview design allowed space for participants to share their experiences as they deemed appropriate for both themselves and the study; in this way, interviewer bias could be challenged and increase the breadth of data collection. Still, this researcher designed interview questions and therefore bias was not eliminated from the interview process. This researcher's own professional, spiritual, and moral beliefs regarding, and experience with suicide also create bias in the interpretation of data.

Another limitation of this study is the notion that individuals who chose to participate likely already had an interest in the topic. Many participants were also gained through an alumni network and thusly most respondents shared a clinical training source. As one participant noted:

 Well, I think in my experience, a lot of people are guided by the policies of wherever they got their license and wherever they are working.
The shared experience of foundational training could likely impact the ways one thinks about the subject of suicide and limit diversity in perspective.

**Future Research**

Wexler (2015) reports that despite the Surgeon General’s call to action to prevent suicide in 1999, national rates of suicide from 2002 to 2010 rose from the 11th to the 10th leading cause of death in the United States. The literature reviewed and data collected from this study reveal a clear need to rethink responses to suicidal ideation amongst persons who are mental health clients. One participant summarized the detrimental way in which the mental health field talks about clients who persistently endorse suicidal ideation:

> We call it treatment resistant patients. I don't think that's a good word at all.

> Because they're not resisting getting better. They're just not getting better. I would really like to see more research kind of done into that population. Of what do you do for someone when they say, "Talk therapy isn't working for me. Meds aren't working for me. And I'm really truly at the end of my rope." I'd like more research to be done in that population.

This study implicates the need of further research to support the implementation and accessibility to alternative interventions of suicidal ideation. Missing from this study is also the voice of those individual’s receiving care; such perspectives would be invaluable to develop future research that adequately addresses self-identified client needs.

In this study, once the recording of interviews ended, nearly all participants asked this researcher’s standpoint on the study subject; once another personal perspective was introduced, participants seemed validated to speak more candidly about their views. Thusly, the use of group interviews may support more robustly honest responses to questions asked. Future research could
also be improved by intentionally gaining feedback from a more socially diverse sample whose source of professional training also varied.

**Conclusion**

Significant findings of this study echoed much of the existing literature on the subject of suicidal ideation amongst mental health clients: a person’s ethical right to suicide remains questioned, but the need for improved clinical response to suicidality proves imperative. Such findings nevertheless reflect the NASW Code of Ethics (2017) and its promotion that social workers continue to seek out emerging treatments in order to provide the best care to the clients they work with. If the field of social work, as it currently stands, implores clients to not give up on treatment, then certainly the field of social work must not give up on the persons in its care.
References


Davidson, D. & Lymburner, J. (2017). Furthering the Discussion on a Physician-
Assisted Dying Right for the Mentally Ill: Commentary on Karesa and McBride (2016).


Moody, H. R., & Sasser, J.R. (2012). Controversy 7: Should people have the choice to


Appendix A

Recruitment Letter

Dear (potential participant’s name),

I hope this finds you doing well. I am reaching out to you to discuss the possibility of your participation in my thesis study entitled The Ethics of Dying: An Exploration of Rational Suicide Among Adults who Struggle with Mental Illness, which will be utilized to complete degree requirements for my Master’s of Social Work at Smith College. Participation in this study is voluntary and consists of one interview, up to one hour in length, to be scheduled in the month of February or early March 2018. Overall, the goal of this research is aimed to strengthen clinicians’ upholding of the National Association of Social Workers (NASW) Code of Ethics and increase quality of care for the individuals they work with.

Specifically, I am hoping to interview about twelve Licensed Clinical Social Workers to explore clinician views on suicide and clients’ right to self-determination as it relates to the NASW Code of Ethics. As a participant you must be a Licensed Clinical Social Worker who currently works with adult clients ages 18 and older who have:

- at least one DSM5 diagnosis;
- reported suicidal ideation or suicide attempt within the past two years;
- completed suicide within the past three years.

Should you be interested in participating, I will follow-up with more specifics about signing the consent form and scheduling for an interview. In short, I am happy to schedule an interview to take place in person, over the phone, or via video call, whatever is most convenient for you. Please note that measures will be taken to de-identify all participants, and further details are provided in the attached consent form. Please contact me with any questions or concerns at
s Bair@smith.edu, or, sbair@brattlebororetreat.org. Please also feel welcomed to share this email and my contact information with other Licensed Clinical Social Workers who may be interested in participating.

I appreciate your time, and look forward to hearing from you!

Kind regards,

Shelley Bair
MSW Candidate, Smith College
Appendix B

Informed Consent Agreement

Smith College

Consent to Participate in a Research Study
Smith College • Northampton, MA

Title of Study: The Ethics of Dying: An Exploration of Clinicians’ Perceptions of Mentally Ill Clients’ Right to Suicide and Factors Related to Clinicians’ Decision Making and Intervention of Clients’ Suicidality

Investigator: Shelley Baur, MSW candidate, Smith College

Introduction
You are being asked to be in a research study of clinicians’ processes for determining clients’ right to self-determination as it relates to suicidality.

- You were selected as a possible participant because you are a Licensed Clinical Social Worker who currently works with adult clients ages 18 and older who have:
  - at least one DSM5 diagnosis;
  - reported suicidal ideation or suicide attempt within the past two years;
  - completed suicide within the past three years.
- 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 the study is to explore the process of determining clients’ right to self-determination as it relates to suicidal ideation and the National Association of Social Workers (NASW) Code of Ethics.
- Ultimately, this research may be used to complete investigator’s Master’s of Social Work (MSW) Thesis. The results of the study may also be used in publications and presentations.

Description of the Study Procedures
- If you agree to be in this study, you will be asked to do the following things: review and be agreeable to all aspects of consent form; participate in a semi-structured interview, either in person, via phone or via video chat that will last up to 60 consecutive minutes.
- Topics to be explored in interview include: description of participants’ social identities as they relate to race, religion/spirituality, age and professional degree; exploration of the relationship between clinicians’ view of clients’ right to self-determination and the law as it relates to suicide; history of participants’ experience working with adult clients who have completed suicide; exploration of the components of participants’ decision making process as it relates to clients’ self-determination and suicide. Should discussion of these topics cause participants’ emotional distress, you are encouraged to call the National Crisis Hotline: 1-800-273-8255.
Appendix C

Interview Guide

Demographics

1. What is your professional degree? (ie. MSW or Ph.D)

2. How old are you?

3. How do you identify yourself racially?

4. How do you identify your spirituality/religion?

5. How long have you worked with adult individuals who have been affected by suicidal ideation, suicide attempts, or completed suicide?

Exploration of the relationship between clinicians’ view of clients’ right to self-determination and the law as it relates to suicide

6. Is there ever a situation in which you feel that a client has the right to suicide, but you are obligated by the law to implement prevention measures instead?

7. Is so, what would such a situation look like?

8. Are there certain measures that must first be exhausted before a client would have the right to suicide?

9. Is there a certain clinical presentation that must describe a client before the client would have the right to suicide?

History of clinicians’ experience working with adult clients who have completed suicide

10. Have any of your clients completed suicide?

11. If so, when?

12. Did those clients have previously known attempts of suicide?

13. Did they discuss with you a desire to die?
14. What was their diagnosis?

15. What, if any, preventative measures were taken to intervene with the client’s suicidality?

Exploration of the components of clinicians’ decision making process as it relates to clients’ self-determination and suicide

16. How do you feel clinicians’ beliefs are related to decision making?

17. Do you feel your own beliefs on suicide impact the care you provide your clients?

18. How so?

19. Are there any cases in which this is highlighted for you?
Appendix D

HSR Approval Letter

TO: SHILLELY BAIR
FROM: NNANDI POLL, CHAIR, INSTITUTIONAL REVIEW BOARD, SMITH COLLEGE
SUBJECT: HUMAN SUBJECTS PROPOSAL
DATE: FEBRUARY 9, 2018

PROPOSAL TITLE: THE ETHICS OF DYING: AN EXPLORATION OF CLINICIANS' PERCEPTIONS OF MENTALLY ILL CLIENTS' RIGHT TO SUICIDE AND FACTORS RELATED TO CLINICIANS' DECISION MAKING AND INTERVENTION OF CLIENTS' SUICIDALITY

REVIEW TYPE: EXPEDITED
PROJECT NUMBER: 1718-052
APPROVAL DATE: 6-JUL-2018

The Institutional Review Board at Smith College has reviewed and approved the research protocol referenced above. Please note the following:

- Please submit a copy of the IRB cover page with your faculty adviser’s signature for our records.

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), you must submit these changes to the IRB by filling out and submitting a Change of Protocol form.

Adverse Event Reporting/Deviation from Approved Procedures: Should any adverse events occur during the conduct of your research, you should report them immediately to the chair of the IRB. Additionally, any procedural deviations from your approved proposal must be reported. Explanations of these events and related forms can be found on the IRB website.

Renewal: IRB approval for your study expires exactly one year from the approval date listed above. You must promptly return the annual Research Project Continuation Form to continue IRB oversight for your study.

Consent Forms: When you have completed your study (i.e., data collection is finished), you are required to inform the IRB by submitting a signed Research Project Continuation Form with appropriate box checked.

Consent Forms: All subjects should be given a copy of the consent form or oral consent script in case they have questions later. This can be accomplished by bringing extra copies of the forms to the interviews. In the case of "Chief" consent, participants should be prompted to either print a copy for their records, or contact the investigator to request a copy. If signed consent is to be collected, as noted in your proposal, you must retain signed consent documents for at least three years past completion of the research activity.

Additional Requirements: None.

For Committee Use Only: Any and all requirements completed. Final approval given:

[Signature]
Chair, Institutional Review Board