PRAXIS

Where Reflection & Practice Meet

VOLUME 14

*In Honor of Loyola University Chicago School of Social Work's
Centennial Celebration*

Articles

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Mission Statement
The School of Social Work at Loyola University Chicago created *Praxis: Where Reflection & Practice Meet* to give voice to the scholarly work of students and alumni. Our mission is to encourage and support the development of social work knowledge that will enhance the lives of the clients we serve, embody the humanistic values of our profession and promote social justice and care for vulnerable populations. *Praxis* respects and welcomes all viewpoints.

Editorial Policy
Praxis is published by students in the School of Social Work at Loyola University Chicago. The editorial board is composed of masters and doctoral social work students. The board encourages students and alumni of the School of Social Work to submit papers that provide insight into clinical, policy, research, education and other areas relevant to social work practice. Submissions are accepted throughout the year. Articles should be no longer than 20 double-spaced pages and submitted as a Microsoft Word document file (.doc or .docx). All identifying information, including contact information, should be on a separate page. Responsibility for accuracy of information contained in written submissions rests solely with the authors. Opinions expressed in the journal are those of the authors and do not necessarily reflect the views of the School of Social Work or the Editorial Board.

All inquiries and submissions should be directed to:
Editorial Board, *Praxis: Where Reflection and Practice Meet*
School of Social Work, Loyola University Chicago,
820 N. Michigan Avenue, Chicago, Illinois 60611.
Telephone: (312) 915-7005;
website: http://luc.edu/socialwork/praxis/contactus.html

EDITORIAL

A School Worthy of its Name:

A Tribute to the Centennial Celebration of the School of Social Work

What is social work? The dictionary defines social work simply as "organized work directed toward the betterment of social conditions in the future." The International Federation of Social Workers adopted a more descriptive definition of global social work in 2014, stating: "Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing."

Additionally, the National Association of Social Workers also broadly defines social work practice, including references to case management, therapy and counseling, community engagement, and legislative advocacy. Ultimately, NASW states that "the practice of social work requires knowledge of human development and behavior; of social and economic, and cultural institutions; and of the interaction of all these factors." Although the exact definition can change and evolve, the articles published in *Praxis* demonstrate that each social worker defines the field through their own unique lens, but ultimately, each acts as an advocate for social change.

The founder of the School of Social Work at Loyola University Chicago, Father Frederic Siedenburg, once stated that "Under modern conditions social work is not worthy of the name if it stops with temporary or direct relief." At the time of its founding in 1914, the School of Social Work (then known as the School of Sociology) was the first program of its kind in Chicago. In the century since, Father Siedenburg's words remain vital to our contemporary profession as our field faces new social challenges.

To quote another great theorist, Mahatma Gandhi, "Be the change that you wish to see in the world." As social workers, we work to be that change every day in our profession. Examples of this work have been published in *Praxis* for fourteen years. With this present volume, *Praxis* has published 164 pieces written by 244 Loyola students and alumni. The current volume includes an analysis on dying with dignity legislation; an argument against the rhetoric surrounding depression; an argument for the use of micro and macro practice; reflections on author's experiences with purity, rare illnesses, and the transition from urban education to social work student; a review of the Americans with Disabilities Act; an argument for psychosocial care in nursing homes; an international exploration of artisan cooperatives; and a clinical look at working with transgender women, male victims of interpersonal violence, and children and adolescents with conduct disorders. These articles cover a broad range of populations, treatment methods, policies, and personal experiences, all within the field of social work. These *Praxis* authors have demonstrated the vast range of change our profession can see in the world.

For 100 years, the School of Social Work has trained and prepared its students to fight for social and economic justice for the underprivileged and to be the change we wish to see in our world. For 100 years, the school has molded future social workers to be the conduit for our client's voice in the ongoing struggle for equality and to ultimately define the field of social work. Not only have the voices of our clients been able to rise up, but the voices of the students and alumni have been given the opportunity to share their experiences and research through *Praxis*, allowing for a great dialogue. For that, *Praxis* is proud to reside within a university so deserving of the words "social work."

Amanda M. Walsh, JD, MSW
Master of Laws Candidate
Editor-in-Chief

Death with Dignity

Morgan Albrecht, Richard Rogich, & Andrew Zapke

Abstract

Death with Dignity has recently gained public attention after Oregon resident Brittany Maynard's decision to end her own life on November 1, 2014. The debate over the provisions of Death with Dignity statutes tend to be divided along partisan lines. For supporters, Death with Dignity statutes provide a vital service to terminally ill citizens who choose independence and self-determination over prolonged suffering and financial hardship. To opponents, Death with Dignity statutes are a blunt instrument of abuse by the medical establishment toward vulnerable groups. In the 17 years of its existence, Oregon's Death with Dignity Act has enabled over 700 patients to end their lives in a medically-controlled manner. Poor and at risk populations have not been harmed or taken advantage of as some had claimed. While Oregon is still only one of a handful of jurisdictions that allow physician-assisted-suicide, other states are currently considering the passage of similar legislation.

Keywords: death with dignity, euthanasia, physician-assisted-suicide, terminal illness

Introduction

Death with dignity is a controversial social issue that has recently gained more public attention due to the mass publicity surrounding Oregon resident Brittany Maynard's decision to end her own life on November 1, 2014. It raised public awareness to the question of whether or not terminally ill patients have the right to determine their end-of-life care and the right to die on their own terms.

The people directly affected by the problem are adults and their caregivers. Financial considerations have long played a role in end-of-life decision-making (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2007). Family members and caregivers of individuals diagnosed with a terminal illness are faced with a future of uncertainty and are often left with an overwhelming financial burden. One study on the impact of illness upon patients' families found that nearly a third of the families reported losing most of their savings or primary source of income as a result of a major illness (Sullivan, Hedberg, & Fleming, 2000). Individuals diagnosed with terminal illness faced even greater uncertainty. In 2010, "nearly 60 percent of patients who died in the United States (2,450,000) did not have the vital assistance of palliative care professionals to make their final days less stressful" (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2007). There is also the issue of the amount of healthcare dollars being spent on chronic care and in 2011, "Medicare spending reached close to $554 billion, amounting to 21 percent of the total money spent on U.S. health care in that year. Of that $544 billion, Medicare spent 28 percent, or about $170 billion, on the patients' last six months of life" (Pasternak, 2014).

Several underlying factors contribute to this dilemma, including state legislators, federal courts and Congress, who have the power to affect choices made by patients diagnosed with a terminal illness who wish to choose the liberty to die on their own terms. Another contributing factor is a negative view of physician-assisted suicide and the term euthanasia. One policy that addresses the problem is the Oregon Death with Dignity Act. As of April 11, 2015, the states of Washington, Vermont, Montana and New Mexico have a similar statute or court decision in place, and there are legislative bills in favor of physician-assisted death currently being considered in eighteen other states, including Connecticut, Kansas, and Massachusetts (Death with Dignity National Center, 2015).

Public awareness of these reforms is vital to adults (i.e., eighteen years of age or older) who have been diagnosed with a terminal illness that will lead to death within six months. Those reforms create the autonomy to self-administer a lethal dose of medication that has been prescribed by their primary physician. Numerous groups have expressed opposition to death with dignity, and are resistant to changing the status quo. These groups include the Roman Catholic Church (United States Conference of Catholic Bishops, 2011), Disability Rights

Advocates (Disability Rights Education & Defense Fund [DREDF], 2015), Physicians for Compassionate Care Education Foundation (PCCEF) (Physicians for Compassionate Care Education Foundation, 2015), American College of Physicians-American Society of Internal Medicine (ACP-ASIM) (Snyder & Sulmasy, 2001), International Anti-Euthanasia Task Force, and the American Academy of Hospice and Palliative Medicine (AAHPM) (American Academy of Hospice and Palliative Medicine, 2007). The potential effect of these opposition groups on changing the status quo is that religious institutions funding of political campaigns can make it difficult to pass legal reform. There could be opposition from medical professionals. Medical professionals focus on prolonging a patient's life by offering palliative care or hospice, and according to the American Medical Association (AMA) Code of Ethics, "instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that a cause is impossible" (AMA, 2015). Death with Dignity is the type of reform that could cause the AMA to re-evaluate their code of ethics, especially those that relate to medical futility in end-of-life care along with a change in the patient-doctor relationship where the patient has more control over his or her end-of-life care. The overall benefit of addressing this problem and creating a new healthcare policy is that individuals who are battling a terminal illness will have more options regarding their end-of-life care. They deserve to have a freedom of choice over their own death and the right to self-determination.

Oregon Death with Dignity Act

Self-Determination

Oregon's Death with Dignity Act (ODWDA) addresses the self-determination of terminally ill state residents to end their lives through medical intervention. Unlike euthanasia, a doctor may be present and will prescribe the medications, but the patient must self-administer the lethal dose of the medication (Oregon Public Health Division, 2014b).

Since the act was legally put into effect in 1997, 752 patients have died from medications prescribed under the ODWDA (Oregon Public Health Division, 2013). In that same time period, 1,173 people have had lethal prescriptions written (Oregon Public Health Division, 2013). In the 71 deaths during 2013 under the Oregon Death with Dignity Act, "the three most frequent end-of-life concerns were loss of autonomy (93.0%), decreasing ability to participate in activities that made life enjoyable (88.7%), and loss of dignity (73.2%)," (Oregon Public Health Division, 2013). These results are similar to the concerns mentioned each year the act has been in effect. Nearly 70% of those who died under ODWDA in 2013 were 65 years or older; nearly all were white, and close to 65% of the people had cancer (Oregon Public Health Division, 2013).

Legislative History

Compassion in Dying, an organization dedicated to the care and rights of terminally ill patients, led by Barbara Coombs Lee and Peter Goodwin, got the Oregon Death with Dignity Act onto the ballot as a citizens' initiative, Measure 16, which passed during the general elections of November 1994 with 51% of voters in favor (Oregon Public Health Division, 2010).

Implementation of the Oregon Death with Dignity Act was delayed by a legal injunction in December 1994, before the Act's effective start date (Oregon Public Health Division, 2010). In August 1995, the Act was permanently enjoined by U.S. District Judge Michael Hogan. In *Lee v. State of Oregon*, 107 F.3d 1382 (9th Cir. 1997), the Ninth Circuit Court of Appeals lifted the injunction, allowing ODWDA to move forward and an appeal to the U.S. Supreme Court was denied (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2008). In November 1997, a referendum measure, Measure 51, was placed on the ballot to repeal the Death with Dignity Act, but voters rejected the measure (Oregon Public Health Division, 2010).

In 1999, the Oregon Legislature enacted SB 491, which amended the Oregon Death with Dignity Act (Oregon Public Health Division, 2010). The 1999 amendments allowed health care facilities to prohibit Oregon Death with Dignity Act prescriptions to be written at their locations while protecting doctors from Medical Board censure if they ignored their facility's prohibition (Physician-Assisted Suicide SB 491,1999). The amendments also required the pharmacist filling the lethal prescription to be informed of the purpose of the medication (Physician-Assisted Suicide SB 49, 1999).Additionally, the amendments clarified residency and decision-making capabilities, and allowed local governments to recover costs from estates if the ODWDA patient died in a public place (Physician-Assisted Suicide SB 491, 1999).

In November 2001, U.S. Attorney General John Ashcroft issued a new interpretation of the Controlled Substances Act, which stated that controlled substances could not be used with the intent of hastening death (Oregon Public Health Division, 2010). This decision by Attorney General Ashcroft would have prohibited doctors from prescribing lethal doses of controlled substances for use under the DWDA (Oregon Public Health Division, 2010). In April 2002, U.S. District Judge Robert Jones issued a permanent injunction against Attorney General Ashcroft's order, allowing the ODWDA to stay in place (*Oregon and Rasmussen v. Ashcroft,* 192 F. Supp. 2d 1077 (2002)). The U.S. Department of Justice appealed the injunction to the Ninth Circuit Court of Appeals (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2008). The Ninth Circuit Court of Appeals upheld the injunction in May 2004, saying that the Attorney General's interpretation of the Controlled Substances Act interfered with the state regulation of medical practice (*Gonzales v. Oregon*, 368 F.3d 1118 (9th Cir. 2004)). The U.S. Supreme Court agreed to review this Ninth Circuit decision, affirming the decision in January 2006 and concluding that the Attorney General had "exceeded his authority in interpreting the federal Controlled Substances Act," (*Gonzales v. Oregon*, 126 S.Ct. 904 (2006)).

Statutory Requirements

The ODWDA "allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose," (Oregon Public Health Division, 2014a, p. 1). This requires some government oversight and reporting, but no other resources are required, as it already uses the existing healthcare networks and pharmaceutical supplies (Oregon Public Health Division, 2014a). The ODWDA specifically prohibits euthanasia, in which a physician or other person directly administers a medication to end another's life (Oregon Public Health Division, 2014c). To be prescribed the lethal medications, the ODWDA requires that a patient must be at least 18 years old; a resident of Oregon; and must provide documentation to the attending physician to verify Oregon residency such as an Oregon Driver License, a lease agreement or property ownership document for Oregon, an Oregon voter registration, or a recent Oregon tax return (Oregon Public Health Division, 2014c). "It is up to the attending physician to determine whether or not the patient has adequately established residency" (Oregon Public Health Division, 2014b. p. 1). The patient must be capable of making and communicating health care decisions (Oregon Public Health Division, 2014c). The patient must also be diagnosed with a terminal illness that will lead to death within six months (Oregon Public Health Division, 2014c).

Patients meeting the ODWDA requirements can request a prescription for the lethal medications from a licensed Oregon physician. To receive this prescription, the patient must make "two oral requests to his or her physician, separated by at least 15 days" (Oregon Public Health Division, 2014c). The person requesting the medications must also provide a "written request to his or her physician, signed in the presence of two witnesses" (Oregon Public Health Division, 2014c). Both the prescribing physician and a consulting physician must "confirm the diagnosis and prognosis and both physicians must also "determine whether the patient is capable" (Oregon Public Health Division, 2014c). The person requesting the lethal medication needs to be referred for a psychological exam "if either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder" (Oregon Public Health Division, 2014c).

Additionally, the prescribing physician must "inform the patient of feasible alternatives to ODWDA, including comfort care, hospice care, and pain control. The prescribing physician must request, but may not require, the patient to notify his or her next-of-kin of the prescription request" (Oregon Public Health Division, 2014c). Physicians are required by state law to report all prescriptions for lethal medications to Oregon Health Authority, Vital Records. However, this report is not required "if patients begin the request process but never receive a prescription" (Oregon Public Health Division, 2014c). Doctors must also inform the pharmacist of the intended use of the prescribed medication (Oregon Public Health Division, 2014c).

Both short-term and long-term goals of the policy are to ensure the continued access to additional options for terminal patients in Oregon and guarantee self-determination for those patients. The Act does not specify who must pay for the services, however, insurance companies determine whether the procedure is covered under their policies, as with any other medical procedure (Oregon Public Health Division, 2014b). The statute specifies that participation under the Act is not suicide, so using the Act should not affect insurance benefits (Oregon Public Health Division, 2014b). However, federal funding cannot be used for the medical services under the ODWDA (Oregon Public Health Division, 2014b). The Oregon Medicaid program, which includes federal funds, ensures that any charges for services relating to the Act are paid only with state funds (Oregon Public Health Division, 2014b). The ODWDA requires the Oregon Health Authority, Public Health Division, to collect information on the patients and physicians who participate in the Act and publish a statistical report yearly (Oregon Public Health Division, 2014c).

The National Association of Social Workers (NASW) "does not take a position concerning the morality of end of life decisions, but affirms the right of the individual to determine the level of his or her care," (NASW, 2004, p. 16). However, the NASW filed an *amicus curiae* brief supporting the Oregon Death with Dignity Act in the Supreme Court case of *Gonzales v. Oregon* which upheld Oregon's Act, (Brief of amicus curiae coalition of mental health professionals in support of respondents, 2006), The *NASW Standards for Palliative and End of Life Care* states, "Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients' rights to self-determination and dignity," (NASW, 2004, p. 21).

Death with Dignity and the Greater Good

Policies, Goals, and the Status Quo

The Oregon Death with Dignity Act (ODWDA) provides a detailed legislative scheme for terminally ill Oregon citizens to obtain a prescription for a lethal dose of medication (ODWDA, 1995). The language is quite specific, spelling out a number of definitions and procedures, which are designed to protect those involved in each phase of physician-assisted suicide. In spite of the statute's detail, there is no preamble, preliminary statement or formative language, which expands on a social remedy, overriding goal or underlying policy

Currently, Oregon's policy of physician-assisted suicide is legal, but the legality is by no means guaranteed. The *Gonzales* decision only affirms a state's power to enact a physician-assisted suicide statute—if it so chooses (Gonzalez, 2006). In the case of *Carter v. Canada*, the Canadian Supreme Court recently struck down a statutory ban on physician-assisted suicide (Carter, 2015). To date, however, the U.S. Supreme Court has made no definitive ruling whether there is a "constitutionally guaranteed right" to physician-assisted-suicide in the United States. Only five states, including Oregon, currently authorize the practice (Information for Research on Euthanasia, Physician-assisted-suicide, Living Wills, Mercy Killing, 2014). Thirty-four states have statutes in place that make assisted suicide a crime and nine states have declared assisted suicide a crime by court decision (Information for Research on Euthanasia, Physician-assisted suicide, Living Wills, Mercy Killing, 2014).

The concept of physician-assisted suicide is a politically charged issue that is divided along partisan lines. Republican opponents of physician-assisted suicide trumpeted fears that some physicians would target vulnerable populations, including the elderly, racial or ethnic minorities, and lower income populations, with the intent to manipulate unwilling and unprotected patients into committing suicide (Wineberg & Wirth, 2003). Nevertheless, the ODWDA was approved in an initiative by Oregon voters on two separate occasions: first, in the November 1994 general election, the Act was approved by a margin of 51% to 49%; then, after the statute was passed in 1997, a second voter initiative chose to retain the Act by a 60% to 40% margin (Facts about Death with Dignity, 2014). The act is likewise limited to persons who demonstrate Oregon residency, so the entire process does not expand beyond the borders of the state. Opposition groups have failed to come forward with any study or data which shows that physician-assisted suicide has been used an instrument of abuse towards vulnerable groups.

In American culture, the Declaration of Independence is viewed as a lightning rod for social equality and legal redress. "Life, liberty and the pursuit of happiness" are the patriotic guarantees frequently trumpeted (U.S. Declaration of Independence, 1776). The terminally ill patient is seeking the same liberty and happiness through death. Two of the most frequently cited reasons for requesting the lethal prescription have been the desire to maintain autonomy and independence (Ganzini, et al., 2002). Historically, these are the same values we all hold as important. Under the circumstances, it is difficult to ascribe harmful motives to those who seek to end their suffering in a nonviolent manner through the controlled aid of a physician and other health care providers.

Costs, Healthcare, and Political Posturing

Various determinants or analyses of cost, resources or redistribution are absent from the statute, and the Act does not say who pays for the services or whether any portion of the process is covered by insurance. Federal funding cannot be used for services provided under the Act, and the Oregon Public Health Division collects no cost data applicable to the ODWDA (Facts About Death with Dignity Act, 2014). The statute, however, does go to great lengths to try and ameliorate the potential negative consequences related to the process, and includes the following provisions: no person can be denied life insurance or annuity benefits as a result of the suicide/death; anyone who participates in the process is immune from civil or criminal liability; no doctor or health care provider can be reported to any licensing authority for their participation in the process; no doctor or health care provider is required to participate in the process (ODDA, 1995).

The effectiveness of hospice and palliative care is a factor that bears consideration. Palliative care is care provided in a range of care-settings such as hospital, home and nursing home, which does not cure illness but is intended to ease patient needs and reduce discomfort regardless of the prognosis (Meier, 2011). Hospice provides care options, palliative or otherwise, in a controlled setting for the chronically or terminally ill patient (Meier, 2011). Over the last 25 years there has been a dramatic increase in the growth and expansion of palliative and hospice care (Meier, 2011). This phenomenon has led to difficulties, which include lack of appropriate training, increased medical complications, and a lack of primary care infrastructure, all of which results in ineffective cost and value in health care (Meier, 2011). The ODWDA affords the terminally ill the opportunity to exercise autonomy over his or her life and, at the same time, eliminate the need for cost ineffective care, which does not prolong their lives.

Some would argue that it is duplicitous to suggest that bringing about the death of another contributes to a better life. Death is inevitable, but for the terminally suffering patient it is painfully imminent. Yet there are multiple identifiable medical protections built into the Act. For example**,** the entire process is directed under the supervision of a doctor (ODWDA, 1995). Other medically supervised alternatives to death with dignity are unsavory, including one which has become a common practice in the hospice care industry, known as Voluntarily Refuse all Food and Fluids (VRFF) (Byock, 1995). VRFF is a practice where the terminal patient refuses all fluids and foods, and slowly withers to death with hospice care workers present to witness the suffering (Byock, 1995). Remarkably, studies show that many of these workers have come to believe that VRFF is an acceptable method for a patient to hasten death (Byock, 1995). Other studies have shown that, with increased exposure to physician-assisted suicide, many hospice workers have realized it is an appropriate alternative to VRFF (Harvath, et al., 2004). Tradeoffs between the pain and suffering of life and the enigma of death are an inevitable dilemma of the terminally ill patient, their loved ones, and caretakers, regardless of the precise date of death. Which is better, life or death? This is a question that is inextricably linked to the patient's right to dignity and individual autonomy (Loggers, Starks, Back, Appelbaum, & Stewart, 2013).

Political posturing was an inevitable part of Oregon's Death with Dignity Act**.** After 20 years, the voices against physician-assisted-suicide have not come forward with data that refutes the benign effectiveness of the Act. Studies in both Oregon and the Netherlands (where physician-assisted suicide has been authorized since 2002) found that there was no heightened risk for the elderly, the uninsured, the poor, racial and ethnic minorities, people with non-terminal disabilities or non-terminal illnesses, minors or mature minors (Battin, Cummins, Sevel, & Pedrick, 2014). These findings are borne out by the raw data in Oregon (Facts About Death with Dignity Act, 2014). During the sixteen years since the ODDA was passed a total of 1,173 people have had the lethal prescription filled (an average of 73 per year) and 752 patients have actually died from ingesting the medication (an average of 47 per year) (Facts About Death with Dignity Act, 2014).

Although there is no preamble to the statute, it is clearly designed to provide terminally ill patients the ability to exercise autonomy over end-of-life choices. In light of the small number of persons who have availed themselves of the ODWDA, it is difficult to argue that the statute has impeded relations between the terminally ill and society as a whole. Even the Brittany Maynard case, where a 29-year-old woman availed herself of the Act, failed to rekindle political debates over the appropriateness of physician-assisted suicide. Neither does there appear to be much momentum in the debate over repealing statutes in the vast majority of states where assisted suicide is a crime. The issue is rarely confronted and discussed.

Death with Dignity and the Realm of Social Work

The platform for social work lies in the priority it places on values of self-determination, empowerment, inherent worth and dignity (Cummins, Sevel, & Pedrick, 2012). These values are not specifically stated in the ODWDA, yet they are self-evident in the nature of the profound right it creates for those who suffer from a terminal illness. Additionally, social workers are accustomed to working with patient conflicts, including those presented by the patient's environment and the patient's network of support (Miller, Hedlund, & Soule, 2002). Many social workers have reported that an increasing number of facilities are implementing policies that accommodate the complex nature of end-of-life decisions that utilize physician-assisted suicide (Norton & Miller, 2012). Their increasing exposure to this process have assisted social workers to become increasingly responsive to the patient's desire for autonomy and to facilitate families who struggle with a terminally ill loved one (Ganzini, et al., 2002).

The statutory scheme of the ODWDA is designed to create a dignified process with medical and professional safeguards available to help the terminally ill patient make an informed decision. While Brittany Maynard's demise received much publicity, the attention appeared more focused towards the tragedy of her demise rather than any supposed flaws in the Act itself. Perhaps this means that the statute has accomplished its task in a dignified manner. This lack of controversy regarding the Death with Dignity Act in recent years has proven its value to society as a whole. The poor and vulnerable have not been taken advantage of, and it is surprising that there have not been more patients who have availed themselves of the rights afforded under the Act.

A great irony in the application of this statute is an area that was not given much focus by critics and opponents of the Act -- the effect of physician-assisted suicide on surviving family members. As a group, surviving family members have been found to express gratitude for having given their terminally ill family member the ability to exercise control and autonomy in an uncertain, dire situation (Loggers, et al., 2013). Surviving family members of physician-assisted suicide had less grief, had fewer negative perceptions in relation to the death, felt better-prepared for the loss and were less conflicted over whether they were able to help with a loved one's suffering (Ganzini, et al., 2009). The Act has proven to be a great source of relief to family structures.

Conclusion

Oregon's Death with Dignity Act has been helping terminally ill patients make end-of-life decisions for over 17 years. It has provided a vital service to a compromised group of persons who choose independence versus prolonged suffering. What matters is that they have been given a choice. The debate over its provisions was not without political hyperbole that proved to be without merit. While there was reluctance amongst some physicians and health care providers, many have chosen to participate in a scientific and caring manner, and have come to accept physician-assisted-suicide as a recognized form of end-of-life decisions. Poor and at risk populations have not been harmed or taken advantage of as some had claimed. In the final analysis, facilitating the use of this statute by the terminally ill has created greater patient autonomy and helped ameliorate the suffering of surviving loved ones. While Oregon is in the minority of jurisdictions that allow physician-assisted-suicide, other states are currently considering the passage of similar legislation. They would do well to follow Oregon's lead.

***Morgan Albrecht** is an MSW student at Loyola University Chicago concentrating on School Social Work. She spent the previous four years in California working with women diagnosed with PTSD, co-occurring disorders, and substance-related disorders at a trauma based residential treatment center. She is currently a case manager at Elam Davies Social Service Center and works with clients who suffer from chronic homelessness to obtain transitional housing, mental health services, and employment. Upon graduating, Morgan Albrecht hopes to work with adolescents in a school setting.*

***Richard B. Rogich** is an attorney in Chicago, Illinois and an MSW student at Loyola University Chicago concentrating in Mental Health and Addiction Counseling.*

***Andrew Zapke** is a second-level MSW student at Loyola University Chicago with a concentration in Mental Health. After completing his MA at Johns Hopkins University, he worked as a Sixth Grade Language Arts teacher in Baltimore. After turning to social work, his first internship was at LIFT-Chicago, where he worked as a member advocate, assisting with job and housing searches. He is currently in a clinical internship at Presence Behavioral Health Addiction Services, where he co-facilitates group therapy in an Intensive Outpatient Program.*

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Clinical Care for Transgender Women

Eliot Colin

Abstract

Transgender women can share common life experiences, which lead to specific clinical needs from their mental health providers. This goes far beyond diagnoses and must address the very real lived experiences and issues that transwomen face. Discrimination comes in many forms (poverty, unemployment, lack of access to healthcare, minimal social support, and housing instability) that will impact the therapeutic process. In order to interact with and provide adequate care for transwomen, there are certain strategies that might prove most helpful in building a strong therapeutic alliance. In addition, certain treatment modalities have been beneficial with transwomen (cognitive-behavioral therapy, narrative therapy, a trauma-informed approach, and social support groups). Assisting transgender women through treatment and transition can be a step in the process towards resilience and empowerment that clinicians should want to foster.

Keywords: counseling, LGBTQ, mental health, MTF transgender, transwomen

Introduction

"Seventy-five percent of [transgender people have] received counseling related to their gender identity and an additional 14% hope to receive it someday" (Grant et al., 2011). With such a high percentage of this population seeking care, it is especially pertinent to seek competency in transgender care. Too often, organizations and service professionals working with LGBTQ communities do not have adequate skills in regards to this specific population (Carroll & Gilroy, 2002). On top of this, transgender women often have additional needs due to systemic discriminations they face (in employment, housing, policing, and health). Cultural competence for this population extends to those arenas, and ignorance of these issues leaves potential for further inequalities in treatment. Therefore, the focus of this assessment is on the specific clinical needs and common life experiences of transwomen.

Context & Terminology

There is limited evidence in the existing literature on this topic, and the studies that do focus on transwomen often do so exclusively in the realm of HIV/AIDS risks and rates. Though there is literature on clinical interventions across transgender populations, here it will be directly applied towards the lives of transwomen. For these reasons, some information has been included from those studies, and the language *transgender people* is used in those instances.

Before diving any deeper into this subject matter, the language to be used needs to be defined. This is important in a clinical setting because in order to best converse with transwomen, it is important to be able to speak their language, or at least have a basic understanding of the concepts inherent in what is being discussed. This foundation will allow for deeper conversations to unfurl. To better serve their clients, therapists will need to conceptualize sex and gender as two different categories, both of which exist on a continuum rather than two distinct groups of male and female (Maguen, Shipherd, & Harris, 2005). *Gender* is a composite of identity, expression, and roles (Stringer, 2013). *Sex* is an amalgamation of various components: chromosomes, genitalia, reproductive organs, secondary sex characteristics, and legal designation (Stringer, 2013).

The following terminology has been compiled by Stringer (2013) on behalf of the Heartland Trans* Wellness Group. *Transgender* refers to any person whose current gender identity differs from the sex they were assigned at birth (Stringer, 2013). *Transgender women* (*transwomen* for short) refers to those who identify as female but were assigned male at birth (Stringer, 2013). *Male-to-female* (*MTF*) is also commonly used to describe this population (Stringer, 2013). *Transfeminine* or *feminine of center* refers to those who do not completely identify as female but who lean toward the feminine side of the spectrum (Stringer, 2013). These terms describe identity and have nothing to do with individuals' legal or anatomical status (Stringer, 2013). *Passing* occurs when a transperson is being perceived as the gender in which they identify (Stringer, 2013).

According to Stringer (2013), *transition* refers to a broad range of methods in which transgender people identify, behave, or present in ways that differ from how they were assigned at birth. Stringer (2013) goes on to further breakdown the term *transition* into various categories, such as social, medical, and legal. *Social transition* can include going by a different name, using different pronouns to refer to oneself, and changes in dress or other gendered forms of expression (Stringer, 2013). *Medical transition* is the specific use of hormonal and/or surgical interventions to change the body (Stringer, 2013). *Legal transition* refers to the changing of name and/or gender marker on identity documents, including driver's license, ID, or birth certificate (Stringer, 2013).

Issues Impacting Transgender Clients

This unique terminology also reflects unique lived experiences. One transwoman remarked, "I was kicked out of my house and out of college when I was 18. I became a street hooker, thief, drug abuser, and drug dealer. When I reflect back, it's a miracle that I survived," (Anonymous, as cited in Grant et al., 2011, p. 11). Unfortunately, there are unique intersections of discrimination that transwomen face due to sexism and transphobia (Jefferson, Neilands, & Sevelius, 2013). For transwomen of color, the addition of racism is especially heinous (Jefferson et al., 2013). In accordance with Minority Stress Theory, negative physical and psychological effects are often found in those who experience many of these stressors (Jefferson et al., 2013; Hendricks & Testa, 2012). The following are the most common themes as found by Grant et al. (2011):

- Poverty (Grant et al., 2011): Transpeople are four times more likely than the general population to have a household income of less than $10,000 (p. 22).
- Employment (Grant et al., 2011): For all transpeople, 90% experienced have mistreatment of some kind in the workplace (ex. verbal harassment, physical/sexual abuse, lack of restroom access, job loss, lack of advancement opportunities, etc.) (p. 56). Additionally, they have twice the rate of unemployment compared to the general population, and for transpeople of color, it was four times as much (p. 51). Half of transwomen report being underemployed (p. 55) with 19% participating in underground economies, which is the illegal trading of goods or services (p. 64). Though this includes drug sales and other undocumented incomes, these transwomen were primarily engaged in the underground economy of sex work, at a rate of 15% (p. 64). This is in contrast to the Prostitutes' Education Network estimate that only 1% of women in the U.S. have engaged in sex work.
- Health (Grant et al., 2011)**:** Twenty-four percent of transwomen have been outright denied medical care in doctor's offices and hospitals (p. 73). Another 24% postponed needed care due to this and other kinds of barriers (p. 76). Transwomen have an additionally high risk for HIV infection, at more than four times that of the general population (p. 80).
- Social Support (Grant et al., 2011): Forty-five percent of transwomen have been completely rejected by family (p. 94) with 22% experiencing family violence (p. 100). Sixty-seven percent of transwomen lost friendships (p. 100), and fifty-two percent have experienced verbal harassment/disrespect in public spaces (p. 127).
- Housing (Grant et al., 2011): Transpeople have twice the average rate of homelessness (p. 107), and 16% of transwomen have been evicted due to their trans status (p. 113). Despite this discrepancy, thirty-four percent have been denied access to homeless shelters (p. 116). Even if they do gain access to these shelters, many transwomen face discrimination from peers and/or staff: sixty percent were verbally harassed, twenty-nine percent were physically assaulted, and an astounding 26% were sexually assaulted (pp. 117-118). All of these factors play into the risk of transwomen living on the streets.

Diagnostic Criteria

The statistics provided by Grant et al. (2010) serve to show risk factors that may or may not impact individual clients, but are nonetheless something of which to be keenly aware. Treating transwomen holistically means allowing them to share these kinds of harrowing experiences or otherwise taking steps together to prevent them. When it comes to diagnoses, cultural and socioeconomic factors may come into play.

Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

The DSM-5 is the authority on all matters relating to mental health diagnoses in the United States. The current diagnosis related to transgender people is called Gender Dysphoria, and the main criteria for this diagnosis in adolescents and adults consists of "a marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration" (American Psychiatric Association, 2013, p. 452). This diagnosis must also be "associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning" (p. 453). There are pros and cons for using this diagnosis. Some feel it is a pathologization of transgender identities altogether, while others see it as legitimizing them (Mizock & Fleming, 2011; Lev 2013). Having the diagnosis can open up doors in terms of insurance coverage of other medical treatment (hormones and/or surgery), but it can also do the opposite (Mizock & Fleming, 2011). Clients have reported counseling and medical check-ups being denied due to their insurance not paying for any trans-related charges (Lev, 2013, p. 7). Now that more doctors and surgeons are moving toward an informed consent model (World Professional Association for Transgender Health [WPATH], 2012), it would thus be pertinent to have a discussion about the diagnosis with the client before making it.

WPATH Standards of Care

On a more international scale, the World Professional Association for Transgender Health (2012) is responsible for the most commonly followed standard of care for transgender persons. Its comprehensiveness allows medical and mental health professionals alike to learn how to care for the needs of transgender individuals, families, and communities (WPATH, 2012). Though these standards do not diagnose per say, they do list various criteria for interventions. An example of these guidelines can be seen in their criteria for hormone therapy:

> 1. Persistent, well-documented gender dysphoria;
> 2. Capacity to make a fully informed decision and to consent for treatment;
> 3. Age of majority in a given country (if younger, follow the SOC outlined in section VI);
> 4. If significant medical or mental health concerns are present, they must be reasonably well-controlled (WPATH, 2012, p. 187).

Though this is merely a set of flexible guidelines, it can and should be one of the first places counselors look when learning about transgender care, especially when clients are interested in medically transitioning (WPATH, 2012).

Clinical Methods of Treatment

Clinical care is not only about diagnoses but also involves the ways in which therapists interact with their clients. One theoretical perspective useful for engaging transwomen would be a trauma-informed approach, which would acknowledge that most people have experienced some type of trauma in their lives (Substance Abuse and Mental Health Services Administration, 2014). Traumas that particularly impact transwomen include discrimination and interpersonal violence (Singh & McKleroy, 2011). Given the aforementioned rates of discrimination for transwomen, this approach is a good fit. By knowing about a client's particular history of trauma as well as their triggers, clinicians can use this to help create safe environments.

A therapeutic theory for use with transwomen would be cognitive behavioral therapy (CBT). According to Maguen and colleagues (2005), CBT is a method that confronts maladaptive thought processes in conjunction with adding coping skills and changing behaviors. When Maguen et al. (2005) applied CBT to this population, it was found to work best when challenging catastrophic thoughts and negative self-images. The authors additionally found that role-plays and modeling improved clients' problem solving skills, which were hampered by these maladaptive thoughts. This methodology could be used in individual settings but has additional power when applied to groups.

There are many other types of group therapy that can be beneficial for transwomen, depending on their situation. These groups could be focused on general support, social skills, mental health, or psychoeducation (dickey & Lowey, 2010). These groups can have a unique healing ability for this population because they decrease social isolation and increase peer support (Corliss, Belzer, Forbes, & Wilson, 2007; Jefferson et al., 2013; Maguen et al., 2005). As mentioned previously, these kinds of social supports serve as a powerful protective factor in many areas of mental and physical health (Maguen et al., 2005).

Additionally, constructivist and narrative therapies help transgender clients tell and re-frame their own stories (Carroll & Gilroy, 2002). This can help to diminish the influence of societal assumptions, -isms, and instances of discrimination by allowing the client to focus on their own personal strengths, feelings, and experiences (Carroll & Gilroy, 2002). However, despite the recent advances made in attention to this population, there has still not been enough empirical support for evidence-based practices specific to transwomen to develop.

Recommendations for Building a Therapeutic Alliance

No matter the theory or treatments used, validation of the client is most critical. By respecting the client's gender, this will facilitate trust in the therapeutic relationship (Corliss et al., 2007). Transgender individuals may use a variety of pronouns to refer to themselves (she, he, they, ze, or any combination therein), so it is important not to assume their preference. This means specifically asking what name and pronoun they would like used and, most importantly, actually using them.

Should the client pursue a social transition, therapists might be requested to assist in those arenas. This can include going by a more traditionally feminine name, using "she" pronouns, adopting new clothes, shaving, and growing out her hair or wearing wigs. However, merely helping clients "pass" as a means of following societal gender roles does not help the whole person (Corliss et al., 2007). Additionally, dating and other relationship quandaries and changes might occur and clients might seek additional or different social supports. Even though these are common needs for transwomen, try not to make assumptions about what the client needs.

Allow clients to go at their own pace, and do not try to make them speed up if they are not ready. Just because a person comes out to their therapist does not mean they are ready to do anything else, nor does it mean they *want* to do anything else. Alternatively, do not try to slow a client down too much. This might be their first counseling session, but it is likely they have thought about this for a long time. There is such a diversity of experience amongst transwomen (race, age, education, SES, passability, etc.) that an individualized approach is decidedly helpful (Carroll & Gilroy, 2002). All of these things will help to build a meaningful therapeutic alliance.

Therapists must also keep in mind the clients' previous experiences with service providers and the extent to which inappropriate or discriminatory care can impact current treatment (Corliss et al., 2007). Clients bring that personal history into treatment and might find it harder to engage in the therapeutic process. Sometimes clients have had to educate their providers, which can take away from their role as a client (Mizock & Fleming, 2011). This is why it is helpful for treatment professionals to do their own research (Mizock & Fleming, 2011). In the case where clients respond hesitantly to treatment, this might be a manifestation of transference, though it should not be seen as "resistance" in the traditional sense. Though Koetting (2014) mentions countertransference briefly, no literature could be found on specifically navigating through this in regards to transgender clients.

Despite this potentially complicated relationship, the client's perception of whether or not the therapist is culturally competent can impact the practice's future clientele. Since resources are so scarce, most transgender persons (youth especially) ask for peer advice when seeking counseling (Corliss et al., 2007). Therefore, the knowledge of a clinician's quality of treatment (good and bad) will most likely spread quickly in the community (Corliss et al., 2007).

Themes During Treatment

Once the therapeutic alliance is built, there are numerous topics transgender women might seek to discuss, including issues that affect the general population (American Psychological Association, 2009). This includes depression, anxiety, alcohol/drug abuse, family struggles, etc. (Carroll & Gilroy, 2002; Maguen et al., 2005). Additionally, experiences of trauma and risk of self-harm are higher in transgender populations (Mizock & Fleming, 2011). These factors put transpeople at heightened risk for suicide, and 41% of living transpeople have attempted suicide as compared to 1.6% of the general population (Grant et al., 2011, p. 2).

Identity Development and Social Support

All of the aforementioned troubles stand in the way of the client's self-fulfillment. In order for transwomen to be their authentic selves, they need support in figuring out their identities. According to Wester, McDonough, White, Vogel, & Taylor (2010), gender role conflict is the phenomenon in which an individual experiences negative effects because of their deviation from societal gender expectations. This theory, which was developed specifically for working with transwomen, allows clients to delve into their gendered socialization and imposed gender roles when navigating other issues (Wester et al., 2010). For those assigned male at birth, there is often a pattern of competition and achievement alongside restricted emotionality and affection (Wester et al., 2010). Higher levels of these traits among transwomen have correlated with depression, anxiety, sexual aggression, physiological distress, and relationship issues (Wester et al., 2010). This also corresponds to lower levels of self-esteem, relationship satisfaction, emotional expressiveness, and the seeking of mental health services (Wester et al., 2010).

Despite the influence of gender role conflict, strong identification with transgender identity has shown an increase in the efficacy of coping strategies and thus a decrease in depressive symptoms (Jefferson et al., 2013). Therefore, treatment should include this identity development alongside the exploration of coping skills to decrease the impact of stressors (Jefferson et al., 2013).

This gender identity formation can also require work around sexual identity, which may shift during transition. This could be a "change" in desire from one sex to another because of previous societal pressures that have been alleviated thus allowing them to more freely express their sexuality. For example, transwomen that have been socialized as male in a heterosexist society might pursue relationships with women even though they would prefer men. It could also be a mere re-labeling from gay to straight (or vice versa) given their change in gender identification. For those in existing relationships, their transition can cause strain and break-up, as is the case amongst 57% of transwomen (Grant et al., 2011). Though popular culture would suggest that transwomen are exclusively attracted to men, studies show a greater diversity in sexual expression (Grant et al., 2011). Twenty-nine percent identified as gay/lesbian/same-gender loving, 31% as bisexual, 7% as queer, 23% as heterosexual, 7% asexual, and 2% as other (Grant et al., 2011).

In terms of finding other social supports, this can be a difficult task for transwomen. In nearly all areas of discrimination against transgender persons, family acceptance has shown to be an important protective factor, which could mean that family therapy or education should be an increased area of interest and need (Mizock & Fleming, 2011; Grant et al., 2011). Sometimes this is not possible, which puts an even bigger need on finding and maintaining friends and other support systems, often facilitated through community organizations. However, given the diversity of the transgender community, not every community space will be a good fit for everyone. Even differences between individuals who identify across the LGBTQ (lesbian, gay, bisexual, transgender, and queer) spectrum can further subdivide community (Carroll & Gilroy, 2002), which can be incredibly isolating.

Body Dysphoria

Especially when navigating sexuality, another major piece that will likely come up in therapy is body dysphoria, which can be categorized as "discomfort or distress that is caused by a discrepancy between person's gender identity and that person's" current anatomy (WPATH, 2012, p. 2). Oftentimes, transwomen seek certain clothing or supplements to make them feel more comfortable. For example, a *gaff* is more-or-less underwear that is used for *tucking,* which is a method of hiding the penis and making that area appear more feminine (Transgender & Transsexual Roadmap [TS Roadmap], n.d.). *Breast forms* are silicone inserts that trans women may use to increase their bust. There are similar inserts for extra hip and buttocks padding (TS Roadmap, n.d.). Voice training is also something they might pursue, since having a deep voice can cause many transwomen to experience dysphoria and discrimination (TS Roadmap, n.d.).

Medical Transition

This dysphoria is a component that leads many transwomen to want to medically transition, and many transgender persons initially seek counseling in order to receive letters of recommendation so they may pursue said transition (Sennott & Smith, 2011). In addition, they often need assistance in finding doctors for these services, and so therapists should be knowledgeable about these kinds of referral processes, which differ greatly depending on local policies and resources (Carroll & Gilroy, 2002). Since there is also much risk of further discrimination, clinicians should seek out medical providers that are also competent in transgender care, but the conversation should not stop there (Carroll & Gilroy, 2002). Some clients will want to discuss concerns and questions about these medical topics that they would not have the time to discuss with doctors and surgeons.

For a more in depth understanding of these health topics, The Transgender Health Program's guide entitled "Hormones: A Guide for MTFs" is an easy to understand and comprehensive look into the effects of hormone replacement therapy (Simpson & Goldberg, 2006). The same can be said for "Surgery: A Guide for MTFs," which can be helpful in supporting clients to discuss and figure out what treatments might be beneficial for their wellbeing (Ashbee & Goldberg, 2006). These conversations also need to take into consideration barriers that often come into play, such as cost. One transwoman stated, “I cannot afford gender reassignment surgery which is crucial to my mental well being and thoughts of suicide are always present" (Anonymous, as cited in Grant et al., 2011, p. 79). It is important to note that though much of public discourse around transgender issues surrounds surgery, this topic may or may not be of interest to the individual client (Mizock & Fleming, 2011).

Legal Issues

Identity Documents

On top of these potential life changes, most transwomen want to change their identity documents to reflect their preferred name and gender (Grant et al., 2011). However, changing one's legal name and/or gender marker is an extremely complicated and costly process. There are different steps to change a person's name than there are to change a person's legal gender, and each legal document (driver’s license, ID card, passport, birth certificate, social security card, medical card, etc.) has its own process as well (Equality Illinois, 2015). For more information on this process in Illinois, Equality Illinois has produced a "Know Your Rights" pamphlet (Equality Illinois, 2015). Trying to navigate those complex systems can compound existing mental distress, so it can be instrumental to help clients with this process. This could be through referrals to community organizations, fact sheets, personal knowledge of the process, etc. (Maguen et al., 2005). In addition to alleviating social dysphoria, legal name changes have been seen to improve prospects for education and employment, which, in turn, decrease rates of sex work and housing instability (Corliss et al., 2007).

Police & Prisons

Unfortunately, transwomen continue to experience significant interaction with police and the criminal justice system (Grant et al., 2011). Some transgender women are profiled as sex workers and summarily arrested, causing this phenomenon to be called “walking while transgender” (Grant et al., 2011). Twenty percent of transwomen report having been harassed by police, 6% physically assaulted by police, and 3% sexually assaulted by police (Grant et al., 2011). Twenty-one percent of transwomen have been jailed and/or incarcerated (Grant et al., 2011), compared to 4.9% of men and 2.7% of the general population (Bureau of Justice Statistics, 2003). Once jailed, they face significant harassment by peers and staff alike, including further physical and sexual assault (Grant et al., 2011). One transwoman shared her experiences in jail, stating, “While I only experienced verbal harassment and rape threats during a night in jail, I watched a trans woman arrested with me experience physical and sexual assault from the police that night as well as extensive verbal harassment and humiliation" (Anonymous, as cited in, Grant et al., 2011, p. 166).These experiences, like other traumatic events, can have lasting effects on a client's mental health (Reisner, Bailey, & Sevelius, 2014), the ability to attain employment due to the presence of a record, and can further impede clients' attainment of legal name changes (O. Daniel-McCarter, personal communication, November, 17, 2014). With so many transwomen having been negatively impacted by the criminal justice system, they might not put much faith into the (mental) healthcare system. All of these factors influence one another and impact how clients seek and receive care.

Special Considerations

Given the many intersections of identity that affect every population (age, race, SES, etc.), there are often underserved subgroups that require special considerations. The following are subgroups of transwomen who have specific needs when it comes to counseling services.

Youth

The main reason youth seek therapy or health care services is to begin the path toward hormone replacement therapy (Corliss et al., 2007). However, this does not mean this is their only need, and so once they are "in the door," they might request services or express needs related to other issues, such as histories of abuse, interpersonal violence, or other case management related concerns (Corliss et al., 2007). These youth may not be able to receive the kinds of services they request due to consent or parental notification laws (Corliss et al., 2007). However, it should also be noted that many youth buy hormones off the streets when they are not able, for varied reasons, to get them from doctors (Corliss et al., 2007).

Veterans

At the same time that youth are coming out as transgender at younger ages, older individuals are also coming to terms with their gender identities. Of the existing pool of veterans, there are disproportionate rates of those who identify as transgender, particularly as transwomen (Mizock & Fleming, 2011). It is thought that these individuals joined the military as the result of a "last-ditch effort" in trying to identify as the male gender they had been assigned (Mizock & Fleming, 2011; Maguen et al., 2005). In addition to the risk of PTSD that other soldiers have, this period of "living a lie" can have added negative effects (Maguen et al., 2005). Unfortunately military sexual trauma has also been an experience some have had during their service, which compounds all of the previously mentioned traumas (Maguen et al., 2005). Due to departmental overflow or desires to steer clear of military environments, these clients may end up seeking other providers for their mental or medical healthcare needs.

Chronic Mental Illness

Potentially complicating the issue even further are comorbid mental health concerns. Though depression and anxiety are issues that transgender women face, some evidence suggests this is not distinctly disproportionate from the general population (Cole, O'Boyle, Emory, & Meyer, 1997). These authors suggest substance abuse was the only significant comorbid condition they found, showing transgender persons as being predominantly mentally healthy.

However, some transgender persons do have co-occurring mental health issues, which can complicate the diagnostic process. According to Mizock & Fleming (2011), when individuals have severe mental illnesses like schizophrenia or other mood/anxiety disorders that can present with psychosis, it is unfortunately common that any gender issues are labeled as delusions. These authors state that sometimes a client's gender incongruence can be a symptom of psychosis, which might dissipate with medication; however, it is also likely that this gender identity will not go away as other symptoms do, but persist as with transgender persons without a mental illness. In either case, neglecting the gendered needs of those with psychosis heightens distress for the client, which interferes with recovery. Even if the therapist believes the gender issues are the result of psychosis, providers should not engage in struggles about the validity of client delusions, just as is standard practice in working with those with other serious mental illnesses (Mizock & Fleming, 2011). All of this is to say that transgender people can have these kinds of mental health issues in addition to being authentically transgender.

The potential for further distress, stigma, and discrimination in such settings can cause transgender individuals to avoid seeking help in the first place (Mizock & Fleming, 2011). Especially in inpatient treatment facilities, transgender clients might neglect their specific needs, such as their preferred name or pronouns, out of fear that voicing these needs would lead to an extended hospitalization (Mizock & Fleming, 2011). Additionally, if the client were in a state of crisis, it would prove beneficial to extend the period of evaluation before making an assessment about the presenting gender incongruence (Mizock & Fleming, 2011).

Conclusion

There is some existing literature on learning about cultural competency with transgender individuals, and much evidence about discriminations faced by transwomen specifically. However, there has been less in terms of interacting with and providing care for the specific needs of transwomen. Knowing the kinds of discrimination transwomen commonly face allows clinicians and other providers to see the kinds of issues that impact these clients. This can create awareness about the kinds of additional knowledge (ex. homelessness, drug use, sex work, incarceration, etc.) they should seek. In the process of transition alone, there are many changes happening concurrently, and clinicians should be able to help their clients sort through it all. Therefore, a basic understanding of the aforementioned issues and perspectives will support that process.

Although there are many struggles faced by transgender women, many are still able to exhibit incredible strength and resilience (Grant et al., 2011). With additional support, validation, and advocacy work, we can improve the circumstances in which transwomen find themselves. Transwomen are not only standing up and refusing to be silenced, but they are coming to the forefront of a national conversation on transgender rights. Competent clinical care is a necessary step in the process of empowerment for these women.

***Eliot Colin** is a white trans/queer nerd and feminist pursuing a Master in Social Work at Loyola University Chicago, where they are focusing on issues that impact queer and trans communities. After moving to Chicago, Eliot interned at the Broadway Youth Center, where they deepened their understanding of the needs of queer and trans youth experiencing homelessness. They are currently the Programming Intern with LGBTQI Initiatives at Loyola University Chicago where they can continue to engage their passion for building community and pursuing social justice. In their spare time, Eliot is also building a non-profit, RAD Remedy, which seeks to address healthcare barriers faced by trans communities. Eliot can be reached at eliotcolin@gmail.com.*

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Changing Focus:

Making Psychosocial Care in Nursing Facilities a Priority

Christine Flynn

Abstract

According to federal policy nursing facilities in the United States are mandated to provide the "highest practicable physical, mental and psychosocial well-being of each resident (Department of Health and Humans Services [DHHS], 2003). However, due to a focus on physical care by state surveyors, facilities and, the national rating system, psychosocial care falls to the wayside leading to a deficit in services and comprehensive care (DHHS, 2003; Medicare, 2014c). By increasing the weight these services hold, and expanding the range of services reviewed, in Medicare's Five Star Quality Rating System, facilities that seek to attain a high rating would be forced to make psychosocial care a priority.

Keywords: five star rating system, nursing home facilities, nursing home compare, psychosocial care

Introduction

According to the Omnibus Budget Reconciliation Act (OBRA) of 1987, skilled nursing and nursing facilities are required to provide "medically-related social services to attain, or maintain, the highest practicable physical, mental and psychosocial well-being of each resident" (DHHS, 2003). However, evaluations of this care are often limited only to the existence of a social service provider in a nursing facility, and not necessarily to the level of care being provided (Vourlekis, Zlotnik, & Simons, 2005, p. 2). Evaluation results from nursing facilities became more accessible to the public in 1999 when the Centers for Medicare and Medicaid Services (CMS) debuted the *Nursing Home Compare* website (Center for Medicare and Medicaid Services [CMS], 2015). However, it was not until 2008 that a Five Star Quality Rating System was created to allow for easier comparisons based on a set rubric (CMS, 2015).

Since its inception this rating has served as a measure used by insurance companies, funders and referral sources to separate high functioning facilities from their lower functioning counterparts (Thomas, 2014). Due to the importance that external sources have placed on the rating system, facilities must place their focus and resources on CMS specified measures to be awarded a higher rating. Unlike staffing, health inspections, and medical care, psychosocial care is displayed by only two measures: rates of depression and use of psychotropic drugs (Medicare, 2015). This paper will advance the argument that psychosocial care receive an expanded role in the rating system as a way to motivate facilities to dedicate the necessary resources and care for all residents' psychosocial concerns.

History of Elder Care Nursing Facilities in the United States

As defined by the Social Security Act (SSA), a nursing facility:

> Is primarily engaged in providing residents with skilled nursing care and related services for residents who require medical or nursing care; rehabilitation services for the rehabilitation of injured, disabled, or sick persons; or on a regular basis, health-related care and services to individuals who because of their mental or physical condition require care and services (above the level of room and board) which is available to them only through these facilities, and is not primarily for the care and treatment of mental diseases. (1935)

According to Watson (2009) throughout the 19th and early 20th centuries, the majority of elder care was home-based and provided by the family unit, or community members who received reimbursement from the local government. For those without familial ties, almshouses, colloquially referred to as "poorhouses" became their homes (Watson, 2009). Noted for drastic underfunding, and subpar living conditions, almshouses served as shelter for those deemed “deserving poor,” such as the severely mentally ill, disabled and elderly (Watson, 2010). Even with the title of “deserving poor,” a societal fear existed that providing comprehensive services for these individuals may lead to a culture of dependence and laziness; such biases lead to drastic underfunding of these homes (Watson, 2009).

In the early 20th century, a push for institutionalizing the mentally ill drastically reduced and altered the demographic characteristics of almshouses, leaving the elderly and disabled as the primary consumers of care (Watson, 2009). Demographic shifts occurred once again in 1929 with the crash of the stock market. As Gordon (2014) describes in her history of elder care, there was a drastic increase in demand for already sparse resources in almshouses, resulting in these facilities no longer serving as sustainable vehicles to help all those in need. Programs such as Social Security Administration (SSA) and Old Age Assistance (OAA), were created to supplement community resources that almshouses could no longer provide (Gordon, 2014).

A flood of funding for elder care from the SSA and OAA allowed higher functioning elders to move back to, or remain in, the community (Watson, 2009, p. 942). Alternatively, increased funding led to an expanded market for those who required higher levels of care (Watson, 2009, p. 944). However because only those who were deemed incapable of functioning on their own due to physical limitations, such as an inability to complete activities of daily living (eating, bathing, dressing, toileting, transferring and continence) or cognitive limitations such as, severe dementia were left in these homes owners were forced to provide increased medical services (Watson, 2009, p. 944). This funding led to a drastic increase in facilities, and is noted as the birthplace for the now $124 billion dollar nursing facility industry (Watson, 2009, p. 944; Mahar, 2008).

Despite the increased funding to elder care facilities, these care centers continued to be characterized by impoverished demographics, employed uneducated staff and offered little to no effective nursing services (Watson, 2009). As the older adult population increased, the horrific conditions became publicly evident, resulting in increases in federal regulations (Gordon, 2014). The late 1960s brought about the first wave of government standards for nursing facilities, requiring a full time registered nurse, supervision of meal planning, maintenance of proper medical records and building code requirements (Social Security Amendments of 1967, p. 906-907). Though social workers were not required as members of staff, often social workers in the community were responsible to act as a bridge between the older adults and nursing facilities (Watson, 2009).

While documented by Watson (2009) that social workers were assisting older adults in the community, it is difficult to say specifically how many social workers acted as resource providers, or in facilities themselves. The first challenge in gathering this information is the wide use of the title “social worker” during this time period (Watson, 2009; “Social Work”, 1968). According to the International Encyclopedia of the Social Sciences (1968), in the late 1960s there were a recorded 105,000 social workers in the United States, however only one-fifth had enough training to meet professional social work standards. For the purposes of this paper, an understanding that many individuals were functioning in the role of a social worker, and perhaps calling themselves by this title, skews how involved professional social workers truly were. Secondly due to a lack of requirement for social workers to be members of the staff at nursing facilities, it is difficult to ascertain how many social workers were actually working in these facilities, if any, and what level of training they had (Hartz & Splain, 1997).

It was not until the Nursing Home Reform Act of 1987 (NHRA) (Omnibus Budget Reconciliation Act, 1987) , that a full time social worker became a required staff member for any facility with more than 120 beds. Facilities with less than 120 beds still are required to provide the same level of psychosocial care, which from a social work perspective is defined as recognition, diagnosis, and treatment of mental health conditions, but are not required to employ a full time social worker (Vourlekis et al., 2005).

The NHRA introduced an array of regulations and provisions; the most salient for the social work profession was the inclusion of mental and psychological functioning in the definition of quality of care (Omnibus Budget Reconciliation Act, 1987). Ultimately, what this stipulation meant for nursing facilities was that they had to prove that all residents:

1. Whom displayed mental or psychosocial adjustment difficulty received appropriate treatment and services to correct the assessed problem.

2. Whose assessment did not reveal a mental or psychosocial adjustment difficulty did not display a pattern of decreased social interaction and/or increased withdrawn, angry or depressive behaviors, unless the resident's clinical condition demonstrated that such a pattern was unavoidable. (Omnibus Budget Reconciliation Act, 1987)

Flowing from the NHRA protocols now require that assessments be completed on a regular basis determined by CMS and dependent on the resident's status as a short term or long term resident (Omnibus Budget Reconciliation Act, 1987). These assessments function as check points to track cognitive or emotional changes, however due to lack of staffing and high census numbers, mental health concerns often fall to the wayside, and social workers take on alternate responsibilities making the psychological aspects of their position secondary (DHHS, 2003).

The Medicare Rating System

While evaluations of nursing facilities were required prior to Five Star Quality Rating System, this information was not easily accessible and comparable to consumers in a comprehensive location until the late 2000s (Nursing Home Transparency and Improvement, 2007). In a 2007 meeting of the Senate Special Committee on Aging, regarding the transparency and improvement of nursing homes, Senator Ron Wyden stated "Something is out of whack in this country when it's a lot easier to find information on a washing machine than to find information about long term care facilities" (Nursing Home Transparency and Improvement, 2007, p. 12). The rating system, is partially based on self-reported information from the facility itself (quality measures and staffing), and partially from a state board (health inspection) (Thomas, 2014). For psychosocial measures, however CMS bases the rating on the digital tracking system referred to as the Nursing Home Quality Initiative (NHQI) (CMS, 2014b).

The NHQI has four objectives: regulation and enforcement, consumer information, community & facility based programs, and partnership and collaboration across agencies, organizations and care providers (CMS, 2014b). The information collected under NHQI is recorded into a database entitled the Minimum Data Set (MDS), a digital system that allows for federal monitoring of all medical, therapeutic, and psychological assessments completed in all skilled nursing and nursing facilities (Social Work Policy Institute, 2010; Center for Medicare & Medicaid Services, 2012).

Psychosocial assessments are to be completed with temporary or rehabilitative clients after five, fourteen, thirty, sixty and ninety days of residency at the facility as well as a discharge assessment, while long term residents have a minimum of four assessments per year (more if there is a change in their physical or mental state) (Omnibus Budgetary Reconciliation Act, 1987). Upon admission, readmission or change in status/therapy needs, residents receive a comprehensive examination (Medicare, 2014c). Comprehensive assessments are also completed quarterly at 90 day intervals with all residents (Medicare, 2014c). As part of a comprehensive psychosocial assessment, social services staff are required to present the MDS assessments which includes a Brief Interview of Mental Status (BIMS), measuring cognitive functioning, in addition to a Patient Health Questionnaire (PHQ-9) to assess mood shifts, such as changes in depressive symptoms (CMS, 2014c, C-1-D15). The MDS assessments also assess any changes in ability to communicate, ability to see and hear, evidence of hallucinations or delusions, behavioral concerns and discharge goals (CMS, 2014c, C1-E22,Q1-Q22). Additional parts of the comprehensive assessment evaluate the resident's level of risk to themselves or others, history of abuse/neglect, and their ability to move freely outside of the facility based on cognitive limitations. These parts are not required when completing MDS assessments on fourteen, thirty and sixty day assessments. Once information is entered into MDS, if any specific issues, such as cognitive impairments (i.e. memory loss, confusion), symptoms of depression, or a history of abuse or neglect are entered, MDS triggers what are called Care Area Assessments (CAA) (CMS, 2014c, V-1). These assessments call for further information about the client, and the creation of a care plan that outlines goals and sets a timeline for reassessment (DHHS, 2014). From an outside perspective, these assessments seem to allow for proper monitoring and evaluation of residents. However, in practice, completion of proper documentation is often neglected (DHHS, 2003; DHHS, 2013).

Reality of Care and the Need for Change

According to a Department of Health and Human Services (DHHS) Office of Inspector General (OIG) report (2003), 39% of the resident charts reviewed had incomplete care plans and 46% of individuals with completed care plans did not receive the outlined services. While in a similar DHHS report in 2013 reviewers found that 37% of stays did not meet care plan or service requirements, 26% of stays had no care plans that met requirements, while 31% of stays did not meet discharge planning requirements (DHHS, 2013). The major barriers to completing required documentation and responsibilities were found to be inadequate staffing and time (DHHS, 2003; Social Work Policy Institute, 2010).

The DHHS 2003 report on psychosocial services in skilled nursing facilities stated that 45% of social workers reported that insufficient staff was one of the top barriers to completing their full range of psychosocial services. An alternate study found that, an average caseload for social work directors at facilities with a minimum of 120 beds is made up of 90 or more residents (Social Work Policy Institute, 2010). In addition to the documented staffing deficits, social service staffs are often given tasks that are outside of the realm of psychosocial services. In the same 2003 review by DHHS, 62% of social workers reported that their tasks included items outside of providing psychosocial services, including but not limited to running errands outside of the facility, having eyeglasses repaired and assisting with dining arrangements (p.13).

Despite the preceding documentation that proper psychosocial tasks are not being completed, facilities often do not receive deficiencies on their annual survey, as surveyors have reported that many times they will not go beyond the superficial measure of employing a social worker during surveys unless there has been a complaint (DHHS, 2003). Based on the admittedly small sample taken by DHHS (2003), it is telling that among the thirty-two surveyors that were interviewed they consistently were told that surveyors do not look for deficiencies regarding the provision of psychosocial services. This lack of accountability was critiqued in DHHS 2013 report in which they stated CMS should "increase surveyor efforts…[and] provide more detail guidance to surveyors to improve detection of noncompliance, particularly for discharge planning" (p.17). This lack of consistent enforcement and evaluation of services being provided has allowed for prolonged deficiencies in psychosocial services (DHHS, 2013).

Limited Psychosocial Focus in the Rating System

While the bulk of Medicare ratings are based on staffing levels, health inspections and physical care, there are two aspects of psychosocial care that factor into the star rating, namely: depression levels and rates of psychotropic drug use (Medicare, 2014).

Depression Rates

Depression rates are based on self-reported measures, leaving it to facilities to determine what to code as depressive symptoms (Thomas, 2014). As depression can impact the quality measures rating it is stated that lower rates are better, but lower rates can be misleading (Medicare, 2014c). According to the *Nursing Home Compare* database the national average for depression is 6.1% (Medicare, 2014c). However independent studies have found that depression rates actually stand at roughly 45% (Social Work Policy Institute, 2010). In addition, the Center for Disease Control and Prevention (2014) found that 49% of users of long term care in the United States had documented diagnoses of depression. The gap between 6.1% and 49% suggests that documenting depression rates is not consistent across the nation, and that these assessments are not accurately identifying depressive symptoms.

Psychotropic Drugs

The second aspect of the *Nursing Home Compare* system addressing psychosocial care is the use of psychotropic drugs (Medicare, 2014c). The term "psychotropic drugs" is an umbrella term for a range of medications including anti-psychotics, anti-depressants, anti- anxiety medications, mood stabilizers and ADHD medications (National Alliance on Mental Illness, 2015). While psychotropic medications can be effective for those who suffer from diagnosed mental health conditions, one major use of these drugs in nursing facilities is reducing the behavioral symptoms often related to dementia, such as wandering, outbursts or anger linked to confusion (American Society of Consultant Pharmacists, 2014). For older adults, however, psychotropic drugs have been proven to be disorienting and, in some cases, deadly.

More specifically for older adults diagnosed with dementia, there is a drastically increased risk of severe harm (Lindsey, 2009; Jaffe, 2014). This risk is so great that the FDA has required a label on antipsychotic medication warning of an increased chance of death for those suffering from dementia-related psychosis (Coggins, 2012). Alternate side effects are weight gain, metabolic distress, type 2 diabetes, dyslipidemia, an increased chance of suffering from a stroke, and a decline in cognitive functioning (Coggins, 2012). According to the American Society of Consultant Pharmacists (2014), the use of these medications for behavioral management alone and for long periods of time at high doses can be harmful, deadly and demonstrate a facility's focus on what methods are least challenging for their staff, and not what is best for the resident**.** The push to reduce the use of these drugs by the Center for Medicare and Medicaid Services is an outstanding measure that continues to be absolutely necessary, as these drugs can be inappropriately used, and have the potential for severe harm (American Society of Consultant Pharmacists, 2014). However, it is essential, that in scaling back these medications, a safety net of consistent social service support is established.

Following the logic that a facility was unable to care for the resident without pharmacological behavioral management, it is not unlikely that as these residents begin to wean off medications, that the behaviors that staff were initially unable to manage, will begin to present once again. In fact, one study found that behavioral symptoms may worsen after medication is stopped (Declercq et al.; Petrovic, Azermai, Vander Stichele, De Sutter, van Driel, & Christiaens, 2013). Some researchers have found that non-pharmaceutical interventions such as massage or touch therapy, music therapy, as well as behavior management techniques such as keeping a strict routine, positive reinforcement for behaviors, progressive muscle relaxation, and cognitive behavior therapy, have had preliminary success with managing dementia related behaviors (O'Neil, Freeman, Christensen, Telerant, Addleman, & Kansagara, 2011). Without a trained, supportive and available professional team to practice these behavior management techniques, it is reasonable to believe that staff may once again become overwhelmed with these behaviors. As a result unless social service staff are provided with the training/resources/support needed to complete their duties and provide increased support to residents there is a high potential for negative treatment of residents.

Psychosocial Care Improvements

As established throughout the course of this paper, the five star rating systems has become a motivator for facilities focus on care, as a measure to increase funding, and while there are numerous valid critiques of the rating system, it is still recognized as a valid way for consumers to compare nursing facilities (Thomas, 2014; Medicare, 2014a). Due to the power *Nursing Home Compare* has in shifting focus, there are several measures for psychosocial care that should be considered during future updates. A sampling of possible measures are: the length of time spent with residents during assessments and/or for one-on-one meetings, number of discharge plans completed, number of care plans created and completed.

A second policy that must be carried out to ensure the proper delivery of psychosocial care is staffing level increases and educational requirements. As stated in OBRA (1987) facilities with less than 120 beds are not legally required to employ a social worker full or part-time, but are mandated to provide all required psychosocial care, and those with 120 beds or more are required to have only one. This lack of staffing in combination with a lack of time burdens social service works, creating barriers to care, and therefore violation of OBRA's intent. The latter piece to this policy improvement is an increase in educational requirements. Though social workers are not the only profession that can provide adequate psychosocial care, social workers are specifically named in OBRA (1987), and the social work Code of Ethics, closely corresponds to OBRA's mission of providing an environment, which fosters dignity and self- determination for all residents (National Association of Social Workers, 2008; Zhang, Gammonley, Paek, & Frahm, 2009). Currently, however, only 68% of facilities employ an individual with a degree in social work, and only 47% of those social workers are licensed to practice, which stands in contention of the National Association of Social Workers standards for Long Term Care (Social Work Policy Institute, 2010).

Conclusion

Examining the history of elder care in the United States reveals the array of improvements the system has gone through since the beginning of the twentieth century; yet, it also brings to light the continued lack of enforced regulations. Regulations presented to advance the overall health of elders in long-term care, are often swept to the wayside due to the rating system's lack of focus on psychosocial care. This non-psychosocial focus has led to incomplete documentation of residents' mental states, subpar clinical assessments and inconsistent treatment from social service staff. As the nation is moving toward recognizing mental health as a part of overall care, equal to that of physical health, it is essential that the evaluation systems on which facilities are rated reflect this national shift. In augmenting the system to place a higher and more in depth focus on clinical work, facilities will be pushed to provide greater funding, and resources to ensure that their facility does not lose a high rating due to a disinterest in psychological care.

***Christine Flynn** is an MSW candidate at Loyola University Chicago finishing her degree in May 2015 with a focus in Leadership & Development and Gerontological Education. In addition to her publication in this volume of* Praxis*, she will be featured in the inaugural publication of* Empower Women *with her article We Are Reeds, We Will Rise Again. Her work with older adults at her second year placement in a skilled nursing facility has inspired this research, and her advocacy work to reform long term care. In her personal life, Christine is a Chicago native living with her dog Augustus, an amateur home cook, foodie and blogger.*

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Male Victims of Interpersonal Violence

Allison Garland, Lorena Ornelas, and Stephen Stocker

Abstract

In studying victims of interpersonal violence, the authors of this paper discovered that male victims are disproportionately underrepresented in services, intervention models, research methods and research publications. The complexities and boundaries for male victims are often ignored by domestic violence agencies, courts, police enforcement, mental health professionals and the general public at large. Complexities include gender stereotypes, stigma, male socialization and masculinity tropes. The characteristics and symptoms associated with male victim of interpersonal violence will be discussed.

Keywords: domestic violence, gender socialization, help-seeking, interpersonal violence, intimate partner violence, male victims, masculinity, social work practice

Introduction

There is no question that intimate partner violence (IPV) against women is a serious societal issue. Former U.S. Surgeon General Dr. C. Everett Koop has called it women's number one health problem (Cook, 2009, p. 1). According to the National Coalition Against Domestic Violence (2007), 85% of victims of domestic violence are women, 1 in 5 women have experienced severe physical abuse by an intimate partner, and intimate partner violence (IPV) is most common among women ages 18-24. Additionally, 72% of all murder-suicides involve an intimate partner and 94% of these victims are women (National Coalition Against Domestic Violence, 2007). However, in researching victims of IPV, the authors of this paper aim to show that men and boys represent a substantial amount of victims and are disproportionately underrepresented in services, intervention models, and research publications. The complexities and boundaries to services for male victims are often ignored by domestic violence agencies, courts, police enforcement, mental health professionals and the general public at large. For the purposes of this research, the focus will be on the complexities associated with male victims of IPV including gender stereotypes, stigma, male socialization, and masculinity tropes.

A Note from the Authors

In researching interpersonal violence, the authors of this article found the terms domestic violence and interpersonal violence are often used interchangeably. From this point forward interpersonal violence (IPV) will be used to refer to violence between members of intimate relationships and family violence. It should also be noted the authors of this article recognize gender is not a binary concept and all gender identities should be recognized, respected, and allowed access to interpersonal violence services. However, the focus of this article will be on victims of interpersonal violence who identify as male.

Defining Interpersonal Violence Against Males

The U.S. Department of Justice (n.d) defines interpersonal violence, as "a pattern of abusive behavior in any relationship that is used by one partner to gain or maintain power and control over another." This can include physical, sexual, emotional, economic, or psychological actions or threats of actions that influence another person including behaviors that intimidate, manipulate, humiliate, isolate, frighten, terrorize, coerce, threaten, blame, hurt, injure, or wound someone (United States Department of Justice, 2014). Intimate partner violence is an issue that affects people of all genders and all ages (Tsui, 2014). Although IPV is often used synonymously to describe spousal abuse, family violence can include children, siblings, elders, and partners (Tsui, 2014). According to Centers of Disease Control and Prevention (2014), "the term 'intimate partner violence' describes physical, sexual, or psychological harm by a current or former partner or spouse" (p. 1). There are four main types of intimate partner violence including physical violence, sexual violence, threats of physical and/or sexual violence, and psychological and emotional violence (Saltzman, Fanslow, McMahon, & Shelley, G.A., 2002). The World Health Organization (2014) defines interpersonal violence as "violence that occurs between family members, intimate partners, friends, acquaintances and strangers, and includes child maltreatment, youth violence (including that associated with gangs), violence against women (for example, intimate partner violence and sexual violence) and elder abuse" (p. 2).

Intimate partner violence can be perpetrated by both females and males. In female perpetrated assault, the male victim is more likely to be kicked, slapped or have objects thrown at him (National Coalition Against Domestic Violence [NCADV], 2014). Reports show that, in male-perpetrated assaults, the male victims are more likely to be strangled, beaten with closed fists, and threatened with guns or other weapons (NCADV, 2014). Some commonly published statistics include: 40% of gay and bisexual men will experience abuse at the hands of an intimate partner, 86% of adult men who are physically assaulted were physically assaulted by a man, and 70% of adult men who were raped were raped by a man (NCADV, 2014).

Gender Aspects

The relationship between gender and IPV is a controversial topic. There continues to be debate about the rates at which males and females are subjected to IPV as well as given access to IPV services. It is a commonly held belief that the domestic violence movement originated from feminist theory positing that domestic violence is a result of a patriarchal and male dominant society. For instance, according to a special report done by Stop Abusive and Violence Environments (2010), a non profit victim advocacy organization for IPV legal reform, shows how "men who seek services are sometimes ignored, ridiculed, and even accused of the crime to which they have become unwitting victims" (p. 1). There are several theories on why male victims are often not examined in commonly used domestic violence data resources. Some researchers claim there is not enough research done on male victims to include them in the currently published studies. Bruce Watson (2010) states that the information on IPV against men is unreliable because of the lack of funding to study the problem. The largest single source for IPV research funding, the Department of Justice, has explicitly refused to fund studies on IPV against men in the past because it dispenses funds through its office on violence against women (Watson, 2010). However, Tom Golden (2014) argues that the research on male victims is done but ignored. According to Golden (2014), IPV is complex: women can be perpetrators and males can be victims, but that fact is often ignored by the larger society. Golden argues that activist, clinicians, the media, academics, and researchers are only telling half of the story of IPV (2014). For Golden, the research on male victims is done but major information sources like the Associated Press only mention the female victims, neglecting the male victims (National Coalition for Men, n.d.).

Research Discrepancies

According to a 2010 national survey by the Centers for Disease Control and Department of Justice, more men than women were the victims of intimate partner violence and over 40% of severe physical abuse was directed at men (Hoff, 2012). Despite this finding, there are many more services available to female victims of IPV than services available to men (Hoff, 2012). In regards to physical abuse, the National Intimate Partner and Sexual Violence Survey (NISVS) released in 2011 showed that an estimated 5,365,000 men and 4,741,000 women were victims of intimate partner physical violence in the past 12 months (Hoff, 2012). However, the earlier published National Violence Against Women Survey (NVAWS) estimated that 1.2 million women and 835,000 men were victims of intimate partner physical violence in the preceding 12 months (Hoff, 2012). Whether or not researchers choose to document one finding in favor of the other, there is a clear discrepancy in reports on the rate of physical violence victimization towards men and women.

A sizable gap in the research occurs when the number of female victims is cited as being either 4, 741,000 or 1,300,000 and the number of male victims is either 5, 365,000 or 835,000. How do researchers and advocates account for this significant difference? Researcher and spokesperson for the National Organization for Men Against Sexism (NOMAS), Michael Kimmel (2002) states that "a serious debate has erupted among activists, activist organizations, and individuals about the nature of IPV and, especially, the gender of the perpetrators" (p. 1333). On one side of the debate, numerous studies report the dominant view of male perpetrators of domestic violence against women (Kimmel, 2002). However, other empirical studies suggest that rates of domestic violence by women and men are equal (Kimmel, 2002). Kimmel sheds some light on how such a discrepancy could occur. Kimmel explores advocates' claims of gender symmetry in interpersonal violence by reviewing the empirical research on domestic violence (Kimmel, 2002).

According to Kimmel (2002), there are nearly 100 empirical studies and reports suggesting that the rates of domestic violence between men and women are equivalent. However, the research does not necessarily prove gender symmetry in victims of domestic violence (Kimmel, 2002). On the contrary, the huge gaps in research findings could be due to a lack of explanation of source data (Kimmel, 2002).

Research Tools

The rates of IPV are measured using several data collection methods including questionnaires, surveys, police statistics and many more. However, the vast majority of the aforementioned 100 empirical studies stating an equal rate of victimization between men and women used the Conflict Tactic Scales as the sole measurement tool for the studies. The Conflict Tactic Scales (CTS) was created by Murray Straus in 1979 and is the most widely used instrument in research on family violence (Archer, 2009). One of the arguments for the inaccuracy of the CTS is that it assumes IPV is the result of an argument (Archer, 1999). For example, the opening line of the CTS states "No matter how well a couple gets along, there are times when they disagree, get annoyed with the other person, or just have spats or fights because they're in a bad mood or tired or for some other reason" (Kimmel, 2002, p.1341). This opening statement suggests that domestic violence is the result of a conflict as much as an effort to control or maintain control over another. Secondly, the CTS simply count acts of violence without any account for circumstances, context, or who initiated what (Archer, 1999). Furthermore, the CTS do not measure sexual assault (Archer, 1999). In response to the many concerns of the CTS, the CTS2 was created to account for context and severity of injury as well as seven types of sexual assault (DeKeseredy, W. & Schwartz, M.D., 1998). However, neither the CTS nor CTS2 measure psychological, emotional, and economical abuse (Archer, 1999).

In addition to the CTS, the use of crime victimization studies may contribute to research differences (Kimmel, 2002). Crime victimization surveys are compiled from statistics and questionnaires using large sample sizes (Kimmel, 2002). For example, the National Crime Survey and the National Crime Victimization Study compile data annually on 60,000 households (Kimmel, 2002). These large samples include questions about a wide array of assaults involving current and ex spouses and partners. However, these large data sets only ask about events reported to authorities as a crime and miss events not perceived as and/or reported as a crime (Kimmel, 2002, p. 1338).

It has also been shown that male survivors need help just as much as their female counterparts but are less likely to seek treatment. Why is this? The problem then becomes, how do social workers serve these individuals? The research for interventions and treatment is limited. Without proper evidence based interventions, it is possible that social workers are not asking the right questions, leaving the abuse invisible, doing more damage than good when treating male survivors. The following case example might help to better understand the obstacles that victims of interpersonal violence and their acting social worker may face.

Case Example[1]

Paul was a 21-year-old Caucasian heterosexual male. He was admitted to an emergency room after being sexually and physically assaulted by his male cousin. He had just recently moved to Chicago and his cousin was his main support network in Chicago. He reported various concerns about sexually transmitted diseases and requested to speak with a therapist. When the crisis therapist spoke with him, it became clear that the situation was quite complex. Paul was highly anxious, tearful, and frequently spiraling into emotional deregulation. He was traumatized and in a crisis.

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[1] The case example was an amalgamation of two patients seen by one of the authors in an emergency room setting. It is an amalgamation to maintain anonymity and respect for the patients.

Paul detailed his concern that he might need prophylaxis to treat any possible diseases. He then discussed with the crisis therapist his concern about being gay. He was startled because he was aroused during the sexual assault. He asked for specific services and treatment regarding these feelings. He then detailed his fear of returning home. He currently lived with his cousin and had nowhere else to stay. Paul's anxiety began to grow as he talked about the fear of telling his parents. He was concerned about how they would react so Paul and the crisis therapist discussed how to calm his anxiety.

Lastly, the crisis therapist informed Paul that a police officer would visit the room to file a police report, which raised Paul's anxiety level. Paul explained his concern that the police officer might judge him. After helping to lower his anxiety levels, the therapist explained to Paul the pros and cons of filing a police report. The crisis therapist let Paul know that he would return with information and referrals after speaking with the doctor. The doctor was a male resident and had worked at the hospital for about four months. The doctor had a very passive attitude about Paul's needs. The crisis therapist educated the doctor on assaults happening to everyone, hence the need to help Paul.

The crisis therapist returned to his desk and processed Paul's needs and assessed what services might be most relevant and helpful to him. Paul needed therapy focused on surviving sexual and physical assault, housing, prophylaxis, a family meeting, and more education on the legal process for assault. The crisis therapist went through the referral database; however, all the information and referrals were geared toward assisting female survivors. The crisis therapist changed the handout verbiage to gender-neutral language but was not able to find any referrals. The crisis therapist was trying to avoid creating another crisis for Paul. The crisis therapist returned to Paul with the gender-neutral information, a referral to a therapist with a sexual assault focus (although female based), suggested requesting a family session with the therapist, and problem solved with Paul on where he could stay. Paul chose to spend the night in a hotel until his friend from his hometown arrived the next day. The crisis therapist ended the interaction feeling concerned and unnerved by the unavailability of resources.

Forced Silence

It is often difficult for survivors of sexual violence to come forward and report their assault. Our culture often sees perspectives in an either/or framework (good cop/bad cop; male/female; Republican/Democrat), and it trickles down into our gender socializations where girls are emotional and submissive and boys are stoic and aggressive. When a person visualizes a victim or an aggressor, they may revert to binary assumptions and assume the victim to be female and the aggressor to be male. This assumption obscures the truth about male victims of sexual violence and suppresses the likelihood that male and non-female identified genders will get assistance in dealing with assault. According to the 2000 National Violence Against Women survey (as cited in Tsui 2014), approximately 1.5 million women reported intimate partner violence (IPV) in their relationships in the United States. However, 835,000 men also reported intimate partner violence (Hoff, 2012). It appears there are half as many men reporting IPV than women, which challenges the assumption that only men are aggressors.

Understanding that IPV is non-gender specific allows us to see the shared effects of all victims regardless of gender identification. For example, interpersonal violence has a bearing on relationships and intimacy and is likely to cause long-term emotional, physical, and psychological effects such as depression, withdrawal, avoidance, and possibly post traumatic stress disorder (Rape Victim Advocates Training Power Point Presentation, *"Masculinity and Male Survivors",* n.d., p. 6/17*).* While there are commonalities across the gender spectrum, there are damages male identified victims experience—questioning their sexuality and masculine identity, worries about the believability of their claim— that are specific to their assault. Among the many problematic aspects of traditional gender norms is the way in which masculinity is constructed, perceived, and inhabited both by survivors and the society in which they live. As stated by Lisak (1994), among the 26 interviews conducted with adult male survivors of childhood sexual abuse, feelings of masculine inadequacy were reported. In these interviews, there seems to be a struggle to recognize they were abused and this abuse had long-term effects. There is a struggle for legitimacy in these experiences. Another problematic aspect of gender stereotypes is that society often does not see men as victims.

Consequently, the victims themselves do not identify as such. In the case of "Paul," after experiencing sexual assault, he was unsure if he was a victim since his aggressor was male. The situation was further complicated by Paul questioning as to whether the assault now made him gay. The fact that he reported the assault is remarkable, as the data presented above illustrates, too few men come forward and admit to being sexually assaulted.

In line with shifting our perceptions of gender and interpersonal violence, it is necessary to remember that there is no perfect model of what a victim or an aggressor looks like. Understanding that IPV is non-gender specific allows us to see the shared effects of all victims regardless of gender identification. For example, interpersonal violence has a bearing on relationships and intimacy and often causes long-term emotional, physical, and psychological effects for all victims.

While there are commonalities across the gender spectrum, there are damages male identified victims experience that deviate from the seeming parallel. Among the many problematic aspects of traditional gender norms is the way in which masculinity is constructed, perceived, and inhabited both by survivors and the society in which they live. As stated by Lisak (1994), among the 26 interviews conducted with adult male survivors of childhood sexual abuse, feelings of masculine inadequacy were reported. In these interviews, there seems to be a struggle to recognize they were abused and this abuse had long-term effects. There is a struggle for legitimacy in these experiences.

Another problematic aspect of gender stereotypes is that society often does not see men as victims. Consequently, the victims themselves do not identify as such. In the case of "Paul," after experiencing sexual assault, he was unsure if he was a victim since his aggressor was male and was further complicated by his questioning whether the assault now made him gay. The fact that he reported the assault is remarkable, as too few men come forward and admit to being sexually assaulted. Is this silence forced upon them by society's assumption that victims of IPV are usually women?

Implications for Practice

Considering the challenges of interpreting research and the lack of reported data, it can be assumed there are more men who experience IPV than is currently reported. Therefore, a consideration for social work practice is conscious normalization that IPV happens across the gender spectrum. Such a shift in perspective will help all people who present with both psychological and physical injuries consistent with IPV access the care they need. Therefore, detailed below and further are ways to expand and shift perspectives.

Common Responses

Looking again at the case of "Paul," one sees a unique issue among male survivors, the questioning of his sexual expression following the assault. The experience makes him feel less of a man and he fears the assault may turn him gay. Like "Paul," other heterosexual males express this question, which is again due to gender socialization in our society. Gay male survivors may interpret the assault as a retribution for their lifestyle or their sexual orientation. Male victims may not seek emotional and psychological support not only because the services are limited, but they fear a response that attempts to shame or discredit their sexual expression.

A further complication to the assault is that human bodies may experience involuntary physical arousal so many individuals mistakenly believe that they may have enjoyed the assault, or even asked for it (Rape Victim Advocates Training Manual, n.d., p. 45/117). For men assaulted by other men, there is additional shame in feeling they should have had the strength to fight off their attacker. With the common misperception that men are not supposed to lose control of a situation, they may feel emasculated and ashamed. In instances of heterosexual male victims of assault committed by women, there may be a tendency to disbelieve the assault occurred or that they may have deserved it. Such disbelief from the greater community minimizes the experiences of the male identified victim and creates a barrier to services and emotional and psychological support (Tsui, 2014).

The psychological aspects that male survivors of IPV experience need more attention. Women often receive both physical and psychological treatment after an assault, but men only receive physical treatment for their injuries. This lack of services leads to further psychological trauma and a clear indication of the marginalization of men as victims of IPV. By not offering holistic treatment, male victims of IPV are being re-victimized. In addition to physical treatment, there should to be an inclusive, supporting environment that allows for emotional and medical care.

The under reporting of male sexual assault is a major public health concern. Domestic violence shelters and advocacy agencies are mostly set up for women, leaving out other gender identifications. A challenge to the social work profession is to close this gap of services to include everyone who experiences domestic assault, not just the traditional prototypes of IPV victims. Men are socialized to use anger to respond to feelings of shame and sadness, denying them the ability to express emotions that are often categorized as female emotions. Feelings of anger, coupled with the lack of emotional expression, contribute to the limited services offered to male victims of sexual assault (Rabinowitz, Cochran, 2006).

Considering the inadequate services for male victims of interpersonal violence, it seems sensible that men are often silent about their experiences. The gendered assumptions about interpersonal violence need to be challenged to include all survivors. It is terrifying to think about anyone encountering this form of violence, but it is more terrifying to consider how many males never come forward to address their abuse.

Theories and Treatment

"Paul's" case helps to illustrate the gaps in services and interventions for male survivors. "Paul" was motivated for treatment but the gender paradigm in place hindered him from seeking services. The gender paradigm details that individuals act within predetermined stereotypes of their gender (Kia-Keating et al, 2010). The male gender stereotypes are often emotionally restrictive, "able to handle it on your own," and the belief in machismo (Kia-Keating et al, 2010). Although "Paul" had already taken a step in the right direction by seeking treatment at the emergency room, he did have a moment of ambivalence and took a step back and showed his participation in the gender paradigm. He did not want the police officer to judge his current circumstances because he thought the situation was emasculating. Considering the gender paradigm, social workers need psycho-educational descriptions of feelings that are related to specific events that denigrate personal will, agency, and self-esteem. To expand, there needs to be more research to provide educational materials that do not adhere to strict gender stereotypes. The provision of more gender inclusive materials and resources will assist social workers to be more knowledgeable when working with clients.

In "Paul's" case, falling in line with the gender paradigm, the doctor was passive about his treatment needs. The doctor seemed to operate with the gender stereotype that the patient needed to "man up." Furthermore, the crisis therapist had a difficult time finding resources for "Paul". Most women who come to an emergency room for interpersonal violence are referred to a domestic violence shelter. However, this service was not available for "Paul". The role of social work is to provide services to those in need, to seek social justice, and empower clients (National Association of Social Workers, 1999). In this case, the crisis worker was unable to adequately serve "Paul".

More inclusive treatment could help this population. There is some research regarding gender-inclusive treatment, which Annandale and Riska (2009) define as the belief that men and women have a need for gender-neutral assistance in regards to health. Gender-neutral language could help eliminate the concern that there are no interventions available, as more theories become available for men. As the crisis therapist did for "Paul", making treatment language gender neutral could help to include all who need services regardless of their gender identity. A non-gender exclusive treatment approach will help ensure that others like Paul will be more willing to seek services. Additional research could examine interventions that are geared toward the specific needs of other gender identities . Until additional research happens individuals like "Paul", crisis therapists, and emergency room staff will be left to struggle with an uphill battle.

Conclusion

The current research, although limited and hidden, shows the need to address and assist male survivors of IPV. It has been shown through statistics and research that this population is anything but miniscule. Male survivors have many societal impediments to 1) admitting an assault and 2) the need for assistance. Male survivors will continue to minimally seek assistance or admit to victimization until additional research is done, society accepts it is occurring, services are provided, and evidence based interventions provided.

Allison Garland *received her Master of Social Work degree with a specialization in Mental Health from Loyola University Chicago in 2014. She completed a majority of her practicum training in an inpatient setting working with clients suffering from psychotic disorders who were found Not Guilty by Reason of Insanity. Prior to graduate school, Garland received her Bachelor degree in Political Science from the University of Memphis in her hometown of Memphis, Tennessee. During her undergraduate career Garland spent a semester in Washington D.C. serving as an intern at N Street Village, the largest provider for women-only services in D.C.'s homeless population. Watching the women of N Street Village persevere through multiple challenges including mental illness, addiction, trauma and interpersonal violence she discovered her desire to pursue a career in social work. Allison currently works as a social worker and therapist in an acute psychiatric hospital in Chicago, Illinois.*

Lorena Ornelas *is a dual Masters degree student at Loyola University Chicago with a specialization in Mental Health. In addition to her MSW, she received an MA in Women's Studies and Gender Studies. She has certified training in domestic violence and sexual assault advocacy and is currently completing CADP training for Partner Abuse Intervention group co-facilitators. Her first internship was with Deborah's Place providing counseling with a trauma- informed, feminist focus to survivors of domestic violence, homelessness, and substance abuse. Her second internship was as a counseling intern with the Lycée Français de Chicago teaching a socioemotional curriculum, providing individual counseling and group facilitation with K-12 students. She is a first generation college graduate whose research interests include violence against women and working with communities of color. Lorena hopes to work with children of immigrants dealing with ambiguous loss related to grandparents, migration, and identity formation.*

Stephen Stocker *is currently a Master of Social Work student with specializations in Mental Health/Health care at Loyola University Chicago. Stephen received his undergraduate degree from Indiana University Purdue University of Indianapolis in Psychology. Stephen currently is an intern at an inpatient psychiatric unit doing social work and therapy. Stephen also works part time as a crisis worker in an emergency room hospital in Chicago. Stephen has an interest in acute mental illness and interventions to address this population.*

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A Case Against Remission:

A Rhetorical Critique of the DSM-5

Paige Gesicki

Abstract

The purpose of this article is to examine the power of language, with particular attention to how diagnostic terms can negatively impact someone who is diagnosed with major depressive disorder. The DSM-5 uses the term "remission" to describe a patient whose depressive symptoms are lessening. This writer argues that by categorizing someone who no longer has depressive symptoms as "in remission", instead of simply removing their diagnostic label completely, the person is subsequently tied to his or her diagnosis longer than necessary. Considering the unfortunate stigma associated with mental illness, tying someone to their diagnosis permanently may cause them to internalize the pathology instead of fully identifying with recovery.

Keywords: depression, DSM-5, language, depression, narrative theory, remission

Introduction

If "language is where power is embedded and where the struggle for emancipation can occur," perhaps the right language could emancipate someone from a stigmatizing mental health diagnosis, or even the emotional turmoil itself (Crawford, Johnson, Brown, & Nolan, 1999, p. 338). Often, words are too removed from lived experience to adequately describe the intricacies of human emotional phenomena. However, language, a socially constructed system of symbols, is the primary way that humans attempt to communicate their experiences, including a pervasive mood state such as major depressive disorder. Unlike disease states of the physical body, the presence of major depressive disorder lacks easily observable and agreed upon biological markers and is therefore difficult to diagnose through physical symptoms. Currently, the means of detecting depression are limited to subtle molecular and neural changes that are complicated to read and not yet unanimously agreed upon (Krishnan & Nestler, 2010). Thus, the path of major depressive disorder, from its onset through recovery, is often tracked through verbal and written accounts—the development of the illness is relegated to the malleable world of words.

When considering the importance of language as it pertains to mental health, it makes sense to start by examining the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), the canonical text on mental health diagnoses. Mental health professionals refer to this comprehensive list of diagnostic criteria in the DSM-5 to diagnose individual psychopathologies. Diagnoses are helpful to clinical work because they provide a standardized description of the individual's "problem" which thereafter guides clinical treatment (Ishibashi, 2005). This article will examine how the language of the DSM-5 shapes an individual's experience of his or her mental health state.

This article uses the rhetoric-centric perspective of narrative theory to examine the validity of the language used in the diagnostic criteria for major depressive disorder diagnosis in the DSM-5 with particular attention to the term "remission." According to narrative theory, language is a social construct that has the powerful ability to generate meaning in our lives—essentially, the story we hear about ourselves affects the story we tell ourselves, thus creating our reality (Coady & Lehmann, 2008). Narrative theory promotes paying rigorous attention to an individual's word choice and phrasing; this article recommends applying these same rhetorical standards to the widely used DSM-5. This article questions whether the term "remission", defined as symptom resolution, should be included in such a prescriptive text as the DSM-5 which, because of its widespread medical authority, has the power to affect a diagnosed individual's sense of self.

This article argues that remission is an inappropriate and potentially harmful term to describe a person's relationship to major depressive disorder for numerous reasons. First, measuring recovery on the basis of a decrease of negative symptoms on a standardized list (a score of less than 7 on the Hamilton depression rating scale[1]) is problematic because major depressive disorder cannot be measured objectively, and "in the absence of biological markers of the disease state, remission from depression has been defined phenomenologically" (Zimmerman, McGlinchey, Posternak, Friedman, Attiulah & Boerescu, 2006, p. 148). Additionally, "remission" is an idea constructed by a medical and mental health team, yet studies show that people who have actually experienced depression believe that this definition does not accurately reflect the lived experience of recovery, which is less about the absence of negative symptoms and more about the presence of positive qualities (Zimmerman, et. al., 2006). Finally, and most importantly, since language has the power to affect one's thought and behaviors, diagnosing someone as "in partial or full remission" risks the possibility of that individual feeling permanently tied to his or her pathological diagnosis.

Studying the intersection of linguistic anthropology and social work, Ishibashi (2011) charges clinical social workers with the responsibility of asking, "what influence might the language of diagnosis impose, and how a specific diagnosis, as a label, impacts the way clinicians treat clients" (p. 67). By qualifying someone's recovery as "in remission," the clinician robs the person of his or her ability to be fully healed; the experience of depression is no longer viewed as a transient stage, but instead a fixed state of being or a pathological life sentence.

Considering the prescriptive quality of language when issuing a diagnosis, it is important to look critically at the language used in the DSM-5 and helpful to view the diagnostic manual through the lens of narrative theory, which contends that an individual's problem or condition is socially constructed through language, and therefore the problem can, and should, be resolved through language (Coady & Lehmann, 2008). When applying narrative theory to the experience of clinical depression, the question arises: is it possible to generate a new meaning for the words used in the clinical description of depression, a meaning that is curing and healing instead of incarcerating and heavy? For a narrative theorist, this would entail deconstructing the client's reality and creating a new conversation. As per the theory, it is important to recreate an empowering alternate story through conversation or discourse*,* either spoken or written because language gains power in its exchange with another. For example, leading narrative clinician David Epston writes a summarizing letter to his client after most interviews which serves as a clinical note; in doing so, Epston creates a shared body of knowledge that disperses power between professional and client and promotes an egalitarian relationship (White & Epston 1990). This article introduces two examples where narrative theory mitigates against the potentially harmful effects of being diagnosed with major depressive disorder in remission. These two structured treatments—the clinical practice of narrative theory and mood memoirs—encourage an individual to be the protagonist of his or her own life story.

The Inadequacy of the Definition of Major Depressive Disorder

In the DSM-5, major depressive disorder "represents the classic condition in this group of (depressive) disorders," unifying the other depressive disorders through the common characteristics of "the presence of sad, empty or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function" (American Psychological Association, 2013, p. 155). Because it provides the base for all depressive disorders, major depressive disorder is the most illustrative example and will therefore be the focus of this article. The contrived diagnostic

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[1] The Hamilton Depression Rating Scale (HAM-D), also called Hamilton Rating Scale for Depression (HRSD), is a multiple item questionnaire designed to provide an indication of depressive symptoms in an adult. Using a rating scale to assess level of severity, the questionnaire includes items on mood, feelings of guilt, suicidal ideation, insomnia, agitation or retardation, anxiety, weight loss, and somatic symptoms. Although there are other scales to measure depression, such as Bech's melancholia scale (Bech et.al. 1981) and Gibbons' global depression severity (Gibbons-8), among others, the HAM-D Scale continues to serve as a leading measure of depression, especially in clinical trials that test the efficacy of antidepressant medication (Ballesteros, J., Bobes, J., Bulbena, A., Luque, A., Dal-Re, R., Ibarra, N., Guemes, I., 2007).

language of the DSM-5 attempts to describe the experience of depression in words that are accessible to mental health professionals through standardization of language; however, the words feel too far removed and flat to describe the reality of the psychological phenomenon.

The linguistic shortcomings to describe depression are not limited to the DSM-5. Levitt, Korman & Angus (2000) studied the use of "burden" metaphors used by clients in therapy as they attempted to described their experience of depression. The study acknowledges that the subjective experience was so difficult to verbalize that clients turned to descriptive metaphors in their attempt to "more accurately capture of the quality of an emotion (instead of using) an adjective or an emotional label" (Levitt, Korman & Angus, 2000, p. 24).

Additionally, the word "depression" has become so diluted in mainstream English vernacular that it not only grossly fails to describe the lived experience of a clinical depression, but it also has assumed a distinctly different meaning in its common use. Pulitzer Prize winning author William Styron describes the "semantic damage" of the misuse of the word, which "has slithered innocuously through the language like a slug, leaving little trace of its intrinsic malevolence and preventing…a general awareness of the horrible intensity of the disease..." (Styron, 2010, p. 37). In his memoir, *Visible Darkness,* Styron (2010) describes his frustration with the descriptive limits of language, as well as a brief demonstration of the evolution of words in their social construction; he writes:

> When I was first aware that I had been laid low by the disease (major depressive disorder), I felt a need, among other things, to register a strong protest against the word "depression." Depression, most people know, used to be termed "melancholia," a word which…would still appear to be a far more apt and evocative word for the blacker forms of the disorder, but it was usurped by a noun with a blank tonality and lacking any magisterial presence, used indifferently to describe an economic decline or a rut in the ground, a true wimp of a word for such a major illness. (p. 136)

Styron's memoir is characterized as a mood memoir for its in-depth description of his firsthand account of his depression, which he calls "the disease". Styron demonstrates the healing benefits of externalizing the problem, a strategy that is often utilized in narrative therapy. He successfully used his mastery of language to gain enough distance from his debilitating experience of the mood disorder to write an illuminating first-hand account. According to the DSM-5, Styron might have been characterized as in remission from his major depressive disorder, which would be a treatment success, since experts "suggest that achieving remission of symptoms should be viewed as the primary goal (of treatment)" (Zimmerman, Martinez, Attiullah, Friedman, Toba, & Boerescu, 2012, p. 78). However, in light of his criticism about the limitations of language to adequately describe the complexity of depression, Styron himself would likely not describe his own recovery in the static terms of "remission."

The Questionable Basis of "Remission"

If remission is the primary objective of clinical treatment, the question should be posed: what exactly characterizes remission in the realm of mental health? In 1988, the MacArthur Foundation Research Network on the Psychobiology of Depression organized a conference to review and tighten the definition of many "recovery" terms, including the term remission (Frank, Prien, Jarrett, Keller, Kupfer, Lavori, et al., 1991). After acknowledging the considerable inconsistencies in the views of the course of depression, the task force agreed that remission would thereafter refer to when an individual is asymptomatic for a brief duration, which can occur spontaneously with or without treatment (Moller, Riedel, & Seemuller, 2011). Symptomatic does not mean the complete absence of symptoms. Instead, it is defined as the presence of no more than minimal symptoms, as proven by a score of 7 or lower on the 17-item Hamilton Depression Rating scale (Zimmerman, 2006, p. 148).

Judging a person's recovery on the Hamilton depression rating scale is problematic because the scale has been criticized as an outcome measurement for numerous reasons, including its inability "to define remission with appropriate and empirically derived cutoff points" (Ballesteros, Bobes, Luque, Dal-Re, Ibarra, & Guemes, 2007, p. 94). As stated previously, there are no "empirically driven" biological markers to prove the presence or absence of depression. In fact, the DSM-5 concedes that, "although an extensive literature exists describing neuroanatomical, neuroendocrinological, and neurophysiological correlates of major depressive disorder, no laboratory test has yielded results of sufficient sensitivity and specificity to be used as a diagnostic tool for the disorder" (American Psychological Association, 2013, p. 165).

Across medical fields, if a patient is deemed "in remission" the individual is not necessarily free of the illness or disease at hand; instead, the phrase implies that the illness has abated temporarily and may return; therefore, if someone is diagnosed with depression in full remission, the implication is that they have not experienced any "significant signs or symptoms of the disturbance" in the past two months (American Psychological Association, 2013, p. 188). The DSM-5 relies even further on the measurability of major depressive disorder by providing the additional qualifier of "partial remission," which is when symptoms are present but full criteria are not met for major depressive disorder (American Psychological Association, 2013, p. 188). Thus, it follows that major depressive disorder, according to the DSM-5, is not a transient mood state from which a person can fully recover. Likewise, the grassroots mental wellness advocacy group NAMI, the National Alliance on Mental Illness, defines depression as "a life-long condition in which periods of wellness alternate with recurrences of illness" (Duckworth & Shelton, 2012, p.1).

Although it is true that individuals with major depressive disorder often experience recurring depressive episodes, adding the qualifier "in remission" to the diagnosis, instead of eliminating the diagnosis entirely, pathologizes a person (Duckworth & Shelton, 2012). The individual is now medically regarded as a "depressive in remission" instead of an individual who once suffered or occasionally suffers from a depressive episode. According to narrative theory, "in remission" suggests that the illness will return. This insinuation makes it hard to integrate depression as a past episode of one's life story, due to the looming fear that an episode will return at any given time. Instead of being rid of the pathology altogether, the label remains with a qualifier. In the terms of narrative theory, a client who self-identifies as "in remission" due to the prognosis provided by a clinician provides "life support" and fuel to the problem, therefore keeping the problem alive.

Perhaps an additional problem lies in who has the "last word" in establishing recovery or a lack thereof. In his article entitled "How Should Remission from Depression be Defined? The Depressed Patient's Perspective," Dr. Mark Zimmerman, M.D., strays from the traditional "medical model" in favor of a client-centered perspective, which is traditional to the social work paradigm. He found that patients who deemed themselves free of the depressive state reported that the "presence of positive features of mental health such as optimism, vigor, and self-confidence was a better indicator of remission than the absence of the symptoms of depression" (Zimmerman, 2006, pg. 150). Thus, the experts on the depression, the individuals who experienced it themselves, agreed that the DSM-5's definition does not accurately reflect the lived experience and the imposition of labels, even positive terms such as "remission" can be limiting due to the inequality of power inherent in the act of naming an experience that is not your own.

Implication for Practice: Narrative Therapy & Mood Memoirs

The DSM-5's medical model adheres to a modernist approach, which prioritize objectivity and tend to be more diagnostic in nature, often creating a power dynamic with therapist as expert and client as a subject (Ishibashi, 2011, p. 70); therefore, when a clinician applies a particular diagnosis to an individual, he or she utilizes a rhetorical currency that only privileged professionals can speak with authority, excluding others from the conversation. The resulting power dynamic directly contradicts the National Association of Social Workers Code of Ethics, which states, "Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people *as partners* in the helping process" (NASW Code of Ethics, 2008).

In line with the egalitarian mission of social work, narrative theory is *post*modern, and asserts that reality is socially constructed through language, which is comprised of a formal system of symbols (Coady & Lehmann, 2008). Narrative therapy is a clinical model based on narrative theory, which "emphasizes an elaboration of constraining monologues to liberating dialogues and/or the deconstruction or rewriting of problem-saturated stories to stories of courage, strength, and competence" (Coady & Lehmann, 2008, p. 371). This type of therapy aligns with narrative theory's assertion that language is not an individual endeavor—problems are created through discourse with others and therefore need to be addressed in conversation with others.

This dialogical imperative introduces the second method of narrative healing—the mood memoir. A journal that a writer keeps to him or herself can be cathartic, but explaining an experience in one's own words and sharing that with a willing listener or reader is powerful because of its discourse. Memoirs of depression, such as Joan Didion's *The Year of Magical Thinking,* Kay Redfield Jamison's *An Unquiet Mind* and the aforementioned William Styron's *Visible Darkness* confront mental illness stereotypes and stigmas by providing an alternative, truer story (Kramer, 2005). Through mood memoirs, individuals are invited to externalize depression as a problem to be faced and overcome, instead of an innate character flaw or unavoidable life sentence.

Rhetoric scholar Katie Rose Pryal (2010) describes the "mood memoir" as a literary genre that provides a space for those with mood disorders, who may be otherwise deemed as illegitimate rhetorical sources, to gain power through telling their stories. She argues that "mood memoirs can be read as narrative-based responses to rhetorical exclusion by the psychiatrically disabled" (p. 480). Pryal's work outlines a new genre; however her point about gaining authority through the written word is salient to the idea of empowerment through creating one's own story. Many clinicians outside of the narrative school of thought, such as cognitive behavioral therapists, encourage clients to use journaling as a supplement to treatment in order to clarify and gain ownership over their experiences (Smith, Holcroft, Rebeck, Thompson, & Wekowitch). This illustrates the clinical application of Pryal's (2010) argument that power can to be restored to the individual in treatment through rhetoric.

Conclusion

This article establishes that the term remission in the diagnostic criteria for major depressive disorder is problematic for numerous reasons including its attempt to apply an empirical standard to an unobservable mood disorder, as well as the potentially destructive implication that an individual can never fully recover from depression. Narrative theory aids in the examination of the DSM-5 by providing a lens through which to view the linguistic repercussions of the text. Not only does narrative theory provide a mode to critique the diagnosis, it also offers ways to use language to heal an individual diagnosed with major depressive disorder.

Narrative theory contends that language provides a system for us to make meaning of our experiences. If we are told by a medical professional with privileged vocabulary that we cannot recover from a painful disorder, but instead that we will live in a limbo, vacillating between full and partial remission, we may internalize that story to become our own fate. In order to counteract this loss of agency at the hands of misused language in the DSM-5, narrative therapy and mood memoirs provide empowering autobiographical counter narratives to the stories about mental illness offered by doctors, policy makers, therapists, and the general public.

Paige Gesicki *is an MSW student at Loyola University Chicago concentrating in Mental Health. After receiving a BA in American Studies and Gender Studies from the University of Notre Dame, she worked as a case manager for older adults and grant writer at Catholic Charities in New Jersey. She then moved to San Diego to serve as a family support counselor for foster youth as part of the Jesuit Volunteer Corps. Her first internship at Loyola was with StreetWise, Inc., a street paper employment agency, where she worked as a housing specialist for unstably housed Chicagoans. Her current internship is with NAMI Chicago, the National Alliance on Mental Illness, where she answers a crisis helpline and promotes advocacy and education about mental illness. Paige hopes to combine social justice and clinical work upon graduating.*

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Artesanas Indígenas in Southern Mexico:

An Overview Of Female Artisan Cooperatives and The Role of Social Work

Kelsey Greenwood

Abstract

Indigenous women in Southern Mexico have their work cut out for them; they are expected to clean the house, raise the children, weave/mend the clothes, go to the market, and the list goes on. And before the creation of artisan weaving cooperatives, they did all of this with close to zero personal autonomy. This article explores the significance of the weaving trade in indigenous Mayan culture and the history of the weaving cooperatives. It also identifies the effects of the intersection of the cooperatives, the Zapatista movement, and the Latino culture in general. It speaks to the positive and negative consequences that result from the creation of the cooperatives and the autonomy it provides the female artesanas (artisans). This information is explored through a lens of involvement with Aid to Artisans (ATA), a grassroots organization that coaches indigenous artesanas on how to reap more benefits from the beautiful woven crafts they create through guidance and empowerment. The article showcases the integral role that social workers can play in the implementation of these groups by helping to support the positive changes and ameliorate the negative outcomes that arise. It calls for more involved action by social workers to foster the success of the artesanas and their families through greater, bigger-picture understanding of how women's autonomy can bolster the benefits awarded to each stakeholder involved.

Keywords: artisan, cooperatives, indigenous, international, Latino, social work, weaving

Introduction

Southern Mexico, namely the state of Chiapas and the town of San Cristóbal de Las Casas, is known worldwide for its textiles produced by the *artesanas indígenas,* indigenous artisans of the region. The people who produce the textiles are mostly people of Mayan heritage. Throughout history, the indigenous people of Mexico have been both directly and indirectly discriminated against and exploited by the Spanish conquistadores (Albert, 2008). This discrimination has become so systematized and institutionalized that it is woven into the fabric of their society today, and the native people continue to feel the imbedded effects of the conquistadores' domination over them. Until the Zapatista movement in 1994, the indigenous people were not allowed to walk on the sidewalks (M. Lopez Hernandez, personal communication, June 20, 2014). The Zapatista movement brought recognition to the indigenous struggle, but not all issues were adequately attended.

The indigenous women still struggle to be fully recognized as respected, wage-earning individuals. They are seen mostly as homemakers and child-raisers in their communities. Although they produce the textiles that are praised throughout the world, they face strict gendered expectations, which limit their ability to fully participate in all sectors of the community. Despite these oppressive expectations, they have gathered together to form artisan cooperatives and assert their rights as artisan women.

This article reviews the literature surrounding these cooperatives and the issues the indigenous women of southern Mexico face when implementing and maintaining these grassroots organizations. It makes a case for how social workers could help improve the social conditions in which these groups function. It offers several examples and suggestions for how the social work profession could be more involved with artisan cooperatives, including combating issues such as gender inequality, group dynamics, structural violence, and the challenges with conducting program evaluations. It also highlights social workers' ability to apply cultural sensitivity throughout this process. It provides the reader with specific ways to be involved in this type of work, and calls for greater organization at the local level to implement the proposed changes.

Situating the Knowledge

The author is a second year social work student completing an internship in San Cristóbal de Las Casas in Chiapas, México, working toward her Masters degree through Loyola University Chicago. The author interned with Aid to Artisans (ATA), a worldwide organization that empowers local artisans and helps them strengthen their business strategies by teaching individual cooperatives new techniques and designs, and trains certain members to be leaders and representatives. ATA stays for three to five years in the regions it gets involved. During that time, they provide artisans with the tools and knowledge they need to carry out their own negotiations with public and private clients. Although there are no social workers on staff, the employees embody and practice core social work values, such as worth and dignity of the person, competence, importance of human relationships and social justice (National Association of Social Workers [NASW], 2008). They operate from an empowerment, educational, and strengths-based perspective.

The author had the opportunity to interview thirty cooperative groups in the municipalities surrounding San Cristóbal about the impact that ATA has made on their artisan work in the last two years. She took this chance to speak with these incredible women to inquire about their daily struggle as an indigenous people. This literature review includes portions of these interviews in order to provide supplemental insights into the current issues they face.

While it has been difficult to truly come to know and understand these women and their situation within the span of two months, the author learned a lot about their culture and practices. Working with ATA provided a unique position from which to meet these incredible women; the author was able to visit them at their homes, witness their learning of new techniques and designs, and attend workshops with them on how to tailor their goods to be more attractive to consumers around the world. The learning happened side-by-side, as the author inquired about their work and they inquire about life and customs of people in the United States. It was truly a reciprocal and inspiring partnership.

Importance of Weaving Culture

Weaving dates back more than a thousand years, and anthropologists have found archives that depict the role weaving played throughout history (Brumfiel, 2006). In classic Mayan heritage, weaving defined class. In Aztec Mexico, different weaving patterns or styles signified specific gender identities. In twentieth century Mesoamerica, weaving classified ethnicity (Brumfiel, 2006). Back-strap weaving is the oldest form of weaving and remains the main type of weaving that is practiced by the indigenous cultures in Chiapas today (E. Lardo, personal communication, July 2, 2014). Back-strap weaving involves strapping the loom around the waist and tying the other end of the loom high up on a post or stronghold. The weaver either sits or kneels as she manipulates the threads. The work is very taxing on the back, legs, hands, and eyes, but produces very sturdy fabric. The significance of this ancient practice can be seen through its preservation throughout the centuries.

Some of the symbolic meaning has been lost in the expanse of time. For example, when the author attended an embroidery workshop in San Andrés Larrainzar, a municipality outside San Cristóbal, the women were presented with a long cloth that contained many different symbols. When asked about their meaning, the indigenous weavers only knew what a few of them actually depicted. Additionally, when Chip Morris, an expert in Mayan textiles and co-founder of Sna Jolobil (an 800-member weaving cooperative in San Cristóbal), arrived in Chiapas in 1972, he found that the meanings of the textile symbols were nearly lost (Mayan Exploration Center, 2014). His research during the last forty years has focused on resurrecting the meaning of the ancient symbols.

Globalization plays an enormous role in the importance of the weaving tradition. Cultural tourism is on the rise (Edwards, 2009) and with it the demand for authentic handmade textiles from southern Mexico. Edwards (2009) refers to the changing economy and focus on the importance of local artisans following the economic crisis of the late 1980s, when she says that "the growth of cultural tourism has resulted in increased commercialization" (p. 21). The increased global interest in handmade textiles over the last few decades has not only heightened the number of artisans participating in the trade, but also the need for social organization. Some might argue that this heightened attention on textiles and the increased participation by weavers dissolves the true meanings of the designs, as many weavers do not know the symbolism and cannot pass it down to younger generations. Others might argue that the heightened interest awakens people such as Chip Morris, and more attention is focused on restoring this ancient and sacred practice.

Due to this increased focus, native textiles from Latin America have become more popular in the international market, with increased sales in Europe and Australia (E. Lardo, personal communication, July 21, 2014). This popularization caused shifts in the production of this art, creating a ripple effect on the social fabric of the artist's lives. In response to these changes, autonomous artisan cooperatives have formed over the last thirty years, allowing for more formalized access to the global market. The cooperatives are present in most parts of Mexico and other second- and third-world countries as well (Aid To Artisans, n.d.). So what do these weaving cooperatives look like and how to they function?

Overview of Artisan Cooperatives

Stephen (2005a) explains that during the late 1970s and into the 1990s in southern Mexico, particularly in the poverty-stricken state of Oaxaca, women started banning together to create cooperatives that included a variety of crafts such as pottery, basket-making, and textile weaving. They took this initiative in response to the increasing class stratification that was prevalent during that time. The result of this class stratification was that people of lower income were subject to be "contracted laborers or pieceworkers" (Stephen, 2005a, p. 254) for wealthier merchant families in the community. This 'forced' labor restricted their upward mobility and autonomy, and perpetuated their low-income status. When the North American Free Trade Agreement (NAFTA) was enacted in 1994, the class divide grew even wider. With more orders flooding in from North America and increasing demand for the products, the merchant families needed more contracted laborers to fill the orders (Stephen, 2005a). The merchants turned to their usual workers, but this time with less luck, thanks to the popularity of the cooperative movement.

By this time the cooperative movement had gained momentum. According to King, Adler, and Grieves (2013), cooperatives are "autonomous associations of persons united voluntarily to meet their common economic, social and cultural needs and aspirations through jointly-owned and democratically-controlled enterprise" (p. 165). The main founders of these cooperatives were female migrants who returned enlightened from their journeys and began to question the extreme gendered oppression, control, and limitations that males placed on them. By creating such cooperatives, the women hoped to bypass the merchant control of the textile industry and earn political and cultural rights in their communities. In doing so, they not only stood up against powerful wealthy families but also pioneered a new age in gender relations (Stephen, 2005a). These cooperatives also served to uphold "social responsibility and the values of self-help, self-responsibility, democracy, equality, equity, and solidarity" (King, Adler, & Grieves, 2013, p. 165).

Eber and Tanski (2001) outline the changing gender roles and relations that arose from the creation of cooperatives. Participating women became more politically aware and active, and created alternative economic development strategies, both of which are roles traditionally held by men. They challenged the patriarchal power structure by forming decentralized groups, allowing each individual group more autonomy. These decentralized groups serve the purpose of allowing the women to stay close to home, as to not too drastically disrupt the gendered expectations. This structure helps to discretely strengthen their autonomy as women without the scrupulous control of male "power brokers" (Eber & Tanski, 2001, p. 449) by combating the injustice present both within and outside their communities from inside their homes.

Effects of the Zapatista Movement

Women played a significant role in the EZLN (*Ejército Zapatista Liberación Nacional*, a synonym for Zapatista) movement. For example, *Comandante* Ramona and *Comandante* Trini were two of the most well-known female leaders of the movement and provided the indigenous women with an empowering voice by representing their concerns in the political arena (Millán, 1997). Together, the marginalized women wrote *Las Leyes Revolucionarias de*

Mujeres (Women's Revolutionary Laws), which include the right to freely choose one's partner, to hold public office, and to make decisions about one's own sexuality (Hernández-Castillo, 2007). These ten laws are not legally binding, but carry great social weight. The women were able to claim their right to fair treatment based on these laws. This is not to say that all abuse has dissipated with the formation of these laws, but rather gives women a platform from which to exercise their right to make their own autonomous decisions (Millán, 1997).

The EZLN movement has supported cooperatives with the application of Zapatista support bases. These bases are groups comprised of men, women and adolescents who continue to meet on a regular basis to make sure that the Zapatista agenda is being realized and applied to their local communities (Eber & Tanski, 2001). This widespread social commitment to upholding the EZLN values continues to help maintain the progress that was made during the uprising. This piece of the equation is crucial in carrying out true social change and helps to ensure the women continue to be treated fairly in accordance with the Revolutionary Laws.

According to Morris (2011), weaving has played a larger part than ever since the Zapatista uprising. He says:

> Textiles play a huge role in the politics of cultural identity - a phenomenon that we have witnessed over the last ten to fifteen years. The reasons behind the resurgence can be traced back to the Zapatista uprising. Through gains from the uprising, indigenous populations throughout the region experienced renewed confidence - *los indios* began to again feel pride in their cultural identity and traditions. (p. 38)

Negative Outcomes

The cooperative movement represents huge forward advancements for the indigenous women of southern Mexico. Unfortunately, these advancements do not come freely. Participants have paid a price for their successes by risking their societal reputation and jeopardizing their safety and even their lives. Several articles cite that women put themselves at risk for interpersonal violence when participating in cooperatives (Hernández-Castillo, 1997; Eber & Tanski, 2001; Castro-Apreza, 2003; Nash, 2003; Stephen, 2005a). The most extreme example is cited by Nash (1993) in Eber and Kovic, (2003) wherein she reveals the most serious consequence of involvement in an artisan cooperative (p. 128-129, p. 6). Petrona López, the president of a cooperative of female potters in Amatenango del Valle, Chiapas, was murdered in the 1980s. Nash suggests that she was murdered for challenging male authority and the perceived threat her autonomy represented. While this is an extreme example and the reasons behind the murder remain a speculation, it illustrates just how imbedded the gender norms are in these communities and how dangerous it can be to challenge them.

The author encountered an example of this violence when speaking to an artisan from the weaving group *Las Golondrinas* (The Swallows) in Chenalhó, an indigenous community in Chiapas. She was attacked, seemingly at random, by several men with machetes and can no longer perform her artisan work as she used to, as the attack severed tendons in her right hand and arm. In broken Spanish, she said, "I want to know my rights as a woman and receive more training about violence. I want to open my eyes to the power of women and our rights" (V. Arias Ruiz, personal communication, July 11, 2014). While she does not know the reason she was attacked, this author cannot help but wonder if it had anything to do with her involvement in the cooperatives. She was, and continues to be, an outspoken representative for the group. At any rate, her strength and resilience truly shines with this statement and her willingness to continue the fight against injustice.

Another of the most notable issues is the sheer amount of work that the women are expected to perform, adding to their stress and exhaustion. While their female artisan work often supports the family more than the male's work does (Blumberg, 2012), they are still required to attend to all the household chores and raise the children. From this realization, women in one Zapatista support base decided that only women who are single, divorced or without children should hold leadership positions, as it is too difficult for wives and mothers to manage all the demands (Eber & Tanski, 2001). This form of discrimination has been damaging to the sense of autonomy they strive for. It also highlights the pervasive expectations placed on these women by the cultural values, specifically *machismo*, inherent in their culture (Stephen, 2005b) and their steadfast commitment to maintaining them.

Two of the artisans the author spoke with echoed this concern. One noted, "The hardest part is when I go to the market or *ferias* [fairs]. I have no one to take care of my children. The balance of responsibilities is the hardest part" (A. Hernandez Lopez, personal communication, July 17, 2014). Another artisan mentioned the added weight of traveling to her responsibilities. She said:

> The hardest thing for us is having to travel from the countryside all the time. It takes so much time. We have so much work to do, so many orders to fill. We have to help in the fields with the sowing and reaping, take care of the children, and do our artisan work. Sometimes our husbands help with the children, but not very much. (M. Gonzalez Perez, personal communication, July 10, 2014)

Other negative results of these cooperatives include the fact that, in some cases, the artisans must wait six to eight months to receive pay for their work (Eber & Rosenbaum, 1993), as opposed to immediate profit when selling their wares in the informal market. Also, the formalization of certain groups opens the door for corruption by the leaders and/or representatives (Eber & Rosenbaum, 1993).

Similarly, when people from other countries or cultures come to work with them, the foreign aid workers usually lack the necessary expertise when marketing their special products. While their errors in effectively exhibiting or disseminating the group's work is almost always unintentional, the effects of poor representation can still be felt in the loss of respect for the product and the sacred symbolism of the designs (Eber & Rosenbaum, 1993).

Stephen (2005a) notes that cooperatives might not serve the neediest of people. She states that they are designed so that people with modest means, the people with money to buy the *hilo* (thread) and who are able to travel freely, are the ones most likely to profit from the cooperative. This serves more to maintain the middle class than to raise the people in the most destitute of situations out of poverty. But, as the recent collapse of the middle class in the United States illustrates, the maintenance of the middle class proves to be a crucial part of stabilizing vulnerable societies and economies, and may not prove to be such a negative result.

Positive Outcomes

Despite the risks that women face when participating in cooperatives, there are many positive aspects that accompany these opportunities. The women acquire many new abilities including decision-making skills, leadership skills, and marketing tactics. They have control in the production and distribution of their wares (Castro-Apreza, 2003). They learn how to search for and directly connect to local, national and international markets (Bartra, 2003; Eber & Rosenbaum, 1993). This not only makes their products available to a wider range of people, but also allows them to bypass the 'middle man' merchants and keep more of their hard-earned money in their own pockets.

Before cooperatives were formed, women rarely handled the money and did not know much about how to manage it (Stephen, 2005a). With the help of agencies such as ATA, they learn how to appropriately price their products and how to keep track of their finances through accounting and administration techniques (Castro-Apreza, 2003). They receive fair prices for their hard work (Eber & Rosenbaum, 1993) instead of selling them to unaware or uninformed tourists on the street at extremely inexpensive rates. Also, cooperatives create a formal business environment allowing the women to apply for financial aid in the form of grants or loans from state and federal government officials (Eber & Rosenbaum, 1993).

This is not to say, however, that gender roles regarding the management of money have completely transformed. In some of the communities, the man of the household still requires the woman to give him all the money she makes (Blumberg, 2012). There is no doubt, however, that the women gain knowledge of financial management through participation in cooperatives and organizations such as ATA. Women combat these gender issues by creating community-based savings accounts called *cajas de ahorro,* or savings boxes. By creating these communal accounts, men do not have the ability to control the money, giving the women more financial autonomy (Carranza-Cerda, 2009).

There are many positive social implications as well. Women are free to speak their native languages within their cooperatives, which promotes autonomy and preserves their cultural heritage. The all-female environment provides a safe space, free from the oppressive presence of males, to express themselves without hesitation or caution. The heritage of weaving is passed down through the generations, as the younger women learn the art from the older women (Eber & Rosenbaum, 1993). They form close-knit relationships and social support networks with the other women in the cooperative, which enriches their ability to rely on one another in times of need (Stephen, 2005a, 2005b).

Also, through workshops conducted by organizations such as ATA, artisans learn how to tailor their indigenous patterns to more modern-day, wearable designs. Through this process, their designs can be enjoyed on a daily basis by people throughout the world, thereby preserving these valued traditions even further. The women take pride in knowing that people throughout the world speak about and exhibit their artwork like living, walking canvases. This type of work increases their self-esteem and strengthens their sense of self-worth (Eber & Tanski, 2001). This idea was supported by an artisan from Pantelhó, Chiapas when she stated, "My favorite part of being an *artesana* is knowing that I can make these beautiful things. It's the *orgullo* (pride) that I feel when I have finished a complicated product and I know that someone will buy it and use it" (M. A. Perez Diaz, personal communication, July 23, 2014). And as another woman in Aldama, Chiapas said:

> My favorite part is how many different things I can make - pillows, table cloths, iPod cases, backpacks… Before we couldn't make these things, but with the help of a designer who came to teach us, we were all able to learn how to make the things that people want. ATA gives us the designs and the exact measurements, and we give the talent. (R. Vasquez Gomes, personal communication, July 28, 2014)

The Role of Social Work

Most of the research written on this topic comes from anthropological, marketing and social justice standpoints; not much directly relevant information originates from social work literature. This is understandable as, on the surface, the theme deals with business tactics, trainings, and neoliberal policies. But the true heart of the matter does indeed directly relate to social work, as the participants fight for basic human rights such as autonomy to make one's own decisions and a life free of gendered control. These cooperatives were formed because people were exploited, a phenomenon that social workers strive to eradicate.

While this movement did not come from the minds and hands of trained social workers, the profession can offer the tools to assist with change efforts, such as theoretical knowledge, self advocacy skills, and interpersonal wisdom. Social work practice is based on empowering individuals to make changes for themselves (NASW, 2008), which is precisely the type of change that ATA strives to promote. The concepts of dignity and worth of a person and commitment to social justice are not values that these women are familiar with, as they live in a culture where men are superior to women and such social injustices are just the cross they have to bear (Peña, 1991). Thus, social workers can serve as coaches to the participating *artesanas* for navigating these unfamiliar concepts.

The most tangible example the author has witnessed of how a trained social worker could be of help was at a design workshop in San Andrés Larrainzar. The facilitators (professional designers) were two men who presented the material in a manner that was simple enough for the women to follow, but the facilitators seemed to have no real knowledge on how to successfully run a group. They did not employ any of the techniques for an empowerment group such as social action, political awareness, the right to say and to 'have a say,' recognizing oneself and being recognized as competent, and the use of power (Breton, 1994). These techniques have proven to provide the group members with a sense of pride and ownership in their work, and would prove to be very useful in these design workshops where the members are encouraged to use their imagination and adopt the design as their own. The facilitators also seemed to act somewhat aloof to the project. To an outsider aware of the culture, it seemed like they were talking down to the women and were not recognizing their strengths to the extent they could. Strengths-based education is crucial to the success of the students (Anderson, 2005), and these women could use encouragement in every facet of their work.

Within a group where language is a barrier, special attention must be paid to ensure that all participants understand the material. There were several disengaged women, who perked up only when their native language was spoken, indicating that they were disengaged because they did not understand. Also, during the actual production portion of the workshop, there sat a group of three people who did not have anything drawn on their papers and were looking around the room in a confused manner. The facilitators only paid passing attention to them and did not make efforts to fully include them and make sure they understood the assignment. It is possible that these three might have been new to the trade, but that does not justify leaving them to guess how to navigate the project on their own. According to Wilson (1956), all groups have two kinds of structure: "(a) interpersonal relationships seen as the process of acceptance creates isolates, pairs, and triangles; and (b) division of labor through which roles are assigned to 'get things done,'" (para. 18). The first of these two structures highlights the issue of how non-acceptance and neglect creates isolated individuals. This is far from being the ultimate goal of these facilitators, which was to cultivate effective artisans.

Most social workers should understand group dynamics and the ways in which a group should be run in order to maximize participant gains. Perhaps organizations such as ATA could either employ a social worker on staff or consult one when conducting these types of groups, which are crucial for the success and livelihood of the participants. Most social workers are also aware of interpersonal interactions via their educational training. They should be able to notice when someone is disengaged and have the skills to engage them (Abrams & Moio, 2006). In the same vein, social workers are tuned into the intricacies of communication and the potential negative consequences that can arise when not fully realized. A social worker would not be able to diminish the language barrier, but would be able to make sure that all parties were fully involved by effectively utilizing a skilled interpreter (Abrams & Moio, 2006).

Not to be overlooked is how social workers can help to facilitate the grand shifts in social interactions and gender roles. As described, these women face many obstacles as they work to enhance their cooperatives, including emotional and physical violence. Many *extranjeros* [outsiders] come in to help with design and organizational workshops, but leave without attending to the social changes they generate. A social worker could be stationed in a participating community to provide supplemental support to the women and men long after the change process begins. This support could be in the form of educational workshops on the benefits of the empowerment of women, women's rights, and even some sort of self-defense classes. When enough trust has been built within the community, the social worker and the artisans could even engage in one-on-one or group 'counseling' sessions, whether formal or informal, to discuss the ongoing issues. Special attention must be paid, however, to ensure that this type of support is more helpful than harmful, as some cultures/communities shun these types of supportive activities (Leach, 2015).

Throughout this process, another skill that social workers might utilize is their knowledge of international interaction and the importance of cultural sensitivity. Many setbacks arise during this project due to differences in expectations, communication, and notions of time. The employees at ATA are knowledgeable about these differences and, most of the time, handle them with grace, but a social worker might be able to offer ideas on how to prevent such lapses in the future, instead of bearing the frustration time and time again. Based on CSWE educational standards, social workers should possess the knowledge of how to best solve these issues sensitively and with concern for cultural differences, regardless of their own personal background (Abrams & Moio, 2006).

Social workers should also have a passion for social justice. The cooperative movement is rooted in social justice and it advocates for the marginalized people in this society. It fights to give women the same rights as men, and to empower them to support themselves and their families in times of economic hardship. It provides an alternate solution to poverty and stagnation, and helps the participants realize their strength as income-earning and dignified workers. Social workers (BSW and MSW) should receive detailed training that addresses the aforementioned goals, which should set them apart from passionate social justice advocates who receive no formal training (NASW, 2008). The push for these cooperatives is directly in line with inherent social work goals and values (NASW, 2008).

In addition, social workers could offer program evaluation and research. These projects are extremely valuable to all the involved stakeholders and crucial flaws might go unnoticed if a proper program evaluation is not conducted. While not all social workers are keen on research and program evaluation, all should receive training on how to properly do so, as stated in the NASW Code of Ethics, (NASW, 2008). Cross-cultural training and sensitivity to interpersonal differences equips social workers to notice a missing piece of the equation by probing in areas that marketing or business researchers might not.

The author conducted a program evaluation with ATA in San Cristóbal de las Casas. Upon her arrival, she discovered the baseline evaluation to be methodologically and theoretically lacking. The author and the marketing coordinator tailored the midline evaluation to be more methodologically sound and more equipped to capture the information the organization and their funders needed. The lack of attention to this research is nobody's fault, as no one was hired to gather such data and the employees were occupied with the organization's daily procedures. This is a prime example of how a social worker can aid such organizations, even if only on a temporary contract.

With all of this said, it should be noted that social workers cannot solve all the problems an international agency might encounter, and are vulnerable to mistakes and miscommunication just as much as anyone else. It takes a team of professionals to conduct this type of work, and one social worker cannot do it alone. This multi-faceted project requires marketing experts, business professionals, interpreters, and designers. It needs people who are familiar with the terrain, the populations, and their cultures. While social workers are not superhuman miracle-workers and may not be able to answer all the questions nor provide solutions to all the issues, they do have the specialized training to tune into the intricacies of empowerment in an international setting.

Conclusion

Cooperatives are powerful vehicles that provide the impoverished women of rural southern Mexico with an organizational basis from which to disperse their detailed and celebrated textiles. Cooperatives offer many positive gains to the participants and challenge the gendered power structure. The problems that arise from the cooperatives are faced with stern determination by the women who sacrifice so much to participate. *Poco a poco*, little by little, is a term used by the indigenous folk to describe the rate of change, and the author has witnessed the significance and accuracy of this sentiment felt and lived by the people. They fight this uphill battle for autonomy and recognition every day, while still tending to the daily duties that accompany the life of an indigenous woman. ATA is working hard to attend to the artisans' needs, but is their involvement in providing the *hilo* [thread], connecting them with clients, and teaching them new designs enough to sustain the progress they make after they no longer have the guidance of the organization?

Not many social workers are currently involved in the facilitation of these groups, but as this article states, their wide array of skills are needed and could be greatly utilized. Structural change is not achieved easily - it requires the community as a whole to support the cause and to agree with the outcome of the movement. Social workers are familiar with the long and tireless fight for women's rights and empowerment, and could be invaluable additions to the team of people already *luchando* [fighting] for this noble cause.

It is the author's intent to bring the importance of this organization to light, and to encourage the participation of all available and interested social workers in empowering the women of rural southern Mexico within their artisan cooperatives. Perhaps if one cannot be involved directly, consider purchasing next year’s holiday presents online at a fair price from these diligent *artesanas* and join in the celebration of this beautiful culture.

Kelsey Greenwood *hails from Baraboo, WI, with a degree in Psychology and minor in Spanish from UW-LaCrosse. She is an LSW graduate from Loyola, with an emphasis in Mental Health and Migration Studies. She traces her passion for victims of structural violence since she was a young girl witnessing her mother’s leadership in Haiti Medical Mission of Wisconsin; she yearns to learn more not just about the elements that lead to suppression, but even more so the solutions that can be found with passion and dedication to the cause. She currently works for Thresholds as an outreach worker to those with severe and persistent mental illness. She is not sure where her future will lead her, but she hopes to continue working with the Latino population in some capacity.*

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Making Sense of Two Worlds:

A Reflection of an Urban Educator Turned Graduate Student

Daniel Guzman

Abstract

This article highlights my tumultuous journey from my role as an urban educator in Oakland, CA to that of a graduate student at Loyola, dexterously relaying the use of interdisciplinary theories and applying them to real life context in and outside of the classroom. The article serves to capture my candid experiences doing extensive, hands-on social justice work in a disenfranchised community and to show the disconnect to my role now, which is that of sitting in a classroom and learning about social justice in an esoteric manner. My intention is to make sense of both worlds as I transition to my new role as a graduate student at Loyola University Chicago (LUC), while aiming to bridge the gap between theory and practice. This article will also discuss the stressors of real-world practice and how that affected my role as a teacher and mentor.

Keywords: community, disenfranchisement, education, mental health, practice, social justice, stressors, theory, stressors

Stepping off my plane from California to Chicago brought a myriad of mixed feelings. I was filled with immense hope that I was finally going to learn the alchemical secrets that would help me become an excellent social worker dedicated to promoting social change on the grassroots level, as well as the political arena. By the same token, I was filled with uncanny sadness knowing I left behind supportive comrades and aspiring students who looked up to me. With two suitcases in my hands, I had no clue where I would be living. All I knew was that this impulsive decision to exchange sunny days in California for cold fronts and freezing temperatures in Chicago would involve a constant process of change and adaptation. This courageous act of faith was spurred by intuition and a sense of righteousness to use my acceptance into graduate school as a platform to advance my education to better serve my community back home. Chicago, being an urban mecca, famous for its pioneering research in the field of sociology, pried me away from attending graduate school in the Bay Area. Moreover, I wanted to further explore the social inequities manifested within the city to understand the implications behind Chicago being dubbed "Chiraq." [1] Throughout this article, I will highlight my transition from urban educator to graduate student, shedding light on the disconnect between the theoretical jargons used in "privileged" classrooms and the practicality of applying these epistemologies in communities such as Oakland.

Before moving to Chicago, I worked as a middle school teacher in East Oakland. My decision to work in Oakland was influenced by my early childhood memories living in this city in the California Bay Area. Although my family later relocated to a suburb twenty-five minutes away to escape the high crime rates and low performing schools in the Oakland Unified School District, I felt a beloved attachment to the city and realized that my family was one of the few Latino families to escape the marginalized conditions. My upbringing in Dublin, California exposed me to suburban homogenous culture, wherein the dominant narrative was that of a white middle-class perspective.

Pierre Bourdieu's famous literary work, *Reproduction in Education, Society, and Culture* (1990), developed theories analyzing the interplay between the roles of schools and standard pedagogical approaches used to uphold and maintain social inequality and social inclusion. Bourdieu's (1990) theory of cultural capital, which describes how the characteristics of one's social class can impact one's social mobility, highlights my experience as one of the few minority students in a predominately Caucasian school. While I was expected to perform and excel in the classroom and follow the rules by my parents, I was often subject to

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[1] A reference comparing the Chicago homicide rates to the war in Iraq.

unfair and questionable treatment by authority figures. The lack of cultural competency, coupled with the racial microaggressions echoed by teachers, administrators, and some of my peers, led to feelings of inferiority and self-doubt in regards to my overall capabilities in school. A team of professors characterized racial microagressions as "subtle and contemporary forms of racism in everyday occurrences" (Sue et al., 2007, p. 272). Post-racialized society has condemned blatant racism, however the ambiguous nature of racial microaggressions make them easy scapegoats for accidental slip-ups or jesting behavior. For example, being sent out of the classroom for appearing to be under the influence of marijuana did not sit well with me. In another example, Mexican and African American students were warned by the principal to not wear red due to a recent gang-related fight that occurred near campus. The same standards did not apply to the rest of the student body, hence creating a distinct separation between which individuals were labeled or classified as gang members. Despite the messages being echoed in the classroom and the negative depiction of Latino/as in the media, summer trips as a young boy to a small-impoverished ranch in Mexico reconnected me to my roots and exposed me to absolute poverty. Indeed, these trips taught me that the world was bigger than my backyard and empowered me to pursue a higher education to counter false stereotypes and educate others on the injustices impacting Latino/as.

The school I was hired at was located on 98th Avenue, located in the flatlands of East Oakland, anecdotally known as the heart and soul of the community. The harrowing reality of people living within the confines of East Oakland is warranted and actualized by the well-known fact: life expectancy for residents in East Oakland is 10-15 years shorter than that of people living just 1.3 miles away in the Oakland Hills (Ratner & Robison, 2013, p.4). Likewise, Oakland is consistently listed as one of the most dangerous U.S. cities (Hess, 2014).[2] Before accepting the position, I researched the school online and found a video on YouTube that had been disseminated by local media outlets. The video displays a wild melee involving a clear, physical altercation between a student and substitute teacher during class (YOUTOUBEBESTVIDEO, 2013). In the video, the teacher picks up a desk in an effort to ward off the student shortly before the student is while screaming and yelling at the teacher (YOUTOUBEBESTVIDEO, 2013). Most people would be deeply disturbed by the video and might refuse to work in such a hostile environment, but I knew this was where my presence was most needed. Moreover, my previous work experience at a local non-profit (Youth UpRising) as an academic advisor and career coach for youth on probation and in the foster care system solidified my ties to the community and augmented my interest in learning more about the interrelation between the school-to-prison pipeline and the faulty education system in underserved communities.

During my first day teaching at Alliance Middle School, I had to pry a razor out of a student's hand because she was visibly cutting her arms during class. This incident served as a premonition to other harrowing accounts that would occur later on in the year. The most tragic incident occurred in January when one of our eighth grade students was murdered, marking the city's first homicide of the year. Even more tragic was that his older brother was killed merely three weeks later while on his way to pay a cell phone bill with a friend. I felt a sense of guilt having worked with the older brother on various occasions during my stint at Youth UpRising. In conversation with many of my peers who have lost former students to needless violence, there is a habitual period of self-doubt and frustration, followed by the burdening question: could I have done more?

Although the school hosted a peace rally and both students and teachers marched fervently around the streets to protest violence in the community, it had little effect on curbing the violence and failed to dismantle the pervasiveness of what Anderson (2000) calls the "code of the streets" (p. 75). The "code of the streets" exists as a set of norms and regulations within inner city communities and is unrestricted to conventional classroom settings (Anderson, 2000). They are used to resist mainstream systems and reclaim power in historically disenfranchised communities. The "code of the streets"' was apparent at Alliance Middle School and could be used to describe the shared sense of desensitization plaguing the community—it seemed as though students, teachers, administrators, and community members alike

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[2] In 2014, Oakland was ranked the second most dangerous city in America behind Detroit, Michigan (Hess, 2014).

were numb and calloused to the grave issues deteriorating the community.

I was frustrated with the shortsighted resolutions enacted by the school district and administrative leadership. The resolutions were imposed to temporarily assuage the campus climate, yet they failed to address long-term implications of being surrounded by violence. If we as educators are to cultivate a sense of hope in our students, especially students from underserved communities, we must provide them with an enriching educational experience that is culturally relevant and responsive to the social mores highlighted in the "code of the streets." At that moment, I knew I lacked the theory and knowledge as an educator to promote social change and address the structural inequalities suppressing my students, many of whom had already lost faith in the education system.

For the last three months of the school year, I walked the same streets as my students from my house on 70th Street to the school site on 98th Avenue. I began to empathize with their struggle of balancing the "code of the streets" with the cultural hegemony of the school. The most frequented path used by students and their families ran down International Boulevard, which bears witness to dilapidated housing, boarded-up convenience stores, rampant liquor stores, drug deals being executed on the corner, and candle light vigils honoring homicide victims.

Bandura's (1971) social learning theory helps illustrate my students' struggle to balance the contrasting expectations of the streets and their school. Accordingly, social learning theory is a cognitive process that takes into account the social-environmental context and explains the manners in which behavior is learned through a combination of modeled behavior, direct experience, observation, and imitation (Bandura, 1971). Indeed, Bandura's theory can help rationalize students being pressured to conform and adapt to the "code of the streets." Following the rules and exceling academically in school comes into conflict with the very real possibility of being the victim of a violent crime simply by walking home. Having to balance two divergent worlds at such a young age places immense expectations on students as they are challenged with learning how to survive in the streets while being a good student in the classroom.

I came to understand that my attempts to promote education as a practical vehicle for social mobility offered little hope for my students when they faced the vexing circumstances and structural inequalities permeating the surrounding community. Fortunately, from a young age, my parents had been able to provide me with a safe environment and the necessary tools to succeed academically. This was not the case at Alliance Middle School where I was habitually handing out pens and paper to my students.

I engaged in daily battles trying to convince my students that the pen was indeed mightier than the sword. The cliché message of excelling in school so they can go on to college and eventually land a high paying job was a fleeting idea when it came to their vexing reality. Professor Randall Collins' (1971) article, *Functional and Conflict Theories of Educational Stratification*, spoke volumes to the structural inequalities I saw manifested in the politics of the school and helps disentangle the myth that school is the most viable option for disenfranchised students looking to climb the social ladder. Collins' (1971) theory argues that schools are merely preparing students to obtain an occupational position relevant to their social class. Unfortunately, I find his ideas to be true as most teachers did not deviate from standard pedagogical approaches. Teachers at Alliance were forced to teach diluted curriculum and organizational leadership was unable to collaboratively and positively impact the school culture to chip away at the higher powers perpetuating social inequities.

In spite of the lack of resources and a volatile environment, there were a handful of students who displayed incredible resilience to the toxicity of the community and achieve incredible academic success. With little resources and support from the school and administration, I tutored a handful of students after school in a cramped, under-resourced computer lab in an effort to increase students' academic self-confidence and emotional well-being. By acknowledging and valuing students' real life experiences, I found that restorative justice practices provided students with a sense of consciousness and wholeness, consequently spurring spiritual and intellectual growth. Restorative justice is an alternative paradigm to current punitive practices and involves fostering dialogue between individuals or groups that have had conflict in the past (National Council on Crime and Delinquency, 2015). Instead of letting tensions spill over and give life to the flame, restorative justice practices facilitated a "safe space" that led to critical thinking and authentic self-reflection. I was humbled by my edifying experiences as a teacher from 2013-2014, yet my lack of self-care took a damaging toll on my body and mental health.

As a result of the stress, I developed unhealthy behaviors and made irrational decisions during the final weeks of the school year. For example, I started over-eating as a way to cope with the anxiety of my role at the school. Additionally, my sleeping patterns were greatly affected due to the regularity of sporadic gunshots on the weekends, the blaring melodious exchange of Banda and Hip Hop music escaping the loud speakers of speeding cars, and the relentless barking from dogs in the neighborhood. I was not accustomed to the habitual noise at night because of my upbringing in a reserved suburban community. Most days, I would leave work feeling hopeless, frustrated, and overwhelmed. Consequently, my self-esteem greatly plummeted and I preferred to stay in the house and sleep rather than go out with my friends. I desperately looked for healthy resolutions to cope with my anxieties, but failed to find a positive outlet. I am still processing the many experiences and life lessons from my teaching experiences in Oakland and I now find myself in a new phase of my life—one with new stressors—in which I am adjusting to life in a new city, far away from home, eager to establish secure roots and gain financial independence.

As I walk around Loyola, I am awestruck by the beauty of the university and marvel at the pristine location of both the Lakeshore Campus and Water Tower Campus. The community bears little resemblance to the food desert I was living in. The houses are spacious and well kept. The neighborhood is quiet and peaceful. My current neighborhood is filled with enthusiastic undergraduates students looking to further their education, contrast this with working class families struggling to stay afloat.

I take my usual ride on the "L"[3] or hop on the bus to attend my evening classes at the Water Tower Campus and listen to lectures that are often times too disconnected and abstract from my experiences in Oakland. Although theory and research is significant in fostering change, I also believe that mentorship and experienced practitioners with tangible experience in my related field are just as important. As soon as I exit my classes, I gaze at the multi-million dollar high rises, expensive retail stores decorating the Magnificent Mile, and exotic Lamborghinis on display outside the Bentley Gold Coast car dealership on Pearson Street across from the Water Tower Campus, I am reminded of the economic castration permeating the streets of Oakland. My transition of having lived within the heart of East Oakland, to attending Loyola University and living in a community that has an abundance of wealth and resources is surreal

My social context and living environment has been immensely altered within the last few months, and I find myself struggling to adapt to this new setting where there is a level of privilege that I had previously not been exposed to. Professors and students alike theorize about social justice issues with a sense of normalcy, whereas my perspective to converse about these issues is underlined with a sense of urgency due to having lost a former classmate and a former student to homicide earlier this year. Indeed, I am also self-conscious about my status as a Latino male in a graduate program heavily dominated by Caucasian women. I was made well aware of my minority status the day I walked into the social work orientation and failed to identify and relate with other students who looked like me and had similar work experience. Furthermore, I have the added pressure of succeeding so that my brother and younger cousins can follow suit. I am the first in my family to leave home with the aspiration of obtaining a graduate degree and will inevitably encounter new stressors living in a city far from home without the emotional support of my close-knit family or diverse group of friends.

As I learn to navigate the graduate school trajectory for the next three years, I will undoubtedly encounter new stressors that will challenge my intellectual capabilities and test my resiliency to adapt to a new environment. I am adjusting to life as a graduate student and learning how to balance my course work with a new job. My past experience has taught me to practice self-care. I have committed myself to doing at least 30 minutes of daily exercise and have made a determined effort to build a strong community in Chicago to alleviate anticipated developmental stressors related to a change in my environment and the unfamiliarity of living independently. I often question my decision to

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[3] The "L" is the nickname of the mass transit subway system in Chicago (Manker, 2012).

relocate to Chicago and feel lost in an endless maze. I feel trapped by my subconscious, which takes me back to Alliance Middle School where I was teaching and promoting community transformation to the youth in Oakland. I taught my students to take pride in their education, be committed life-long learners, and hustle hard for their endeavors. This was my way of "keeping it real" with them and fostering their individual talents and aspirations. The work was challenging and exhausting at times, nevertheless it was wholly rewarding. Regardless of my current financial stressors and other related insecurities, I have acquired resilience through an array of hardships within the last year, and I intend on capitalizing on my dynamic experiences and using them as an adaptive tool to making the best possible experience during my time at Loyola University.

***Daniel Guzman** is a first-year dual masters (MSW/MA Social Justice) student at Loyola University Chicago (LUC). He graduated from San Jose State University with a BA in Sociology, with a concentration in criminology and a minor in Mexican American Studies. As someone committed to lifelong learning, he views his graduate studies at LUC as a fundamental step to continuing his development as both a scholar and leader dedicated to advancing social justice issues in the city of Chicago. He dedicates his accolades and achievements to his loving family and friends. He recognizes that they are his biggest supporters and motivation, and thanks them for seeing his potential and taking the time to polish a diamond in the rough. Upon graduating, he looks forward to speaking truth to power and continuing his two-fold process of a compassionate pedagogy that educates both the heart and mind.*

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Treating Depressive Symptoms in Children and Adolescents with Conduct Disorder

Ewa Pastuszewska

Abstract

Although only a small percentage of people are diagnosed with conduct disorder (CD) and antisocial personality disorder (APD), they are more likely to be incarcerated than the general population. (Walker, Thomas, & Allen, 2003, p. 564). Follow-back studies have shown that a significant percentage of adults who met APD criteria had also met criteria for both depression and CD as children (Lahey, Lober, Burke, & Applegate, 2005, p. 390). This article will examine how screening for and treating Major Depressive Disorder (MDD), which has a high comorbidity rate with traumatized individuals diagnosed with Post -Traumatic Stress Disorder (PTSD) (Van der Kolk, Roth, Pelcovitz, Sunday, & Spinazzola, 2005, p. 396), in children and adolescents may help prevent APD or lessen its severity. In addition, the article will explore the unique ways in which depression manifests itself in individuals who have APD or CD in order to better work towards alleviating these symptoms. This article will be utilizing two case studies, one of a 12-year-old boy with comorbid CD and MDD and the other of deceased contract killer Richard "The Iceman" Kuklinski, to better illustrate the correlation of these disorders.

Keywords: antisocial personality disorder, comorbidity, conduct disorder, treatment

Introduction

Conduct disorder (CD) is a mental illness in children and adolescents under age 18 that is characterized by a pattern of behavior that includes violence, cruelty towards people and animals, as well as lying and manipulation (American Psychiatric Association, 2013, p. 469-70). Depending on the severity of the behavior, symptoms may include destruction of property and use of a deadly weapon, among other behavior that goes against social norms (American Psychiatric Association, 2013, p. 469-70). Depending on environmental factors, such as the affection and attention children and adolescents with CD receive from their caretakers, the severity of APD symptoms can be greatly reduced (Shi, Bureau, Easterbrooks, Zhao, & Lyons-Ruth, 2012, p. 66). However, many children who exhibit severe CD behavior go on to develop antisocial personality disorder (APD) in adulthood (Lahey, Burke, Loeher, & Applegate, 2005, p. 389), the symptoms and characteristics of which will be discussed later in this paper. Though APD only affects 1% of the population, this 1% makes up a large portion of the prison and criminal system, including criminals who commit socio and psychopathic crimes (Hare, 1993). Individuals with APD are responsible for over 50% of all serious crime (Walker et al, 2003, p. 564). Further, of the offenders responsible for killing a police officer, 44% were diagnosed with APD (Federal Bureau of Investigation, 1992).

As stated above, various factors play a significant role in whether a child or adolescent with CD goes on to develop and be diagnosed with APD. Experiencing trauma such as physical or sexual abuse and/or meeting criteria for a posttraumatic stress disorder diagnosis is a contributing risk factor for developing CD and APD (Steiner, 1997, p.125). A study has shown that 93% of boys and 84% of girls in juvenile detention centers have experienced one or more traumatic events in their lives (Kerig, Bennet, Thompson & Becker, 2012, p. 272). Furthermore, trauma is strongly correlated with major depressive disorder (Grant, Beck, Marques, Palyo, & Clapp, 2008, p. 662). Of all incarcerated jueveniles, nearly 11% of boys and 29% of girls were diagnosed with MDD (Fazel, Doll, & Långström, 2008, p. 1010). Additionally, a little over 50% of both boys and girls had conduct disorder (Fazel, Doll, & Långström, 2008, p. 1015). Studies have shown a significant co-occurrence of CD and MDD and, thus, a pattern of comorbid diagnoses of CD and MDD (Lahey et al., 2005, p. 390). Forty-five percent of adults diagnosed with APD previously received a childhood or adolescent diagnosis of comorbid MDD and CD. (Lahey et al., 2005, p. 390). This article argues that screening for and treating, not only current, but also past trauma and depressive symptoms, will aid in either preventing a diagnosis of APD or alleviating its severity. Treating current, as well as past trauma and depressive symptoms, will not only help individual patients, but will also work toward decreasing criminal activity. A study by Rohde Rohde, Clarke, Mace, Jorgensen, & Seeley (2004), which tested the effectiveness of treating comorbid CD and MDD with Adolescent Coping with Depression (CWD-A), has already shown to be acutely effective. This article will examine how MDD and depressive symptoms manifest themselves in individuals with CD and APD and how intervention by treatment of MDD may help prevent APD. To do so, it will utilize two case examples. The first case study describes a twelve-year-old boy who will be referred to as "John." John was diagnosed with CD and MDD concurrently a year earlier at age eleven and has been in treatment since. John's social worker, who was also a former professor of mine, reached out to me, asking if I was willing to work with John by meeting informally with him at his home weekly. I would then consult with his social worker about our interaction and my observations. Ultimately our interaction was meant for him to receive personal attention that his social worker suspected he was missing in the hopes of alleviating some of his depressive symptoms and for the social worker to gain a more holistic understanding of John i.e. his home enviornment. The second case example is of the deceased notorious contract killer Richard "The Iceman" Kuklinski, whose information I gathered from the HBO series done on him, including a video of him interacting with a psychologist (Thebaut, 2004).

Cases

Case 1

John is a twelve-year-old Caucasian boy who was adopted when he was four-years-old. John was taken away from his biological parents who both had substance abuse disorders and now lives with his adoptive parents and sister. John exibits manipulative behavior. He has attacked his mother physically and regularly gets into fights in school. John also mentioned trying to beat up a squirrel, but said that it was too fast and got away. When asked what he thinks makes him want to hurt the squirrel and fight with his classmates, he answered that he "didn't know" and that he simply "had to do it." After bringing a pellet gun to school, the administration told his parents to seek professional help or that John would be expelled. John also presents with depressive symptoms. He sleeps during the day, describes being sad, often talks about death and has attempted suicide. During a session with his social worker, he began crying because he did not know what was going on with him.

Case 2

Richard Kuklinski is a deceased contract killer. As a contract killer, the mafia paid him to murder people (Thebaut, 2004). He presented with CD as a child and APD later in adulthood. As a child, he was severely abused by his parents and bullied by other children and teenagers (Thebaut, 2004). He began torturing and killing animals when he was five years old (Thebaut, 2004). He killed many people prior to becoming a contract killer (Thebaut, 2004). He first killed a human being at age 18 and killed an estimated 200 people in total (Thebaut, 2004). Kuklinski cited never feeling guilty about the murders he committed except for his first two but said he did not feel "bad" for long (Thebaut, 2004). His only regret was the pain that he caused his family by committing those murders (Thebaut, 2004). During an interview in which he discussed his reasons for murder, he said, "If I had a choice I wouldn't…At the time I didn't have a choice" (Thebaut, 2004). Later, he said "I would like to be different than what I am" (Thebaut, 2004).

Presentation of CD and APD in John and Kuklinski

As stated earlier, CD is characterized by a variety of violent and deviant behavior that violates social norms (American Psychiatric Association, 2013, p. 469-70). Both John and Kuklinski presented with this behavior. Though John was adopted and is now living in a safe environment, the time he endured living in an abusive home had a major effect on him. He has had trouble bonding and forming friendships. This is demonstrated by the number of physical (two-three a week) and verbal (daily) fights he gets into with other students. Additionally, he is unable to integrate himself into any extracurricular activities and disclosed to me that he does not have any friends. When asked why he attacked a fellow student, John stated that he did not think about it. He then proceeded to ask if I believed it made him evil. This can be read as John feeling that he cannot control his behavior. Though John also has inclinations toward hurting animals, he has only tried to hurt one, which proved to be an impossible target. However, his suicide attempts, which both characterize CD and MDD, and bringing a pellet gun to school, are examples and precursors to developing and fitting the criteria for APD once John turns 18 (American Psychiatric Association, 2013, p. 659).

APD encompasses the characteristics of CD, but its symptoms are more severe and the lack of remorse involved in APD is even greater than among children and adolescents diagnosed with CD (American Psychiatric Association, 2013, p. 659-63). As described in his case, Kuklinski fit the DSM-5 criteria for an APD diagnosis (American Psychiatric Association, 2013, p. 659). To be ascribed an APD diagnosis, Kuklinski had to meet A-D criteria as listed in the DSM-5 (American Psychiatric Association, 2013, p. 659). This included meeting three out of seven symptoms under criteria A (American Psychiatric Association, 2013, p. 659). Kuklinski presented with six of the seven symptoms under criteria A. As stated in the the DSM-5 these symptoms include:

1. Failure to conform to social norms with respect to lawful behaviors, as indicated by repeatedly peforming acts that are grounds for arrest.
2. Deceitfulness, as indicated by repeated lying, use of aliases, or conning others for personal profit or pleasure.
3. Impulsivity or failure to plan ahead.
4. Irritability and aggressiveness, as indicated by reapeated physical fights or assaults.
5. Reckless disregard for safety of self or others.
6. Lack of remorse, as indicated by being indifferent to or rationalizing having hurt, mistreated, or stolen from another. (American Psychiatric Association, 2013, p. 659)

Kuklinski demonstrated symptom one by his work as a contract killer, murdering around 200 people (Thebaut, 2004). His family was unaware of his work as a contract killer, creating a fake profession (Thebaut, 2004), thus meeting symptom two. As a young adult the murders he commited, including his first kill, were done on impulse (Thebaut, 2004), meeting criteria three. Kuklinski physically attacked his wife multiple times (Thebaut, 2004) demonstrating symptoms four and five. Finally, Kuklinski stated that he had felt no emotion while commiting most murders (Thebeaut, 2004), demonstrating symptom six. Kuklinski also fit criteria B, which states that he was at least 18 years old (American Psychiatric Association, 2013, p. 659). Additionally, he fit criteria C, which states that there was evidence of CD before he was 15 years of age (American Psychiatric Association, 2013, p. 659) as diagnosed by a psychiatrist (Thebeaut, 2004). Finally, Kuklinski fit criteria D, which states that the aforementioned behavior did not occur soley during episodes of schizophrenia or bipolar disorder (American Psychiatric Association, 2013, p. 659).

However, while he presented with a lack of emotion and guilt, it is noted that he did feel some guilt and remorse when he committed his first two murders, but later learned “not to think about it” in an attempt to cope with those feelings (Thebaut, 2004.) Presenting with remorse and guilt, Kuklinski shows that if there was intervention in treating his trauma—trauma that forged emotional detachment—there may have been the opportunity to change his and many others lives. While “[he] can’t change yesterday” (Thebaut, 2004), intervention may be beneficial to others with similar backgrounds who have yet to exihibt serious antisocial behavior.

Manifestation of MDD in Individuals with CD and APD

Depressive symptoms, and thus evidence of a relationship between CD and depression, can go unrecognized because symptoms of CD may be more severe and consistent, as opposed to depressive symptoms that are often episodic (Drabick, Gadow, & Sprafkin, 2006, p. 772). Therefore, it is important to focus not only on symptoms of CD but also to screen for any current or past depressive symptoms. These symptoms clearly presented themselves in John’s case. He described himself as sad and constantly tired. However, Kuklinski did not exhibit typical depressive symptoms during his interviews. I believe this was, in part, due to emotional dissociation, which I will discuss later. His depressive symptoms were manifested by the exertion of mental control over others.

Individuals with CD and APD are often manipulative. This manipulation is usually meant to incite fear and/or anxiety into another individual (American Psychiatric Association, 2013, p. 470). By inciting fear and anxiety, they are asserting control over other people. Though Kuklinski may not have demonstrated depressive symptoms, I believe his manipulative behavior was meant to control others because he could not control himself. By exerting control over others, he was compensating for the lack of control he had over himself, exhibiting MDD with anxious features (Association of Psychiatry, 2013, p. 163 & 184). Kuklinski expressed, during all three videotapes, that he felt he had no control over his actions, and he did not understand why he did what he did (Thebaut, 2004). At the end of "The Iceman Interviews" (2004), the psychiatrist explains to Kuklinski his diagnosis and gives him some context for his behavior. At this time, it is evident that Kuklinski felt relief, showing the inner turmoil he had been experiencing throughout his lifetime. The emotionality expressed by Kuklinski speaks to the value in understanding and treating deviant child or adolescent behavior. This could give insight into a potential genetic predisposition and/or trauma they have experienced that may have influenced their behavior.

Trauma and Emotional Dissociation in Age Transition

Genetics are important in determining whether an individual is likely to have traits or symptoms of CD or APD. However, the type of environment a child or adolescent grows up in can negate genetics. A study found that 59.1% contribution to APD was enviornmental while 40.1% was genetic. (Shi, Bureau, Easterbrooks, Zhao, Lyons-Ruth, 2012, p. 56). Therefore, as discussed earlier, trauma holds an important role in determining whether an individual will have CD or APD and how severe the case may be. With age, a pattern of continuous or untreated trauma and abuse can cause individuals to emotionally dissociate from what they see, what is done to them and from what they do (Kerig, Bennet, Thompson, & Becker, 2012, p. 273). This disassociation aids individuals in coping with the trauma they experienced.

Individuals with CD show little to no guilt or fear when they do something that society would deem immoral or if they were to risk bringing any harm to themselves (Cimbora & Mcintosh, 2010, p. 296-297). Violating and hurting people and animals without feeling or exihibiting remorse or a regard for social norms are characteristic of a sociopathic and psychopathic thought process. Furthermore, these charactristics are related to emotional dissociation, which is associated with selfish ego-centric behavior (Osumi & Ohira, 2010, p. 451). As children grow older, emotional detachment and dissociation become more evident in their actions.

Individuals with childhood-onset CD often exhibit more violent and aggressive behavior than individuals with adolescent-onset CD (Cimbora & Mcintosh, 2003). They are also more likely to exihibit antisocial behavior as adults (Cimbora & Mcintosh, 2010). This article argues that those with childhood-onset CD are likely to have experienced trauma early in their lifetime. Having experienced that trauma, they separate themselves from their emotions in order to cope with the trauma. Especially as children, they are not able to advocate for themselves. As children with CD age, they become more emotionally detached and, thus, less guilt ridden. Therefore, this article argues, that if depressive symptoms are not treated prior to a child or adolescent reaching adulthood, they are more likely to exihibt antisocial behavior. Kuklinski had exihibited antisocial behavior as a child, including torturing animals, but he did not commit murder till he turned 18 (Thebaut, 2004). He stated in an interview that he had felt some guilt when commiting his first two murders (Thebaut, 2004). This article hypothesizes that the antisocial feautures he exihibited may not have been as severe had he received treatment for the trauma he endured i.e recurrent physical abuse (Thebaut, 2004). John was very violent, but after eight months of therapy, his violent outbursts and aggressive behavior had decreased. His improvement is an argument for the importance of screening for depressive symptoms that may have resulted from trauma, so that the symptoms can be treated to help both the individual and society as a whole.

Treatment of Comorbid MDD and CD

Unfortunatly, there have been a limited amount of studies done on treating comorrbid MDD and CD. Thus far, cognitive behavior therapy (CBT) has been used to control and treat comorbid diagnosis (Kaufman, Rohde, Clarke, Seeley, & Stice, 2005, p. 38). CBT addresses the negative thought processes associated with MDD and helps children and adolescents presenting with CD adjust their behavior by learning social skills and finding positive activities that they may find pleasurable (Kaufman et al., 2005, p. 38). Though patients found a reduction in symptoms, their progress was short lived. A few months after terminating treatment, many of the patients had a resurfacing of symptoms (Kaufman et al., 2005, p. 38).

Often, individuals with CD and APD exhibit egocentric behavior and blame society and/or specific individuals for their behavior rather than examining or acknowledging their part in it. This tends to correlate with these individuals' belief that their behavior is not wrong, but rather, that society is wrong for deeming their behavior unacceptable. Since they do not believe they are wrong, individuals with APD often do not seek mental health treatment on their own. Instead, they do so when forced or mandated (Walker et al., 2003, p. 557). Symptoms of CD amongst children and adolescents are less severe than similar symptoms of APD in adults. Therefore, children and adolescents are often more open to some form of treatment. Since children and adolescents with CD have difficulty forming bonds and integrating into both their families and society, CBT is effective in teaching them skills to do so. However, as stated above, CD is characterized by an egocentric thought process. Therefore, studies utilizing treatment that focused on integrating and teaching the individual socially acceptable thought processes and behavior have only proven successful in the short term (Rohde et al., 2004, p. 666).

In order to help improve symptoms in a person with an egocentric personality, it useful to utilize individual talk therapy in addition to CBT. Talk therapy allows the individual to focus on their story and behavior. Clients are more likely to have the time to find some meaning behind their actions. Though this treatment modality may seem to enable their egocentric thought process and behavior, it also gives clients a sense of control, which could potentially decrease their desire to manipulate and control others. Talk therapy is also likely to identify any symptoms that may be due to trauma.

It is important to note that talk therapy is more likely to be useful with children and adolescents. Studies have shown that adults with APD, especially those that are psychologically minded, try to manipulate their therapist (Walker, et al., 2003, p. 558). It is important to take into account the severity of the patient's diagnosis when deciding whether this would be beneficial. Furthermore, treating a patient who has CD or APD requires training and preparation so that the patient does not intimate or scare the therapist, especially if they are in a criminal setting. However, talk therapy should be considered, especially when working with children and adolescents who exhibit or have exhibited depressive symptoms.

Conclusion

Though many children and adolescents who have CD go on to be emotionally healthy adults, there are some who develop APD. APD affects only 1% of the population, but those who do have APD often commit crimes, which range from theft to multiple murders (Hare, 1993). Although individuals with CD often have a genetic predisposition to it, environmental factors, such as a loving home, can negate dangerous and detrimental behavior (Shi, Bureau, Easterbrooks, Zhao, Lyons-Ruth, 2012 p. 56). However, children and adolescents who grow up experiencing any form of trauma are more likely to develop CD and, which could potentially lead to APD. The link between trauma exposure and juevinle delinquency demonstrates why the likelihood that they develop APD is greater if they begin to emotionally dissociate. Emotionally dissociating enables them to feel little to no guilt for engaging in delinquent behavior, which in turn makes it more likely that they will continue their deviant behavior (Kerig et al., 2012, p. 272).

This paper argues that screening for and treating depressive symptoms will help prevent or alleviate the severity of an APD diagnosis. Psychosocial assessments, particularly with children and adolecents who display Oppositional Defiant Disorder (ODD) or CD, may be beneficial in the long term. The Beck Depression Inventory and Children's Depression Inventory may also be helpful tools in taking the first step toward treatment. Though some studies have shown that talk therapy may not be effective with adults with APD, this writer argues that talk therapy (with proper training and preparation) coupled with CBT can impact children and adolescents in a positive way. After eight months of talk therapy, John's behavior has significantly improved. He also had someone to advocate for him so that he found a loving home with parents who are intent on helping him. Though he is still impulsive, has aggressive outbursts and has difficulty creating friendships, he has stopped attacking his mother and sister and is willing to keep trying to modify his deviant behavior.

***E. Pastuszewska** is an MSW candidate at Loyola University Chicago specializing in mental health. After receiving her BA in cinema and media studies from the University of Chicago, she volunteered as a tutor and mentor at organizations that are devoted to working with at-risk youth. She then went on to work with women and children who were survivors of domestic violence. Her first internship was at Friedman Place in which she worked with individuals who are blind or visually impaired in a residential setting. Her second internship will be at Chicago Children's Center for Behavioral Health. Upon graduating, E. Pastuszewska hopes to work with children and adolescents in a mental health setting.*

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Bridging Micro and Macro Perspectives to Advance Social Justice:

An Essay

Padraic Stanley

A Foreword About Words

In this article, some terminology may be utilized or discussed that have debatable meanings and definitions for different social workers and other professionals. For the purpose of clear and effective communication of the author's ideas and opinions based off of readings and research, some of this terminology will be defined in this section. I cannot promise that all of the readers of this article will agree with the terminology or how it is defined; however, I believe that clearly understanding the points made in this article are crucial in understanding many of the ideas and calls to action in this article.

First, this article will discuss how the realms of social work practice- macro, mezzo, and micro are not mutually exclusive, and should not be mutually exclusive in our pursuit of social justice. However, in order to discuss this existing distinction, I will attempt to define what is micro, what is mezzo, and what is macro; for the purposes of this article, I will not be discussing mezzo social work in depth. Micro social work involves any social work practice that involves direct interaction with clients and community members, in which the social worker is providing a service. One of the first things I learned in my first social work course was that any interaction with those we are trying to serve is inherently clinical, essentially meeting the clients' psychosocial needs and working together to achieve tasks and goals. Therefore, I may use "clinical" and "micro" interchangeably in order to denote these interactions. Micro work is not limited to clinical or therapeutic work, but can include case management and other one-on-one interactions.

Macro social work, as utilized in this article, refers to work in social administration such as advocacy, evaluation, community organizing, and community outreach. Many may categorize these practices as mezzo-level social work; however, there is little consistency in literature regarding which level these practices fall under (Wuenschel, 2008; Austin, Coombs, Barr, 2008). Macro work can also include policy analysis and advocacy, which will be briefly discussed as well. This definition of macro work is significantly broader; however, since the 1980s, many schools of social work have been teaching these practices under the umbrella of "macro practice" because these practices draw on similar sets of skills and appeal to similar groups of social work students (Wuenschel, 2008). Just as any interaction with clients is inherently clinical, as will be explained later, any direct interaction with clients can also be coined as social justice (Birkenmaier, 2003). From that standpoint, the process by which we include clients in macro-focused processes through task groups, community organization, or volunteerism directly empowers individuals, creates opportunities for socialization and feelings of belonging and purpose, and contributes to the overall psychosocial wellbeing of those involved (Austin, et al., 2008; Birkenmaier, 2003; Perez, Espinoza, Ramos, Coronado, & Cortes, 2010).

Although it will not be discussed explicitly in this article, mezzo social work in this context includes group social work, psychoeducational groups and workshops, program management and evaluation, and program development. The point of this article is not to debate semantics but to act as more of a call to action, as well as to provoke more social work students and practitioners to think critically and more intentionally about how their work fits into the grander scheme of social work as a profession.

It will be helpful to include my social location in this discussion, in order for readers to think more critically about the points being made. I am currently a social work graduate student, having completed internships in case management for unaccompanied minors, program management and development for an immigrant rights coalition, as well as completing a fellowship performing counseling and psycho-education with undocumented immigrants and individuals from mixed-status families. Before pursuing my graduate education, I was a community organizer with undocumented youth. My involvement in all of these functions working within the same population, has helped me to see how interconnected all social work practice can be. I use a feminist perspective to inform my work, acknowledging that individual interactions and perceptions are impacted, if not formed, by structures at play in our society.

Introduction

Over time, social work has become a broader field; however, a dichotomy exists within the profession that stems all the way back to debates between community-focused interventions in the settlement houses to friendly visitors in Charity Organization Societies (Netting, Kettner, McMurty, & Thomas, 2012). Today, social work practice has largely been divided into the domains of micro versus macro social work amongst professionals and academics alike (Austin et al., 2008). The debate about what social work "is" and what our role pertains to as social workers has continued on, especially in schools of social work in regards to curriculum and how students are prepared for professional practice. The debate has continued on, even following the creation of the Council on Social Work Education (CSWE) in 1952 (as cited in Wuenschel, 2008). Many schools of social work today offer different tracks and specializations, giving students the opportunity to cater their studies to their personal interests and career objectives (Wuenschel, 2008). Unfortunately, many social work programs now do not offer macro or administration-focused specializations, and programs have a low number of macro-focused courses (Rothman & Mizrahi, 2014; Wuenschel, 2008). This shortcoming in social work education has largely been the result of a change in demand for social workers to become more clinically-focused and an increase in other schools of thought such as public administration, public health, business, and law taking more interest in work with nonprofit organizations and agencies (Jacobson, 2001; Weunschel, 2008). Additionally, a declining number of students are choosing to pursue macro or community-focused tracks in social work school, lessening the demand for macro coursework, macro-focused instructors, and essentially devaluing macro practice (Birkenmaier, 2003; Jacobson, 2001, Weuncshel 2008).

In my personal experience, studying an administrative track at a school in which the majority of students choose to study direct-practice clinical work has fostered a personal style of leadership, management, and development that I believe could be called a "clinically-informed" macro perspective. Throughout my social work education, I have been able to take a wide range of classes such as clinical practice classes, classes on racial and economic justice, and classes in social service administration. Continually hearing the commentary and reflections of my fellow social work students, as well, has prompted some extensive reflection about my role as a social worker, social work curriculum, and the role of our profession in addressing the oppression and marginalization felt by members of our society. .

Every social worker should, in theory, incorporate macro, mezzo, and micro perspectives into his or her approach to his or her function in the profession, regardless of employment title, agency, or role (Netting et al., 2012). This pragmatic perspective is integral to social work, allowing us to better assess the clients and communities we serve (Birkenmaier, 2003). This three-tiered perspective is designed to help us form a more comprehensive view of the clients we are serving and their communities, regardless of whether we are working as clinicians, case managers, executive directors, community organizers, or any other position in which we utilize our social work education (Wuenschel, 2006; Birkenmaier, 2003).

These reflections have prompted numerous discussions within my classroom experience, textbooks, and literature regarding the identity of social work practice, and what exactly the role of a social worker *is*. Social workers in numerous states are debating what it means to call oneself a social worker by title, issuing laws and policies that regulate who can call himself/herself a social worker (National Association of Social Workers, 2009) This is still a heated debate among students, academics, and professionals (Birkenmaier, 2003; Wuenschel, 2006; Rothman & Mizrahi, 2014). Many social workers are pushing for the professionalization of social work through licensure and requiring more clinical knowledge from practitioners and in social work education, while many believe that over-professionalization of the social work practice takes the profession away from its radical roots in community-building and social justice (Pelton, 2001). This debate frequently manifests itself in conferences, curriculum, accreditation, and discussions of licensure (Birkenmaier, 2003). As a result of these debates and splits taking part in schools of social work and among academics, social work practitioners also fall victim to a split within the profession when it comes to what methods are considered the most effective in advancing social justice and social change—macro or micro?

Some participating in this debate may believe that social workers' roles are simply to work within a broken system to improve the quality of life of those we serve; however, many believe social workers should take a more active role in changing the systems of oppression and marginalization that symptomatize, pathologize, and stigmatize our clients and our communities (Birkenmaier, 2003; Jacobson, 2001; Austin et al., 2008). This seemingly lofty goal assumes that social workers indeed have the ability to make an impact on the structural issues that bring our clients in through the door; however, we typically only have forty hours in a work week, and many social workers do not possess the political prowess necessary to directly affect political and social change (Birkenmaier, 2003). However, this commitment to social justice should not be taken lightly. A radical point of view I hold regarding the social work profession is one that may be considered that—radical. Social workers, regardless of their practice, make their living by working with clients or communities who have experienced injustices or hardships because of social injustices, caused by social inequalities perpetuated by society. Additionally, our clients largely come from these oppressed and marginalized communities. Social workers make their salaries and make their living by addressing these subsequent issues, and therefore social workers essentially benefit from oppression and marginalization. If social inequalities and social injustices did not exist, social workers would not have jobs, and it is imperative that as social workers we recognize the privilege we have to benefit from these social locations. Clients continue to pursue services in response to aspects present in society that continue to oppress and marginalize them. Therefore, if social workers are not doing anything to address the structural issues that continue to bring clients through the door, then the social workers in question are perpetuating oppression and systemic disadvantages for their own benefit. This reiterates the moral and ethical obligations social workers have to our clients and their communities.

Pursuing Social Justice

We have an ethical dilemma in social work practice: social workers are simply falling short in their ethical obligations to social justice (Birkenmaier, 2003). However, there are only 40 hours in a workweek, and social workers are notoriously overworked and underpaid. Additionally, some social workers may lack the intrinsic motivation or the dedication to social justice that is mandated in the NASW Code of Ethics. Unfortunately, one may assume that not all social workers pursue the profession to advance social justice. Additionally, many individuals with social work education and training may have a difference of opinion in how to best address those social disparities. Unfortunately, social justice and advocacy-focused organizing positions are relatively low-paid and undervalued (Birkenamier, 2003; Wuenschel, 2006). Social work students and professionals alike frequently discuss the importance of advocating for ourselves and for our profession—advocating for more benefits, more reasonable hours, better pay, etc. (Weunschel, 2006; Jacobson, 2001). However, Julie Birkenmaier (2003) suggests that when working in an agency or clinical setting, we can still take time to step back from our work and determine the social structures that create and sustain the social inequalities that are affecting our clients. We can do this by maintaining a "critical consciousness about the structures that create and maintain [clients'] issues, and seek[ing] to empower clients to become involved in the community efforts toward institutional change and reform" (Birkenmaier, 2003, p.45). Once these particular issues of focus are determined, social workers can work toward developing potential interventions where advocacy can be focused. Instead of adding on responsibilities to existing positions, those within the agency or organization could be advocating for the creation of staff positions that focus solely on advocacy for the structural issues that are affecting the clientele served by the organization or agency. Of course, this raises the question of organizational capacity and potentially the need for coalition building, collaboration, and further agency partnerships. Not only does this form of advocacy make headway in creating social change for our clients and their communities, it strengthens most agencies' commitments to their missions and visions. This also presents opportunities for social workers to become dynamic agents of change within agencies and structures, fortifying highly desired skills in leadership and development. Social work practitioners in all roles can also advocate for organizational and community change through implementing program or organizational evaluations (Gitterman, 2014).

While service delivery and activist roles can be viewed as competing, it is more beneficial towards achieving the mandates of our Code of Ethics to view the roles as "complementary and intertwined" (Birkenmaier, 2003, p. 42). For example, when doing policy or community work, or even when implementing programming as administrators, in order to be effective in our delivery of services or in implementing meaningful changes it is necessary to work collaboratively with or explicitly inform and involve community members in the process of determining and prioritizing community needs. This way, policies and actions are more likely to reflect the contributions and wishes of those served. From this perspective, the human interactions present in community organizing are inherently clinical. Outreaching, interacting, and engaging with community members and leaders helps social workers to find out what the strengths are of a community, its leadership, and its resources. By helping identify these strengths, we are utilizing a tried-and-true social work idea of the "strengths perspective," applied to communities (D'Agostino & Kloby, 2011). By utilizing the strengths and resources present within the community, we take on the perspective that all of the tools necessary for positive change are already present within the client (or in this case, the community), pushing forward the goals that are determined by those served (D'Agostino & Kloby, 2011).

Overall, social workers are trained through education and practice to incorporate perspectives from all three tiers of social work practice—micro, mezzo, and macro. Clinicians, case managers, and other direct-practice social workers can play a vital and important role in the advancement of social justice of communities through individual work. Macro social workers can also implement clinical perspectives into community work or administration; clinicians have a unique perspective, directly interacting with oppressed peoples within the intimate client-therapist relationship. Additionally, many direct-practice social workers have the capacity for an intimate understanding of their clients, giving them insight into their clients' experiences navigating through society and the structural issues that affect the people they see.

The devaluing of clinical practice within social work debates from macro-focused academics and practitioners must end (Austin et al., 2008). Additionally, an overly harsh critique of formalization, licensure, and psychotherapeutic practice only perpetuates the false dichotomy that is splitting our profession (Weunschel, 2006; Austin et al., 2008). It is important to recognize that there are multiple levels of advocacy, and social workers must stand in solidarity together to advance social justice, continuing to provide more comprehensive interventions to advance social justice. Social justice applied to only one or a few people is still crucial and certainly not less influential than social justice on a larger scale. By empowering clients by pointing out their strengths and giving them the tools necessary for success, we are still practicing the advancement of social justice (Birkenmaier, 2006; Morris, 2001). Meanwhile, social workers who decide to focus on macro work such as policy work and organizing or mezzo work such as programming and group work also should not have to struggle for legitimization within social work communities.

However, there is always the question of how we can do *more*, how we can do *better*, and how we can more pragmatically serve our communities and our missions. All social workers should be challenging themselves to create a better existence for their clients and the communities they serve, not out of obligation, but rather out of the desire to truly strive for social justice.

Reflections in Practice

At my current internship, I have been working on a specific project that I believe bridges direct service and macro perspectives to advance the social justice of a racially and economically oppressed community. I work at a coalition of community-based organizations, and part of my internship requires that I take on different projects from member organizations in order to build their organizational capacity or help them plan or evaluate programs. One project I have taken on is a community center in the south side of the city that serves a community that is mostly low-income Latinos/as, many who are undocumented. My goal at this agency is to increase the capacity of their weekly food bank. Currently, about 100 families wait every week for food, but unfortunately the organization only receives enough food donations and space to make 45 small bags every week. This means that every week, more than 50 families go home empty-handed. Although the idea of gaining more donations and getting the food pantry up to 100 bags a week seems like an easy fix, this project requires a significant amount of program planning, meetings with staff and administrators, applications for grants and partnerships, phone calls and emails, networking, and marketing. It involves building relationships with community members and leaders, with other organizations, with businesses, and with donors—establishing rapport and convincing these key stakeholders of why they should take an active interest in a weekly food bank. These are all considered macro-practice skills to most social workers; however, the final objective of this work is to increase the capacity of a direct service.

In order to incorporate inclusive, sustainable, and culturally sensitive interventions into the program, I make sure to incorporate current volunteers and community members into these organizational changes. I have established a volunteer committee where volunteers bounce ideas back and forth about how to improve the food pantry, as well as how to recruit and train more volunteers. Being members of the community they are serving, they have an in-depth knowledge about the resources and dynamics of their communities, and they can also vouch for the organization and my consulting agency amongst other community leaders. This way, I am utilizing direct practice perspectives such as establishing rapport, building a relationship, and setting goals together into the macro practice of organizational management, development, and community organizing. While reflecting on this experience, I'm proud of the approaches I am taking in my internship toward social justice and empowerment. However, this also made me reflect on how, during my last internship, I did not do enough in direct practice to change the structural issues impacting my clients.

At my previous internship, I was a family reunification specialist for unaccompanied immigrant minors who were detained while crossing the border without inspection. The minors were remitted to my facility by the Office of Refugee Resettlement for medical, educational, and acculturative services and to reunite them with appropriate familial sponsors within the United States. Although we provided comprehensive services and treated the children with dignity while they were in our facility, I couldn't help but feel that by working within a broken immigration system I was perpetuating and benefitting from the structural oppression faced by these migrant children. I knew I was doing my best to help these children by reunifying them with their families, aiding in the provision of services to them, and connecting them to appropriate services in their new homes, but the guilt was still present in my reflections and supervision.

By working as a family reunification specialist, I had no impact on immigrant policy, immigration policy, or the transnational economic policies that contribute as push factors to migration. While we were offering comprehensive services for these children within the confines of oppressive immigration policy, we would then reunite them with their families, where they would be subject to issues such as discrimination, racism, gentrification, workplace abuse, and violence, and would continue to suffer the constant fear of immigration raids and deportations.

This reflection is not to say that family reunification or refugee resettlement is a frivolous position, similarly in a way that this article is not meant to degrade or minimize micro social work; however, reflecting and analyzing my role and perspectives in this work was beneficial in seeing how we fit, as social workers, into the lives of our clients and structures of society. These reflections made me evaluate my role as a social worker in advancing social justice. Interacting with these children and hearing their stories intensified my passion for working with immigrant and refugee populations and opened my eyes to the experiences of irregular migration. Although I did not have a direct impact on the oppressive structures that affect these clients, recognizing my social location in this work contributed significantly to a more macro understanding of the multiple factors at work, and has strongly inspired me to pursue advocacy efforts in addressing these shortcomings.

Social Work as Social Justice

Social workers' approaches and perspectives are intertwined with the values of social justice and social philosophy (Birkenmaier, 2003; Morris, 2001). The idea that internal factors such as resilience and external factors like support systems and education both heavily influence the wellbeing of our clients is a concept deeply embedded in multiple approaches to social justice (Birkenmaier, 2003). "Self-determination, the right of each person to shape her or his own life, is at the core of the capabilities perspective and plays a pivotal role in social work" (Morris, 2001, p. 371). Additionally, the educational aspect of therapy, as well as the perspectives of strengths-based empowerment in clinical practice, affirm the role of social workers in addressing the social inequalities created by oppression, recognizing that some people are more in need of resources and advocacy than others (Morris, 2001; Nussbaum, 2003). Social inequalities are for many not simply layered but exponentially influential in lived experiences and outcomes (Morris, 2001; Nussbaum, 2003).

To illustrate this stance on social justice, we can focus on one of my mentor's clients. This elderly client lives in a very poor area of Chicago right across the street from a factory that has been polluting this particularly impoverished neighborhood for years despite numerous protests and investigations. The pollution creates soot and dirt throughout his entire home, and he is on an oxygen machine. Given his social location of being poor, undocumented, and elderly, this client does not have the capacity to move elsewhere; however, his health continues to decline and his oxygen needs continue to rise. Because of the pollution terrorizing his house, the property would be impossible for him to sell. This illustrates how power and privilege manifest themselves exponentially within our society and the continued devaluation and invisibility of the oppressed. This situation highlights how a more comprehensive view incorporating micro and macro perspectives is imperative in understanding the many colluding factors affecting our clients and their communities. It would be impossible to help this man or even to understand his situation using only one perspective. This story illustrates the need for social workers and collaborating professionals addressing social determinants of health to develop structural interventions that not only address practical issues, but also public attitudes and structures through advocacy and empowerment.

Conclusion

In closing the readers of this article should challenge themselves to be more cognizant of their roles as social justice advocates, incorporating the concepts of economic and racial justice into their daily work and advocating for the best services and interventions for their clients' communities. The social work profession's commitment to social justice can be furthered and strengthened by implementing clinical and direct-practice perspectives and frameworks into macro practice, as well as encouraging direct practice staff to utilize methods of advancing social justice. I also believe it is important to advocate within the social work communities of academia and professionals to break the false dichotomy of micro and macro practice, in order to better address the lived experiences of the communities we serve.

***Padraic Stanley** is preparing to graduate from Loyola University Chicago with his Master's Degree in Social Work, where he specializes in social service administration. He is a Albert Schweitzer Public Health Fellow, and has completed field practicums at the Heartland Alliance and the Illinois Coalition for Immigrant and Refugee Rights. Before moving to Chicago, Padraic was a community organizer for an activist group for undocumented immigrant youth, and before that performed Spanish-speaking community outreach and other field organizing through numerous political campaigns. His research and practice interests surround undocumented immigration and migration.*

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Mindset, Misconception, and Money:

Social Reactions to ADA Accommodation in the Workplace

Hayley Stokar, MSW

Abstract

Despite the existence of the Americans with Disabilities Act of 1990, discrimination against workers with disabilities is still a pervasive problem. Though there is a baseline tendency for employers to attribute the lack of disability hiring to the monetary costs of accommodation, it is arguable that the central issues of disability exclusion are more directly based on constructed social biases. Research and anecdotal experience indicate that social variables are involved in the decision-making process of people without disabilities. Theoretical lenses such as stigma theory and causal attribution theory are helpful in understanding the human behavior that may be steering reasonable accommodation legislation away from its optimal efficacy. This paper will provide an analysis of social theoretical issues, along with economic stances, as they relate to hiring policies for persons with disabilities. Implications for practice in disability advocacy will also be discussed.

Keywords: accommodation, ADA, causal attribution, cost effectiveness, disability, discrimination, employment, stigma

Introduction

People with disabilities are notably disadvantaged in the work arena. Though physical and sensory limitations may preclude them from performing certain tasks, individuals with disabilities are denied opportunities in a staggering array of different jobs, despite their ability to perform the job well using accommodations. Scholars in disability studies and related fields have probed the issue at length. Despite the existence of federal legislation—namely, the Americans with Disabilities Act of 1990 — discrimination against workers with disabilities is still a pervasive problem. The U.S. Department of Labor's Bureau of Labor Statistics indicated that as of 2014, the unemployment rate for people with disabilities was 13.2%, compared with 7.1% of nondisabled individuals (2014a). What is the impetus for exclusion? Is it solely a question of perceived costs, or is it rooted in social attitudes? While the Equal Employment Opportunities Commission (EEOC) combs through macro-level data to address the former, a theoretical discourse is building prominently around the latter.

Though there is a baseline tendency for employers to attribute lack of disability hiring to the monetary costs of accommodation, it is arguable that the central issues of disability exclusion are more directly based on constructed social biases. The following article will examine economic processes as well as social theoretical issues as they relate to hiring policies for persons with disabilities. Implications for practice in the fields of social work and disability advocacy will also be discussed.

Dollars, Directives, and Disability

American legal philosopher Ronald Dworkin is quoted for saying, "there is a difference between treating people equally and treating people as equals" (1981, p. 185). The Americans with Disabilities Act (ADA) of 1990 was a game-changer for American workers and employers, galvanizing the idea that workers with disabilities have the same human prerogatives as non-disabled workers, though their work setting and processes may need to be modified. The ADA was the first piece of federal legislation mandating reasonable accommodation for applicants and workers with disabilities, defined as "any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities" (Title I, ADA, 1990). Many accommodations in the workplace are free, such as schedule modification, furniture and office supply rearrangement, and the use of email instead of telephones. Some accommodations, however, come with notable monetary costs, such as installation of ramps, purchasing of special technology, and hiring American Sign Language interpreters.

Throughout the literature on disability in the workplace, associated costs are cited as a reason why businesses are reluctant to hire persons requiring accommodation, even when they can perform the jobs as well as non-disabled workers (Domzal, Houtenville, & Sharma, 2008; Bruyère, Erickson, & VanLooy, 2006; Fraser, Ajzen, Johnson, Hebert, & Chan, 2011; Unger, 2002). Why hire a forklift driver who can do well after $600 worth of Sign Language interpretation for his orientation, when you can hire a forklift driver requiring $0 for orientation? Even if employers believe that workers with disabilities can achieve comparable performance levels, they may perform simple cost-benefit analyses and determine that hiring is not in their best economic interest.

An understanding of microeconomics would suggest that avoiding added costs is a good idea. These employers, however, may be focused only on *direct* costs, and may not account for *indirect* and *intangible* costs (Schartz, Hendricks, & Blank, 2006). For example, when considering the purchase of vehicles for one's work commute, the vehicle with the lowest associated direct cost would be a children's tricycle. The indirect cost of tricycling to the office, however, involves the opportunity cost of taking three times as long as other transit modes, thus leaving you less time for other things. Additionally, the tricycle rider may confront intangible costs such as the loss of dignity and respect of his co-workers.

Trivial examples aside, long-term, indirect costs like employee turnover, as well as potential cost defrayers like federal tax breaks through the Work Opportunity Tax Credit (WOTC), must also be taken into account. The WOTC is a federal tax credit encouraging the hiring of nine target minority hiring groups, of which the disability community is one. It reduces employers' federal income tax liability as much as $2,400 for each new adult hire (Unite States Department of Labor, 2014b). Failure to consider these factors can render employee cost-benefit analyses far from accurate. Instead of costs alone, Greenhalgh (2010) advises critical thinkers to examine *net overall costs* (opportunity costs as well as tangible costs) rather than simple, direct costs in economic analyses. Cost assessment from multiple angles may paint a less expensive picture of disability hiring.

Business size, too, can impact employers' willingness to adhere to the ADA. Bruyère et al. (2006) note differences in hiring attitudes for small companies as compared with large companies. Though a common barrier reported by all employers was the perceived lack of requisite skills on the part of the individual, larger firms were significantly more likely to use attitudes and stereotypes in their reasoning (*ibid.*). Smaller companies were significantly more likely to mention costs of accommodation as a barrier (Bruyère et al., 2006). It is true that for large corporations, accommodating a single worker has a smaller impact on their functional budget than it would for a small business with just a few employees (*ibid.*). Though implicit attitudes about the level of assistance needed by disabled workers may skew their assumptions about how much (or how little) an accommodation actually costs, this study points to the practical cost-benefit analysis being used by employers with more limited budgets (Bruyère et al., 2006) .

The flip side of discriminating in order to shirk accommodation costs involves the risk of incurring a complaint through the Equal Employment Opportunity Commission (EEOC), the federal law enforcement agency monitoring illegal discrimination in the workplace (Equal Employment Opportunity Commission, 2014). After all, discrimination is legally prohibited by the ADA and widely viewed as reprehensible. An analysis of EEOC data revealed that hiring allegations were most likely to be filed against employers with 15–100 employees (McMahon, et al., 2008). From an economic standpoint, it appears that smaller employers have the most to gain *and* the most to lose when it comes to adding even one employee who requires accommodation.

Even with associated costs of accommodation, Schartza, Hendricks, and Blank (2006) confidently assert the companies experience net economic benefit through hiring individuals with disabilities. First, accommodation costs are often lower than assumed, yet blanket assumptions (with little empirical evidence) are employed to argue that the ADA has actually worsened the employment rate of persons with disabilities because of added expenses related to hiring. The few studies that exist on this topic relate only to initial capital needed for accommodations, and do not take into account (a) indirect costs such as time and training, and (b) direct and indirect benefits such as longer retention, improved morale, and technologies such as a ramp or an elevator, from which consumers, visitors, and personnel may all benefit (p. 346).

Investment in a person, whether or not the person has a disability, always carries with it a long-term effect. Though it may seem too "touchy-feely" for some economists, the Theory of Human Capital (Becker, 1962) highlights success with personnel as a function of individual educational and training characteristics. Human capital can be considered an asset, just as physical property or monetary funds are assets. In other words, a reasonable accommodation that allows a worker to flourish can be likened to on-site training towards specialization, or even financial assistance with pursuing a degree in higher education. All of these business decisions, which involve both financial and social relational variables, foster enhanced loyalty due to the traditional experience of disability exclusion or marginalization, and enhance a worker's ability to contribute (Kessler & Lulfesmann, 2006). While the latter two are already acknowledged by employers as valuable long-games, reasonable accommodation is not yet seen in this light.

Attribution, Stigma, and Disability

Despite initial forecasts for change, Title I of ADA (the section mandating reasonable accommodation) has had less success than expected. Research and anecdotal experience indicate that social variables are also involved, such as exposure to disabled individuals (or lack thereof) shaping employer attitudes (Schroedel & Jacobsen, 1978). Several theoretical lenses are helpful in understanding the human behavior that may be steering reasonable accommodation legislation away from its optimal efficacy.

Attitudinal barriers for people with disabilities, both within and outside of employment contexts, are often rooted in stigma. Stigma is the relegation of people with perceptible differences as deviant or *other*, most often with negative associations (Goffman, 1963; Link & Phelan, 2001). It is a multi-dimensional social process that is interpretive in nature and involves meaning that is couched fully within culture, rather than in biology (Yang et al., 2007, Major & O'Brien, 2005). In other words, when people see that individuals possess a characteristic that renders them "different" from the majority, they assign social meaning (mostly negative) to the whole individual on account of that characteristic.

Prototypical characteristics of disability, which feed stereotypes, are seen by some as being the root of the formation of social attitudes toward people with disabilities. McCaughey and Strohmer (2005) highlight stereotypes of disabled people as dependent and emotionally unstable, and assert that these stereotypes can impact employment, social relationships, and misunderstandings about roles in the workplace.

Reviewing national outcomes of discrimination complaints to the EEOC, albeit a method that neglects contextual details can be a way of learning whether a stigmatized characteristic is impacting the assessment of employee performance. Bowe's (2005) examination of EEOC resolutions from 1992-2003 revealed that discrimination complaints from deaf and hard of hearing employees were significantly more likely to be awarded merit. The author suggests that, because hearing loss is particularly obvious in social interactions while relatively unknown-about through personal experience, employers may use this noticeable condition as a disqualifier (Bowes, 2005).

Legal mandates like the ADA, however far-reaching via federal authority, cannot police the nuanced social interactions between people in the workplace. Bowe (2005) asserts that the best remedy to stigmatization is for the applicant/worker herself to bear the responsibility of educating employers: "Applicants who are well prepared to make articulate their qualifications, and to point out the ready availability of low-cost accommodations…may be more likely than others to find success in the world of work" (p. 25).

If there is one thing upon which all literature on disability and employment can agree, it is that people with disabilities are under-represented in the workforce. The contrasting opinion, therefore, , is that non-disabled employers are under-exposed to workers with disabilities. Gething and Wheeler (1992) found that people with lower levels of previous contact with people with disabilities are more likely to experience discomfort when they do encounter them. They suggest some factors influencing this discomfort include fear of the unknown, guilt about one's own lack of a disability, and general aversion to weakness. It is no wonder, then, that employers with no exposure to people with disabilities have nothing to blunt the effect of the factors listed above, and will use what they "understand" about disability to shape their hiring and management decisions.

Causal attribution theory (Hewstone, 1989), also known as attribution theory, is an outgrowth of stigma theory, discussed above. It suggests that the meaning of just one attribute of a person arbitrarily influences how people perceive the entirety of that person. For example, if one sees a man with an eye patch and a parrot on his shoulder, one might assume that he is surely a Caribbean pirate. The pre-existing associations with the smaller characteristics lead us to draw conclusions about the *entire* person. Even if the gentleman in question is simply an ornithologist recovering from cataract surgery, we might be loath to let him near our valuables.

Employing a less frivolous analogy, causal attribution theory could explain why an employer assessing an applicant with a hearing aid may assume that the person does not possess the communication abilities necessary to perform a job function. She is using the perception of an assistive device to create a cognitive shortcut to the conclusion that the disability is insurmountable, rendering the person unqualified. Discrimination is the value assessment in the marketplace of personal characteristics of the worker that are "unrelated to worker productivity" (Arrow, 1971, p. 2).

Special workplace contexts emphasizing visual aesthetics and communication style are a prime arena for attribution to mediate social processes. Sales, fine dining, luxury markets, and entertainment are sectors replete with jobs of which people with disabilities are capable, yet rarely employ people with disabilities in the "front of the house", interacting directly with consumers. It is thought that managers in the field may associate physical difference with the inability to interact "normally" with people without disabilities. Colella and Bruyere (2011) have labeled this phenomenon "aesthetic anxiety or a discomfort interacting with those who deviate from what mainstream society considers physically attractive" (p.475).

Implications for Practice

Two things vocational rehabilitation professionals and advocates can do are to engage in new research and to proliferate information about the ADA in ways that can be understood by employers. While some studies cited herein were conducted in the past five years, many of them date closer to the time of the ADA's passage. Still more are aggregate analyses of EEOC complaints which, while providing some meaningful information about the *results* of workplace discrimination, do less to explain the causes and circumstances. Newer studies would more accurately reflect the situation of workers and employers. To learn more about the matter, it is important to start with open-ended information gathering at the source—namely, the people in the workplaces.

Disability advocates need not only to support job seekers with disabilities—they can also become allies of under-informed employers. Advocates can use relationships to gain knowledge about what the ADA looks and feels like from the *employers'* perspective. By asking them to describe their experiences, opinions, attitudes, and struggles, advocates can paint a more thorough picture of the workplace of disabled persons from the viewpoint of the stakeholders with the most power.

The fields of vocational rehabilitation, social work, and counseling, among other disciplines, emphasize meeting people *where they are* and refraining from judgment (Strupp, 1993; Constantine, 2001). Employers and employees are, ultimately, both human. There may be social tension or discrimination occurring unintentionally that strongly impacts the relationship between non-disabled managers and employees with disabilities. With attitudes changing through exposure and education, decisions can be made that can create beneficial change in the way people work together.

Blackburn (2002) found a significant correlation between employers' attitude toward people with disabilities, awareness of ADA, and willingness to make accommodations. She suggests that awareness of the ADA and people with disabilities can be improved through professional workshops and enrichment trainings. Blank & Slipp (1994), who interviewed workers with disabilities, write that the most important intersection in disability employment is the place where attitude and accommodation overlap. They provide the tough love suggestion of insisting that managers and coworkers simply need to deal with their discomfort, "get over it", and adhere to ADA mandates.

Conclusion

A review of the literature on disability in employment reveals that, while monetary costs of accommodation do play a role, shortcomings of the ADA seem more directly related to social attitudinal barriers and the *incomplete* use of economic reasoning. Limited knowledge about workplace accommodations and the disability for which they correct leads to the perpetuation of discrimination. Social theories, in addition to thoughtful scrutiny of how the ADA and other federal policies manifest in implementation, can be used to create strategies to combat employment discrimination based on disability. Ultimately, people's behavior makes all the difference in the implementation of federal policies like the ADA. Change should manifest in relationships between managers and workers, between people with and without disabilities. Minds may change slowly, but they are not unchangeable.

Hayley Stokar *is a Doctoral Candidate in the School of Social Work at Loyola University Chicago. She also serves as an Employment Specialist at JVS Chicago, where she works with deaf and hard of hearing job seekers and community employers. Hayley holds a BA in Anthropology from Wesleyan University in Middletown, CT, and an MSW from Gallaudet University in Washington, DC.*

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Insider to "the Purity Myth": An Evangelical Christian Perspective and Introduction of Feminist Theory for Best Social Work Practice

Sam Foist Swart

Abstract

Insider to "the Purity Myth" will address the theological background for language pertaining to the ways in which purity and modesty are lived in modern-day society. After a brief, exegetical, evangelical analysis of biblical purity, a discussion of wider implications of this belief system will ensue. The conclusion of this paper will discuss feminist practices and feminist theory relevant for social workers to utilize with their clients.

Keywords: abstinence, Christian, evangelical, feminist, feminist therapy, gender, gender expression, modesty, purity, purity culture, social work, theology

Introduction

The purity movement has had a pervasive influence on western culture since the early 1990s, as evidenced by the "True Love Waits" campaign, an agenda to curb sexual activity in single men and women (Love Matters, 1997). Mostly made up of white, heterosexual individuals, this campaign for purity is a form of worship and belief that God's divine plan is for individuals to abstain from sexual intercourse until marriage. As a nation with a melting pot of ideologies, values and belief systems, evangelical Christians have used their voices for speaking their truth and continue to bring faith into a very public sphere. The goal of the purity movement is to bring followers of Christ closer to God through sexual purity and chastity, thereby exemplifying a purified and holy relationship between Christians and God. The goal of *Insider to "the purity myth": An evangelical Christian perspective*, *and introduction of feminist theory for best social work practice*, is to explore the religious rootedness of the purity movement in an effort to better understand the purity movement in a larger societal context. This context will then be utilized as a backdrop for how feminist therapists can engage with clients who divulge their own personal experiences with purity culture.

Undoubtedly, the purity movement has at least given rise to religious conversations about sex and sexual identity, however, this paper is an exploration of the deeply rooted notions of how purity is linked with a sense of self and how this sense of self is perceived by God. The following sections will be covered: acknowledgement of the authors' situatedness, an exegesis on a few Bible verses that have implications for biblical purity, the ways in which modern, evangelical Christianity engages with the idea of purity, and implications for feminist social work practice. The author will explore the roots of the purity movement and discuss some of the ways in which society has traditionally interacted with those ideas and beliefs. From an insider's perspective, the author will engage in an open dialogue about societal engagement in the purity movement.

Notes About Authorship

Before this topic is explored, the author must take a minute and acknowledge her own situatedness and position of power regarding the information provided in this paper. First, the author wants to disclose that she is a Caucasian, cis-gendered,[1] queer woman. Historically, she has been fully invested in the purity movement, however, she no longer identifies herself as a Christian evangelical. The author was significantly impacted by the purity movement and ultimately left the evangelical church because of the ways gender and sexuality were discussed. The author also acknowledges the amount of power she had when writing this paper. Since the author relied mostly on secondary sources, there were decisions made for which narratives and content to include. No research is completely objective, and by nature it places the subjects into a subordinate position.

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[1] Cis-gendered means that the sex assigned at birth matches an individual's experiences of gender

The author must make it clear that the goal is to explore the issue of purity culture and not to inscribe marginalization toward a group of individuals. Efforts to avoid over-generalizing were made, although some areas of improvement must be acknowledged. As a researcher, the author wanted to approach this topic with care and hopes this paper will lead to larger discussions about how religiosity is tied to the beliefs and attitudes about the way individuals experience purity and communion with the Divine.

Exegetical Analysis

When it comes to a proclamation about sexual purity, one of the most well-known verses is 1 Corinthians 6:18-20. According to the English Standard Version of the Bible, 1 Corinthians 6: 18-20 states:

> Flee from sexual immorality. Every other sin a person commits is outside the body, but the sexually immoral person sins against his own body. Or do you not know that your body is a temple of the Holy Spirit within you, whom you have from God? You are not your own, for you were bought with a price. So glorify God in your body.

The King James Version used the word “fornication” instead of “sexual immorality”. Comparing the King James Version, the English Standard Version, the New American Standard Bible and the New International Version translations of the Bible, yielded little difference in interpretation (Bible Gateway, 2014). Both fornication and sexual immorality are translated from the same Greek word, πορνeia, or porneia, which is a noun referring to either “the defilement of idolatry, as incurred by eating the sacrifices offered to idols” or illicit sexual intercourse, such as, “with a close relative, a divorced individual, adultery, or intercourse with animals” (Blue Letter Bible, 2014a). Porneia stems from the Greek word porneuō, which is a verb meaning to be drawn into idolatry or to “prostitute oneself by participating in unlawful sexual intercourse” (Blue Letter Bible, 2014b). Other variations of the word porneuō include pornē and pornos- each refer to female and male prostitutes, respectively (Blue Letter Bible, 2014c). Finally, the last variation of porneuō, pipraskō, refers to “selling one into slavery”(Blue Letter Bible, 2014d). In Greek, the word fornication occurs 26 times in the New Testament, according to the New American Standard Bible (2014f).

Theological Implications of Honor

The previous verse brings up a few important ideas. First, the verse points toward the idea that if you are a Christian, your body is not solely for your own use. According to the concept of *imago dei*, made in the image of God, humankind was formed and made according to God’s design and plan (Genesis 1:26). Because of God’s close connection to humans, he/she sent Jesus to pay the price of sin so that the connection could be restored and humans could enter into a deeper relationship with the Divine. Because of this price, humans are expected to give their physical body, soul, and will to God for usage in their grand plan. If a Christian’s body is not their own, but instead belongs to a collective group of people that worships as one body, then the collective needs to discover a way to bring honor to God by growing and developing into something more righteous and holy, traits oftentimes associated with God.

As a collective, it makes sense to flee from sexual immorality or fornication. Sexual immorality and fornication in Greek can translate to unlawful sexual acts, such as eating sacrifices offered to idols, prostituting ones’ self, or selling someone into slavery. Immorality and fornication are actions to be avoided, according to the Greek roots of porneia (Blue Letter Bible, 2014b). As a community or large body of Christians, the idea is to flee from that which could turn the focus off of God. As a community that rejects the behaviors just described, this verse gives the directive that humans are temples of God. According to a general, evangelical perspective, God made humans and formed them to be places that they can dwell as the Holy Spirit. According to 1 Corinthians, the notion that bodies are dwelling places for the Divine necessitates certain behavior that leads individuals on the path of righteousness, purity and holiness. For the Holy Spirit to dwell within humans, the walls of the temple cannot be detailed with repeated sins of immorality.

Theological Implications of Divine Connection

The idea of the body being a temple is an issue worth exploring, because it offers a great segue-way into the belief that an individual should save themselves for marriage. If sex outside of the marriage bed is seen as immoral, then keeping the body clean or divorced from all senses of immoral behavior is necessary. The Greek word nä-os is used 45 times in reference to a temple in the New Testament, according to the NASB, and once in reference to a shrine (Blue Letter Bible, 2014e). As a temple, nä-o's refers to the *place* where the image of a god is kept (Blue Letter Bible, 2014e). For Christians, the temple where the God of Abraham and Isaac dwells, is the human flesh. The Holy Spirit lives and works within the flesh to guide humans in their communication with the Lord.

Theological Implications of Sex

One interpretation of keeping the temple clean and undefiled is by keeping the marriage bed pure. For example, Genesis 1:27 and 2:24 state, "So God created man in his own image, in the image of God he created him; male and female he created them…. Therefore a man shall leave his father and his mother and hold fast to his wife, and they shall become one flesh" (ESV). Matthew 19:4-5 references this by stating, "He answered, 'Have you not read that he who created them from the beginning made them male and female', and said, 'Therefore a man shall leave his father and his mother and hold fast to his wife, and the two shall become one flesh'?" To hold fast or join means to cleave, cling or stay with (Bible Study Tools, 2014). The Greek word for join or hold fast is dä·vak' or dabaq (Bible Study Tools, 2014). This joining requires that a man leave his father and mother and become one flesh with his wife. One interpretation is that sexual intimacy occurs at a great cost, requiring leave of the family home and offered protection. The intimacy between a husband and wife binds their flesh together into one body. Two people do not literally walk around in one body after marriage, but spiritually, the two become one with a joint purpose and common goals. Hebrews 13:4 states, "Let marriage be held in honor among all, and let the marriage bed be undefiled, for God will judge the sexually immoral and adulterous (ESV)." From just these few verses, one can make a safe assumption that marriage is viewed very highly. Sexual intimacy between two individuals is viewed as a spiritual act. Keeping in mind the call to keep the temple clean, it makes sense that sex would be viewed in such a way that it is only lawful within the confines of marriage. Joining with another's flesh is something that is not to be taken lightly. Another example exists within the *Song of Songs*, a book located within the Bible:

> Oh that you were like a brother to me who nursed at my mother's breasts! If I found you outside, I would kiss you, and none would despise me. I would lead you and bring you into the house of my mother-- she who used to teach me. I would give you spiced wine to drink, the juice of my pomegranate. His left hand is under my head, and his right hand embraces me! I adjure you, O daughters of Jerusalem, that you not stir up or awaken love until it pleases (ESV, 8:1-4).

This verse references not stirring or awakening love until one is safely in the confines of marriage, a place for "true" expression of sexual intimacy. The next verse offers a good conclusion in that it draws attention toward keeping one pure of sexual immorality because of the Holy Spirit's dwelling place in the temple of human flesh. It states:

> For this is the will of God, your sanctification: that you abstain from sexual immorality; that each one of you know how to control his own body in holiness and honor, not in the passion of lust like the Gentiles who do not know God; that no one transgress and wrong his brother in this matter, because the Lord is an avenger in all these things, as we told you beforehand and solemnly warned you. For God has not called us for impurity, but in holiness. Therefore whoever disregards this, disregards not man but God, who gives his Holy Spirit to you (1 Thessalonians 4: 3-8 ESV).

If abstaining from sexual immorality leads to holiness and honor, it makes sense then, that logically, Christian evangelical circles would seek to negotiate ways to carry out that command. The belief that the body is a temple for the Holy Spirit will impact the actions and behaviors of people seeking to engage with the Divine.

Concluding Remarks on Theological Purity Language

There is a lot of background to the purity culture and it would be foolish to think that this paper could cover all of the specifics. This first section provided a few broad, general ideas of a foundation to the purity movement. If an individual ascribes to the belief that Christians are to collectively keep the temple free of that which draws attention away from purity and holiness, it bares the weight that Christians need specific ways to make the body a temple or dwelling place for God. Nothing is off limits, all areas of life become modalities of analysis. The foundational views of purity, honor and holiness, lead to an intricate belief system, a system often evaluated based upon the sexual character or behavior of an individual. The following will discuss the ways in which beliefs about honor and purity are translated into a modern-day socio-cultural movement.

The Societal Influence of Biblical Purity Language: Abstinence-Only Education

Evangelical, theological beliefs about purity become translated into some ingrained traditions in society. Take for instance, abstinence- only education, according to the Department of Labor, Health and Human Services and Education, and Related Agencies Appropriations Act of 2002: '"Abstinence education' means an educational or motivational program which:

> (A) Has its exclusive purpose, teaching the social, psychological and health gains to be realized by abstaining from sexual activity;
> (B) Teaches abstinence from sexual activity outside marriage as the expected standard for all school age children;
> (C) Teaches that abstinence from sexual activity is the only certain way to avoid out-of-wedlock pregnancy, sexually transmitted diseases, and other associated health problems;
> (D) Teaches that a mutually faithful monogamous relationship in context of marriage is the expected standard of human sexual activity;
> (E) Teaches that sexual activity outside of the context of marriage is likely to have harmful psychological and physical effects;
> (F) Teaches that bearing children out-of-wedlock is likely to have harmful consequences for the child, the child's parents, and society;
> (G) Teaches young people how to reject sexual advances and how alcohol and drug use increases vulnerability to sexual advances; and
> (H) Teaches the importance of attaining self-sufficiency before engaging in sexual activity. (Perrin & DeJoy, 2003)

The goal for abstinence-only education programs is to delay sexual intercourse until marriage, because sex is deemed "safer" within the context of a marriage. This "safety" pertains to protection from: sexually transmitted infections, single parenthood, and multiple sexual partners. However, a 2007 federally funded study, done by Mathematic Policy Research, showed that "youth enrolled in the abstinence- only programs were no more likely than those not in the programs to delay sexual initiation, to have fewer sexual partners, or to abstain entirely from sex" (Advocates for Youth, 2008; Swart, 2013). While waiting to engage in sexual intercourse may have some benefits, oftentimes the conversation surrounding waiting is dealt with in terms of keeping one's self whole or pure for their spouse. Pictures about STI's and pregnancy are used as a scare tactic to keep teens from engaging in sex, for fear they will contract an infection or become pregnant. There is a sort of fear mongering when it comes to these discussions because there is an assumption that a potential spouse will not be attracted to someone who has previously had sex or has an STI. According to Barroso & La Rosa (2007, p. 26):

> This standard for supposedly preparing youth for leading healthy sexual lives has numerous shortcomings, not least among them being the denial of young people's right to full information and freedom of expression. On the level of public health outcomes, it can be particularly damaging to adolescents.

> Because these programs teach only about abstinence, they fail to prepare young people for when they do have sex, making them more at risk for pregnancy and STIs. Furthermore, by claiming that the only accepted context for sexual activity is marriage, abstinence programs alienate young people who do have sex, particularly gay, lesbian, bisexual or questioning youth who may never fit into the model offered.

An example of an abstinence-only curriculum is one developed by Scott Phelps and Libby Gray, in conjunction with A.C. Green, entitled, *Game Plan* (2009). This curriculum uses sports metaphors to explain boundaries, waiting until marriage for sexual intercourse, and how to become "whole" after having a few sexual partners. One such metaphor, avoiding the penalties, is linked with information about STI's, HIV, and AIDS. If an individual engages in premarital sex, infections could be the penalty an individual has to pay for choosing not to wait until marriage. In another section of the curriculum, an individual's value and worth is linked to virginity, by example of a rose whose petals have been picked off. In an exercise called "The Rose", the teacher brings three roses to class and begins the exercise by explaining that all roses are "beautiful, unique, and valuable—just like the students are".

> The teacher then begins peeling the petals off one rose and explains: "This rose illustrates a person who has chosen to be sexually active. When we are sexually active, we are giving ourselves—our body, our heart, our mind." The students are instructed to pass the rose around the room and each pull off a few petals. They are told that "each petal symbolizes a sexual relationship." After it is passed back, the curriculum tells teachers to "explain that 10 years have passed, and now this person wants to get married. What does this person feel that he/she has left to give?"
>
> The teacher then presents the second rose which has all of its petals intact and tells students that this flower represents someone who has chosen to be abstinent until marriage. Students are told to imagine that it is 10 years later and this person wants to get married. "What does this person have left to give? Abstinence is about saving and preserving who you are and what you have."
>
> The exercise then continues with one more rose that is missing just a few of its petals. "This person says, 'I'm not feeling very good about myself, and I don't have to keep doing this. It doesn't matter what I've done in the past, I'm going to stop and save myself for marriage. Although one or two petals are gone, the rose is still beautiful, and so am I, even though I've already been sexually active.' " To conclude the rose exercise, the three roses are held up and students are told: "The choice is yours to make. Which rose would you like to be?" (Filipovic, 2007; Game Plan: Coach's Clipboard, p. 12)

Abstinence-only education is not simply about protection from STI's and pregnancy, but it moralizes the idea that sexual intercourse determines an individual's value and self-worth. Purity is linked with abstaining from sex, thereby instituting a hierarchy of purity. Someone who abstains is touted as being more unique and beautiful than someone who has chosen to "give away pieces of themselves*" (*Filipovic, 2007). This line of thinking calls into question the reduction of an individual's worth, value, and skills. Jessica Valenti, author of *The Purity Myth,* argues with the scare tactics used to ward off sexual behavior and believes more emphasis should be placed on teaching young women that their kindness, compassion and intelligence should define them more than their bodies (Swart, 2013). Valenti states:

> *The Purity Myth* is for women who are suffering every day because of the lie that virginity exists, and that it has some bearing on who we are and how good we are. Consider the implications virginity has on the high school girl who is cruelly labeled slut after an innocuous make out session; the woman from a background so religiously conservative that she opts to have her hymen surgically reattached rather than suffer the consequences of a non-bloody

> bed sheet on her wedding night; or the rape survivor who’s dismissed or even faulted because she dared to have past consensual encounters. (2010, p. 11)

Sex can be a powerful mode of transmitting emotion, care, love, and power. But what about force? What happens when a sexual encounter is not something an individual willingly chooses? According to a Center for Disease Control factsheet on sexual violence (2012), “nearly 1 in 5 women (18.3%) and 1 in 71 (1.4%) men reported experiencing rape at some time in their lives.” Due to underreporting, these statistics are not a fully accurate representation of individuals impacted by sexual assault. The Justice Department, *National Crime Victimization Survey* (2008-2012) estimates that about 60% of sexual assault is underreported.

Even if an individual can be redeemed by abstaining from future sex (wanted or unwanted), the inexplicable damage caused by linking sexuality to an individual’s character or “pureness” does not bode well for an individual trying to heal after a traumatic experience. If sex is used as a scare tactic for dirtiness, trashiness, or infection, the very notion of having sexual experiences determines an individual’s worth and marketability as a friend and partner. Consider the experience of Elizabeth Smart, who was kidnapped at 14 years old and held captive for nine months. During an event to raise awareness about human trafficking, Smart spoke about a teacher who had encouraged abstinence-only education by comparing sex to chewing gum, an experience she drew upon during her time in captivity:

> I thought, ‘Oh my gosh, I’m that chewed up piece of gum, nobody re-chews a piece of gum. You throw it away.’ And that’s how easy it is to feel like you no longer have worth, you no longer have value. Why would it even be worth screaming out? Why would it even make a difference if you are rescued? Your life still has no value. (Frumin, 2013)

The Societal Influence of Biblical Purity Language: Gendered Images of Purity-Purity Rings and Purity Balls

Another tradition of evangelical purity is the purity ring, oftentimes given at a purity ball. A purity ring is a gift given to an individual, as a promise that the receiver will abstain from sex until marriage (Rosenbloom, 2005). The definition of abstaining, in this case, requires that individuals refrain from intercourse, pornography, or lusting after another individual (412Teens, 2014). The ring symbolizes a promise to dress and act in a way that would not cause another person to stumble, that is, lusting or awakening sexual feelings. The idea of the purity ring goes back to the “True Love Waits Campaign” of the 1990’s. The platform for this campaign is to get teens to think critically about their choice of interaction with the opposite sex, but the ultimate goal is for teens to save sexual intercourse until marriage. Much like the abstinence-only curriculum, teens are encouraged to preserve their character by not giving away pieces of themselves to romantic partners or acquaintances that he/she/they met for a one night stand. The ring represents the desire to honor God, by keeping the temple free of sexual immorality (lust, pornographic images, etc.). Even celebrities have been known to wear a purity ring: Jordin Sparks, Miley Cyrus, the Jonas brothers, Jessica Simpson, Selena Gomez, Demi Lovato, and Teyana Taylor (Lee, 2013).

Oftentimes, a purity ring will be given to a woman by her father at a purity ball. A purity ball is described as, “A father-daughter dance where the daughter signs a pledge that she will remain virginal and pure until she gets married. The father pledges to help his daughter remain pure until she marries, at which time the father will place the responsibility for his daughter’s sexuality into the hands of her new husband” (Swart, 2013, p.10; Valenti, 2010). This whole event shows the inextricable link between virginity and the commodification of women’s bodies. Virginity is highly prized and marketable as a wife and mother. In this scenario, a woman’s ownership and control over her own body is virtually non-existent. Someone else dictates the ways in which she can express herself sexually. She is taught that her body is for someone else’s pleasure, to keep under wraps until marriage. The interesting piece of this idea is that even after marriage, a woman’s sexual expression belongs to her husband. Although his might belong to her as well, a man’s sexuality has not been policed to the extent hers has. This model is also problematic because after a couple gets married and engages in sexual intercourse, both parties are expected to pleasure one another, thereby fully expressing and realizing their sexual potential. This seems like a difficult task when sexuality has been used as a scare tactic for unspeakable consequences. Interestingly enough, no such ball exists for boys and their mothers, which begs the question of why evangelical purity is touted so vigorously to women and girls. Individuals in the lesbian, gay, bisexual, transsexual, queer and intersex community are also left out of the purity equation. These examples of gendered expressions of purity translate to heterosexual, heteronormative expressions of gendered purity. Although girls are the main focus during a purity ball, even a girl would be excluded from the movement if she identified as anything other than heterosexual. Purity, marriageability, and good character are for straight, girls and boys, or blatantly, just for girls.

Conclusion of The Societal Influence of Biblical Purity Language

Sexuality and religion intertwine and provide a lens with which individuals view themselves. For the individuals that ascribe to a higher power, actions are dictated by the interpretation of how a relationship can be built with a figure that is ethereal and unseen. Theology is a scope through which individuals evaluate behavior, value systems and doctrine- it permeates the whole personhood. Humans are intersectional beings; we oftentimes hold several ideals and values in contention with one another. Encounters between the self and religious truths can be extremely messy, life-changing, confusing, detrimental, and hopeful. As such, no person experiences such an impactful collision in quite the same way. Evangelical purity rings, abstinence-only education, and language referring to holiness and sexual purity offer specific examples as to how individuals manage the compatibility of sexuality and religion. Collectively, humans are a creative people, each seeking some sort of purpose or grander meaning to life. Evangelical purity culture provides a sense of meaning for some individuals and deserves further evaluation and introspection. As a subculture, that has held a pervasive idealism within the United States, it is hopeful that evangelicalism would continue to grow and change according to the creativity and expression of its members.

Feminist Theory and Practice for Social Workers

An individual may operate within this evangelical framework and never experience contention between the self and environment. Religiosity and its core operational values might become ingrained or instilled, with either conscious or unconscious deliberation on behalf of the self. This research is not debating the merits of religious experiences. Oftentimes, however, an individual's multiple modes of identity will clash at some point. If an individual seeks therapy for difficulties navigating or "fitting" within their environment (i.e. gender expectations of expression, internalized depreciation of self-worth, structural racism and oppression, difficulty making decisions, guilt and shame around sexuality or sexual assault, and feelings of disempowerment) how can a social worker utilize feminist theory as a framework for helping an individual unpack the ways in which multiple core identities interact with and influence one another?

At the forefront of a feminist theoretical framework is the acknowledgement that an individual experiences multiple given roles and sets of identities at any given time. Feminist methodology involves the analysis of those identities and the ways in which society allows for a spectrum from rigidity to fluidness around the expression of those identities. Another concept in feminist theory is the idea of giving the client a chance to tell her story or narrative in a way that does not revolve around the men in her life. Therapists using feminist theory can work with male-identified clients as well, but the purpose of this paper is to evaluate the ways in which female-identified individuals navigate multiple roles and identities. A woman's choices (whether freely made or coerced) are not without influence from other aspects of her environment, as demonstrated by the double standards of moral purity. A feminist therapist helps to empower her client in making decisions, which is especially crucial in a world that assigns her client a heteronormative expectation to pursue just enough independence without rocking the boat. Therapy for a client who feels pressure to conform to certain gender roles or is feeling oppressed by the inability to view her self-worth in terms unrelated to or without judgment of sexual activity must be addressed in terms of larger, systematic marginalization. The self bears responsibility for individual thought patterns, but the institution of those thoughts and beliefs, and the judgments attached, can be linked to societal norms and expectations. If the patriarchal, hierarchical society in which we live has an invasive impact upon our interactions between sexuality and self-worth, how then, can a social worker use the lens of feminist theory to unpack some of the embedded messages within those interactions? Laura Brown (1994, p. 199) asserts that "feminist theory uses the master's tools to re-forge, re-share, and transform each possibility for oppression into one of liberation and social change." The master's tools are the "strategies, methods, and schemata of patriarchal systems" (Brown, 1994, p.178; Lorde, 1984). Brown goes on to define these tools as "the techniques used to classify people, to impose social control- the strategies that see psychotherapy as a form of corporate enterprise in which denial of therapy sessions turns into dividends for shareholders" (1994, p. 199). For instance, the Diagnostic and Statistical Manual of Mental Disorders (DSM) is used to treat individuals with mental illness by providing a label that is easily identifiable and billable through insurance. Brown (1994, p. 181) suggests that according to feminist therapeutic principle, the client should be able to receive a copy of the DSM, in order to be well-informed of the reasons for a particular diagnosis, and to discuss other possible illnesses. Another way to form possibilities for liberation and social change, is for the client to be given "informed consent" before beginning therapy. Informed consent includes a list of policies related to agency rules and regulations, but it also offers a transparent analysis of the risks and benefits of a client's participation in therapy (Brown, 1994, pp. 180-181). While unpacking the ways in which marginalization impacts a client's life could result in benefits of empowerment and desire for social activism, there are very real risks involved when sharing truths that have been kept hidden. The client should be aware of potential stigma incurred with receiving a diagnosis, which is oftentimes necessary in order for insurance companies to bill for services.

Feminist theorists have to navigate the very patriarchal system which doles out oppression and expected norms of behaving in a manner consistent toward keeping the power of hierarchy unchallenged. The feminist social worker helps the client understand ways in which power has been lost and to increase the client's capabilities for trusting her own sense of decision making, intuition, care, and meaning making within the context of her ascribed identities.

***S. Foist Swart** is an MSW/MA in Women's Studies and Gender Studies Candidate at Loyola University Chicago, with a concentration in Children and Families. She grew up living in different parts of the county but most recently hails from Seattle, Washington. Ms. Swart presented this paper at the National Women's Studies Conference in November 2014 and is interested in continuing her studies of gender and sexuality. She is currently working in the field of domestic violence and sexual assault and continues her advocacy work in Chicago, Illinois.*

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Autoethnography, Feminist Social Work, and The Care of Clients with Rare Illnesses

Mary-Margaret Sweeney, MSW

Abstract

Feminist inquiry and practices in various fields has sought to give voice to the experiences of the oppressed. This research explores modalities of care of clients with rare illnesses by medical providers and social workers. It interrogates the standards of care provided by these disciplines, how a feminist approach works to achieve greater parity in the patient/doctor dyad, and how physical health outcomes may too be affected by this enhanced method of care. Autoethnography is used by the researcher to demonstrate the transformative effects of de-centralizing knowledge, bringing the experiences and opinions of the patients into the exam rooms and into academic research.

Keywords: autoethnography, feminist social work, Nail Patella Syndrome, patient, rare illness

Introduction

At present, there are approximately 7,000 known rare illnesses affecting U.S. patients (“Rare Diseases”). These illnesses, according to the group Rare Disease Day, affect less than 200,000 Americans, while Rare Disease UK sets their threshold at less than 5 in 10,000 ("Rare Diseases") The landscape of rare illnesses continues to evolve, as approximately 50 new rare illnesses are recorded each year (“Rare Diseases”). For each diagnosis, the number of patients is small. However, when all of these diagnoses of rare illnesses are taken together, they number over 30 million patients in the U.S.—the same number of patients living with diabetes (Shire Human Genetic Therapies, 2013) (“2014 National Diabetes Statistics Report”). Some of these illnesses are fatal, imposing a race against time for physicians and researchers to understand the illness and work toward curative or palliative treatment. Others, however, present significant quality of life issues, but may not garner the gamut of run/walks, rubber wristbands, and NIH funding dollars. Yet whether the prognosis is terminal or chronic, and no matter where on the spectrum of severity symptoms land, those living with rare illnesses face similar hurdles in daily life.

On the day of my birth, I joined the 30 million Americans diagnosed with a rare illness. Or, more accurately, I joined four confusing days full of questions after my birth. On the day of my birth I was an anomaly, shipped from the small county hospital in which I was born to a larger city hospital several miles away, where I was summarily pricked, prodded, x-rayed, and scanned. The years since have been full of uninformed doctors, overly curious medical students, prying strangers and casual acquaintances, and a constant unspoken awareness that I am to explain myself, that my body belongs to myself but also others, that privacy is a privilege of the able-bodied and normally developed. To bring my experience to bear on this research, I will employ the qualitative research method of autoethnography. Uotinen defines autoethnography as “a research method in which the researcher's personal experiences form both the starting point and the central material of the study” (Uotinen, 2011, p. 1308). Richards (2008) broke down medical autoethnography into three classes: testimonies, emancipatory discourses, and destabilized narratives. As a feminist social worker, the goal of creating an “emancipatory discourse” for clients is perhaps the most compelling. The philosophies of both feminism and social work practice emphasize an examination and redistribution of power, working toward autonomy, particularly recognizing those who are denied of it, and honoring the lived experience—for social workers, “the client is the expert on his or her own life” and for feminists, “the personal is political.” With these personal and professional ethics guiding me, I shall interrogate the relationship between patient and medical provider when the patient is diagnosed with a rare illness. I will use myself as a case study, identifying ways in which a social worker may intervene in the health care setting to foster a therapeutic relationship between provider and patient, as well as between the patient and his or her environment.

Nail Patella Syndrome

When I was born via cesarean section, I was handed to my father first. The doctors and nurses were already prepping a small gurney for my transfer to the nursery as it was clear as soon as I emerged that something was wrong. My legs appeared as if they were on backward, with my heels facing forward and my toes and knees pointing behind me. After ensuring that I could breathe and was in no immediate distress, I was handed to my father while the nurses contacted the neonatal specialists.

"She has the Sweeney thumb nails!" my father noted. The hustle in the room stopped, and suddenly all of the providers descended upon my father and I, looking at his thumb nails and mine, asking him questions about his family and what his legs looked like when he was born. Four days later, after being transferred across town to the larger hospital with a neonatal intensive care unit the results of the exams and genetic counselors were in: my father and I were diagnosed with a rare genetic syndrome called Nail Patella.

Nail Patella Syndrome (NPS), also know as Fong's Disease of HOOD, is a syndrome caused by a genetic mutation that most usually affects the presence and appearance of finger nails and patellas. The appearance and function of elbow and other joints can also be affected, and many experience scoliosis, hip dysplasia, glaucoma and other vision problems, depression, and renal disease (Nail Patella Syndrome Worldwide). Being a syndrome, multiple symptoms exist with different degrees of severity, affecting each patient in different ways (Vollrath et al., 1998). Many patients report inability to gain and maintain weight and upper body muscle mass, symptoms consistent with irritable bowel syndrome, and chronic joint and back pain that have been observed but not yet linked by medical research to NPS. NPS itself is not terminal, but if a patient develops renal disease (30%-50% of NPS patients do so), this can progress to renal failure (3%-5% of NPS patients) (Hawkins, and Smith, 1950). NPS is included in the legislation of all states with medical marijuana legalization as a qualifying condition, including Illinois where the legalization is most strict and includes 40 illnesses (Compassionate Use of Medical Cannabis Pilot Program Act, 2013). Other states with similar legislation include many minor afflictions such as frequent headaches, pushing their total of qualifying conditions closer to three digits.

NPS has nearly the same rate of prevalence as amyotrophic lateral sclerosis (ALS): two per 100,000 people (ALS Association, 2010). Much discussion took place on NPS community message boards concerning the "Ice Bucket Challenge" that took social media by storm in summer 2014. People posted videos of themselves dumping ice water on their heads, and challenged their friends on social media to either do the same or make a donation to ALS research. Objectively, of course, the symptoms of ALS are terminal and thus perhaps more urgent than NPS. Yet living with any chronic disorder feels urgent to the patient experiencing it, and thus the lack of awareness and attention to NPS further isolates the patients with it.

The Psychosocial Effects of Living with a Rare Illness

Ohlson (2012), explored the frustration patients with rare illnesses experience, even just to get the initial diagnosis. Because doctors are not familiar with these rare illnesses, 15% of those with a rare illness reported that it took more than five years to receive the appropriate diagnosis (Ohlson, 2012). Some estimates are as high as 7.6 years (Shire Human Genetic Therapies, 2013). On average, those seeking a diagnosis will see eight providers in the process, four primary care physicians and four specialists, and will receive two to three misdiagnoses (Shire Human Genetic Therapies, 2013, p. 6). These years amount to time wasted seeking curative or palliative care, decreasing quality of life for patients. In my own family's case, my father was not aware that the bizarre constellation of symptoms observed in his family had a name, or that it was an inheritable affliction. Without this knowledge, this precluded genetic counseling my parents may have sought before trying to conceive. It also kept doctors from recommending physical therapy to my father, and they merely corrected his clubfoot via surgery, but did not know other musculoskeletal abnormalities lurked unseen, causing pain and difficulty walking and exercising without corrective therapy. With my early diagnosis, I was able to take advantage of the evidence-based care available to me, albeit scant.

Of course this care also came with social drawbacks as a child. The litany of treatments and therapies I experienced included leg casts, leg braces, physical therapy five days a week for many years, multiple corrective surgeries, eye patches, frequent urinalysis, blood tests, x-rays and other imaging. As these physical interventions provided largely successful returns, my physicians were overjoyed. However, a hospital social worker, which I did not have, may have told a different story. My parents experienced the heartbreak and stress of being told that their child may never walk and, when I did, that I could lose that ability. They then had to explain this to their young child. I quickly maxed out our health insurance coverage and most of the physical therapy I received was paid for out of pocket. It is safe to surmise that had I been born into a lower socioeconomic status, I would not have fared as well, as this "extra" therapy may have been out of reach. I was late to play with other children as I was physically limited and, when I was finally able, I would then take between six weeks and six months away from the playground to recover from the latest surgical procedure. I regularly read a book on the bleachers while my classmates participated in gym class, and each and every physical education teacher I encountered from kindergarten through 12th grade let on that they believed I was exaggerating my disability just to indulge in my bibliophile obsessions. I missed many days of school, which some years placed me in the remedial classes.

The extensive Rare Disease Impact Report (Shire Human Genetic Therapies, 2013) enumerated three keys findings with which any patient with a rare illness could readily agree: a lack of resources and information on “less common illnesses,” the economic impact of “diagnosing and managing rare diseases is significant,” and that rare illnesses can “take a major emotional toll on patients/caregivers” (Shire Human Genetic Therapies, 2013, p. 3). The report ultimately calls for collaboration between primary care physicians and specialists, resources for patients and their caregivers to negotiate the emotional impact of a diagnosis, and more research money funneled toward rare diseases (Shire Human Genetic Therapies, 2013, p. 3). Indeed, the report paints a dire picture of the emotional well-being of those with a rare illness. According to Shire Human Genetic Therapies (2013), 44% of Americans with a rare illness report lower quality of life; the number rises to 58% when there is no known treatment (p. 8). This also affected caregivers of those with rare illnesses, with 72% of U.S. caregivers to those with rare illnesses reporting depression, and 64% reporting isolation from family and friends (Shire Human Genetic Therapies, 2013, p. 8). For my family, this took the form of missed time at work for my parents as they hauled me to various specialists who only work during business hours; unwillingness to hire a baby sitter as the instruction list left for them seemed more hassle than it was worth; and being excluded from spaces where many parents meet their peers, like children's soccer games or the lobby of the dance studio. It is well-known and easy to imagine that caregiving to any patient, whether the affliction is rare or not, is challenging. Hospitals offer support groups for caregivers and my parents attended several. However, there are many people in a hospital caring for cancer patients. Often, the caregiver of a patient with a rare disease has no true peer nearby. My parents sat in groups of parents where each child represented had a different disorder. Common ground was hard to come by, and eventually the group lost all of its members.

The Patient-Provider Relationship

In her book Public Privates, Terri Kapsalis (1997) interrogates the relationship between woman and gynecologist through a feminist lens. She defines the role of a doctor's “ideal patient” as “one who is compliant, passive, and accepting rather than active and questioning” (1997, p. 6). This definition allows for the patient to be acted upon, their body separate from any sort of personhood, allowing the medical provider to treat only the symptoms rather than the whole person. Often, we hear this referred to rather innocuously as “bedside manner.” However, this seems a rather inept way to describe inattention to critical details of a patient's experience. Bedside manner seems to imply affect with the patient—was the doctor gruff, caring, solicitous, dismissive? Were they rough during an examination? For those of us who have spent much time in doctor's offices and hospital rooms, these annoyances are dwarfed by larger concerns. For example, it was through my own research that I learned that individuals with NPS should avoid ibuprofen and opt for acetaminophen instead. Ibuprofen can damage the kidneys, and as up to half of those with NPS develop renal disease, it is not the safest option for my pain relief. This simple fact that could have a complicated impact on my health was discovered first in a message board thread on Facebook, and down the rabbit hole of Internet researching I went to confirm it for myself. I was also the one to bring up the topic of childbearing to my physician, citing research studies I had read on the rate of preeclampsia in pregnant women with NPS. No doctor had ever even approached the topic of bearing children and what that meant for my health, or passing NPS along to my children. While I am the kind of patient who does research and has weighed for many years about the decision to have biological children, many people do not have this same inclination. The accepted dynamic between patient and doctor holds, wherein the patient may believe that if a doctor has not raised an issue, there is not one to be raised. Without having done my own research, which was only accessible to me because of my access to a university library, I may have very well shown up to my doctor's office pregnant, without knowing what serious health risks it carried for me. Often, if a woman brings up concerns about childbearing, it is too late—the woman is already pregnant. The situation then becomes management of symptoms, rather than a conversation about genetic counseling, and what the woman and her partner are willing to risk. I have been the party to bring this conversation into a doctor's appointment, and it is always immediately clear that I possess much more knowledge than my physicians on my illness.

Of course, physicians can also be forgiven being uninitiated with rare illnesses. A general practitioner cannot be an expert on all known ailments that may present in practice. The Rare Disease Impact Report quoted a physician in the U.S. as saying, “You never see enough of them [patients with rare diseases] to build up the expertise” (Shire Human Genetic Therapies, 2013, p. 20). Many NPS patients I have come into contact with via social media support groups for NPS have vetted physicians not by their knowledge of NPS the first time they meet, but their willingness to ask thorough questions and do research before the next appointment. A patient will not know until the next appointment if the doctor has done so, leading to further delays in obtaining trusted, competent medical care.

I have been asked many times why I do not “just” find a specialist, rather than expecting each provider with whom I come into contact to learn about NPS. However, for many of us with rare illnesses, there is not one doctor to understand and address our diagnosis. While someone with a heart condition can see a cardiologist, and a person with a cancer diagnosis can rely on their oncologist to manage most of the moving pieces, an illness such as NPS is a syndrome and requires many specialties. With few cases relative to other chronic illnesses, there are no physicians that specialize specifically in NPS. Even those researching the illness cannot devote all of their attention to it alone, as there is not much funding for rare illnesses that are not terminal. The closest I have come to finding a doctor who understood NPS with any depth was a nephrologist, yet I have not at this point developed kidney disease, so my contact with that physician is limited to an annual check-up.

Those with rare illnesses then are often forced to research on their own. I am reminded of several of my friends who were told upon learning they were pregnant to not do too much online research, as they will only scare themselves, and to rely on their doctors to answer questions. This advice also seems relevant for those of us with rare illnesses, yet we cannot rely on physicians for answers. Left with that choice, we take to the Internet, and often find ourselves up late at night, alone, wondering if our condition might actually be as serious as the personal account we are currently reading on some message board. It was in this manner that I discovered the personal account of NPS patient George McMahon. McMahon was one of the six people included in the 1970s medical marijuana clinical trials carried out by the U.S. government (McMahon & Largen, 2003). In informal reviews of his book, I found several references to NPS as “terminal,” “fatal,” and “horrible.” One radio show he was on in the 1990s began their introduction of him saying that it was a rarity that he was still living. As one might imagine, my heart sank. What didn't I know about my condition?

It took some more digging and an expedited shipping of his book, but it became clear that McMahon was a rare case, and had lost the genetic lottery by developing all the worst symptoms of NPS, and also struggled with other unidentified health issues. It was a reminder of how lonely being a rare illness patient is, with no doctor who can immediately calm you with examples from their years of experience with patients just like you. Even in-person support groups of laypeople are hard to come by, as so few of us exist, and not many would be within driving distance to come together. This has led to many online groups, where people from all over the world share information from their doctors, research articles, and their personal experiences. Some physicians see the value in these groups and welcome their patients bringing this information into their visits, and others do not see them as a valid way to access health information. Yet with so little peer-reviewed research available, and the reality that many patients do not know how to or are not able to access what is out there, seemingly informal, anecdotal information becomes all that we have.

In seeking to look at the patient-provider relationship wherein the patient is doing a lot of educating of the provider, I came to many dead-ends. I employed the services of academic librarians, who also could not find any peer-reviewed work on this topic. All involved kept finding research on "patient education," but in reference to providers educating patients. Much of this rhetoric even came off as paternalistic, with the usual public health information about healthy eating, educating patients on regular exercise, and other seemingly common sense health information. Discouraged, I was unsure how to approach the topic without any existing research. However I believe the dearth of information actually bolsters my claim that more work must be done to make the patient/provider relationship less hierarchical. What does it say that no one in medicine has been interested in what patients have to teach doctors, or at least have not been able to secure funding to study it?

A Feminist Social Work Approach

Feminist work, as detailed earlier in this paper, often wrestles with issues of autonomy, and works to secure agency for people over their bodies and lives. Kapsalis interrogates the "politics of visibility," arguing that "making a spectacle is about power, about who has the power to render visible and who has the power to look" (1997, p. 7). I am regularly asked for permission to be a teaching tool for medical students, subjecting myself to repetitive, invasive questions, somewhat uncomfortable poking and prodding, and longer visits that do not offer me much added value in my healthcare experience. I am rendered visible, and I am seen, but in a context controlled by others, in line with the traditional hierarchy of the medical establishment. However, when I have taken the time to print pamphlets from the Internet that were produced by others with NPS to educate doctors, I have had them dismissed as "un-scientific," or "things we likely already know." Or, they are accepted and shoved into my folder and it is clear upon my return in six months that they have not been read. It is an effort to be seen, and to have my health understood by those who purport to care for it. Yet it falls outside the expected patient/provider dynamic, and I am unseen, and made invisible. Or I will be seen, but only through the way in which the provider grants me visibility.

With Kapsalis' definition of the "ideal patient" in mind, I turned to Webster's dictionary definition. The noun is defined, simply, as "a person receiving or registered to receive medical treatment." Receiving, of course, is a passive word. A person who receives is not a person who is expected to give, or act, or engage. When the word "patient" is used as an adjective, the word means "able to accept or tolerate delays, problems, or suffering without becoming annoyed or anxious" (Kapsalis, 1997). Synonyms from Merriam Webster include forbearing, uncomplaining, tolerant, resigned, and stoical. It should strike us as social workers, then, how marginalized persons may further fulfill this patient role, as it naturally aligns with how they are required to act in society generally ("Patient"). As these roles develop along gender, racial, ethnic, and other identifiers, patients are socialized outside of the medical space to play certain roles. If this role is one similar to the defined role of the patient, medical social workers should be aware that these patients might advocate for themselves less, ask fewer questions, or rely on others in their support and caregiving network to do so for them.

Children, whether male or female, white or children of color, English speaking or not, are consistently reminded of their place in society as people to be taken care of, to ask permission of adults, and to fulfill the definition of Kapsalis' ideal patient. As a pediatric patient, I was often not believed by medical professionals, or told that my opinion on my own health was incorrect. Put in glasses at age two, I expressed for years that wearing said glasses did not improve my vision. Eye doctors assured my parents that I just preferred not wearing them and was looking for reprieve. When I was still expressing the same sentiment at age 12, the male eye doctor told my mother that girls my age were concerned with their looks rather than their health and I was, still, trying to get out of wearing my glasses. It wasn't until I was 17 that I was finally listened to, and glasses were no longer prescribed. A deeper exam revealed that the cause of my near-sightedness was a condition that could not be corrected by lenses, but might have been ameliorated surgically in my youth. The thousands of dollars my family spent were not returned, of course, nor was some of the dignity lost over those years of speaking the truth and being ignored. My pediatric orthopedic surgeon went over the list of risks of my final knee surgery and said in front of me, six years old at the time, that girls fared best with the surgery as we were less active anyway, and didn't miss playing or engaging in sports while recovering—yet, he added that as I aged, I would have a more difficult time as the long unsightly scar on my leg would lead me to eschew skirts and shorts.

These messages were not dissimilar from those sent by my skeptical physical education instructors, and perhaps less upsetting as doctors did not share their messages in front of all my peers. However, my early interactions with the hierarchical medical model set the tone for how I would approach it moving forward. Having a rare illness puts me in the position of consistently needing to advocate for myself, complete my own research, and make important medical decisions for myself without input from a doctor with specialized knowledge. This disruption of the patient role is necessary for a comfortable daily life, and yet is hardly rewarded and often discouraged by providers. As a young woman, I was reminded that I should worry about how my illness affected my appearance, and that if I was not concerned, other adults were. The "politics of visibility" left me open to their critique, and sent a message to a young woman that when someone in a position of authority asks for access to your body, it is best to answer affirmatively.

While physicians have much access to patients, not all patients have access to them or to medical research. My enrollment in a graduate school program allowed me to access more up to date research on my illness and bring this evidence-based information to my physicians. Without this development, I doubt I would have had a conversation with my physicians about child bearing, and I would have perhaps made the decision to carry a child, without access to research suggesting that the risk to my life would be great. My location in a large American city also grants me access to specialists that come nearer to understanding my particular condition, and I may "shop around" if I do not like my initial choice of physician. I feel limited in that I would not opt to move to a more rural setting, but it is a choice that I can make. Though a student with no employment, my partner carries robust health insurance benefits for both of us and I am able to access care. The socioeconomic position of a patient with a rare illness can change their experience of the medical system and the prognosis.

Conclusion

In her medical memoir *Poster Child*, Emily Rapp (2007) details her experience as an amputee after a childhood diagnosis of proximal focal femoral deficiency. She explains her mother's recollections of the nurses and doctors present at the time of her birth. To Rapp's mother, the wife of a minister, a NICU nurse said, "I don't understand how this could happen to you. You two must live closer to God than anyone else" (Rapp, 2007, p. 10). Rapp's comment on this exchange in the memoir is, "Blame. To whom or what does it belong?" (Rapp, 2007, p. 10). Those of us with rare illnesses and our families are often pitied, and the natural anger and confusion and frustration of those around us might seep in, causing us to wonder what we did wrong, if we deserve this, or if there is a way to undo our past deeds.

As Rapp navigated corrective surgeries and therapies as a child, her parents and others in the community rallied around her, making her feel like a hero. When the time came when the only treatment left is an amputation of her left leg, the event was almost celebrated, with everyone telling Rapp that she is strong, that she can do anything. This relenting positivity and encouragement leaves little room for Rapp, a frightened little girl, to express her fear or questions. She must play the role of the brave cheerful sick child. She eventually becomes somewhat of a celebrity, appearing on telethons and other national campaigns for fundraising efforts, unable to show anything but a cheerful, hopeful exterior. She has been made a saint by her illness, a person without nuance or dimension.

Feminist social work practice seeks to

recognize the nuance in patients, and encourages them to work outside the definitions of "patient" herein—expressing negative emotions is healthy, truthful, and necessary for them and so too for the physicians. Trained to save and cure, those of us with rare illnesses present a challenge to the very definition of "doctor." It is time to shift the definitions of both parties involved in this troubled relationship, working toward a more holistic, equal, realistic, and therapeutic alliance where true healing may begin.

***Mary-Margaret Sweeney** is a graduate of the Loyola University Chicago School of Social Work. She is currently in practice as a medical case manager with a refugee resettlement agency. Previous work includes sex positive sexual health education, case management with homeless GLBTQ youth, freelance writer of academic, journalism, and creative non-fiction, and a brief detour into the technology start-up world. After a decade in Chicago, IL, Ms. Sweeney now resides in Indianapolis, IN, serving the large refugee community*

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