Addressing Compassion Fatigue of a Family

Caregiver of Adolescents in a Mental Health Setting:

A Practice Change Project

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#### **Abstract**

Family members who care for adolescents with a mental health disorder (AMHD) have yet to be recognized as an at-risk population for developing Compassion Fatigue (CF).

The project introduced the concept of CF and the development of a program for family caregivers of AMHD at New Haven, a residential treatment center (RTC) for adolescent girls with mental health disorders.

Staff therapists, nurses, educators, and support staff attended an educational program on CF, validated screening tools, interventions, and educational materials for family caregivers. A pre/post-Continuing Professional Development Reaction Questionnaire (CPDRQ) was used to measure their intention to change practice.

Family caregivers attended a one-hour group session led by a staff therapist and completed a Family Quality of Life (FQoL) survey a modified Professional Quality of Life Survey and received interventions of knowledge, coping strategies, peer support programs, self-help, guided self-help.

Predictive validity was estimated by comparing the pre-post scores of the CPDRQ. Overall, there was an increase in scores for all constructs with the most significant for the construct of intention and beliefs about capabilities.

The results of the FQoL survey found a moderate level of burnout and secondary traumatic stress, which are indicators of CF. Follow up survey, 60.5 % who received the information on CF reported considering implementation or implemented an intervention. 50% reported sharing information with someone they trusted, 37 % reported making sleep a priority, eating a healthy diet, and learn to relax and meditate.

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The CPDRQ indicates the staffs' intention to change their practice suggested by the change in intention and beliefs about capabilities response. The results of the FQoL survey suggest that family caregivers are at risk for CF. The families who participated and received information on CF gained a new understanding and considered or had implemented one or more of the interventions.

Keywords: compassion fatigue, family caregivers, adolescent with a mental health disorder

Addressing Compassion Fatigue of a Family Caregiver of Adolescents in a Mental Health

Setting: A Practice Change Project

Compassion fatigue (CF) is a phenomenon found in professional caregivers or family caregivers, resulting in physical, emotional, and spiritual distress. It is the effect of the relationship between the caregiver and the patient/family member (Figley, 1995; Lynch, & Lobo, 2012). Family caregivers who care for an adolescent with a mental health disorder (AMHD) have many of the same risk factors as caregivers who develop CF. Despite the similarities, CF is not addressed as a problem for family caregivers of an AMHD.

The family caregiver over time may develop a phenomenon referred to as CF, the adverse physical, emotional, and spiritual symptoms associated with caregiving. The concept of CF, referred to as the "cost of caring" (Figley, 1995), has included formal and informal/family caregivers. Early research focused on professional caregivers and the impact of caring for patients who have suffered trauma, have a terminal illness or chronic disease or disability. The term CF reported by Carla Joinson in 1992 suggested that CF was a unique form of burnout in nursing that resulted in overwhelming invasive stress. Charles Figley's (1995) work in traumatology, began to publish on CF as a result of professional caring for victims of trauma and violence resulting in burnout and secondary traumatic stress. Recently this concept has expanded to include the family caregiver, primarily those caring for an aging adult with a chronic debilitating disease or disability such as Alzheimer's or terminal illness as at risk for CF.

The cost of caring for family caregivers have many comparisons to a health professional who have reported CF (Sinclair et al., 2017; Sorenson et al., 2017). Caregivers list sadness, poor self-care, depleted energy, hopelessness, isolation, and self-sacrifice as an outcome of caregiving. Other symptoms include sleep disturbances, difficulty focusing, substance abuse,

absenteeism, diminished sense of personal worth, low self-esteem, gastrointestinal complaints, chronic fatigue, hypertension, anxiety, and apathy. Lynch & Lobo (2012), utilizing Wilson's concept analysis strategy, found similarities between the current concept of CF attributed to HCP and family caregivers, noting that both have caring and empathetic relationships. It is the nature of the relationship with the family member that adds to the stress of caring for the family caregiver. Unlike the professional caregiver, family caregiver strain can result from the lack of training needed to provide ongoing care. The inability to leave and to seek respite from caregiving is also a complicating factor (Lynch, Shuster & Lobo, 2017). Parents, siblings, and grandparents of adolescents who have a AMHD and have the primary role of the family caregiver and have significant challenges when caring for an AMHD, which places them at risk for CF.

CF has become recognized in family caregivers as more responsibility for care is shifted to home. Approximately 43.5 million caregivers are providing unpaid care to an adult or child in the United States ("Caregiver Statistics: Demographics," 2016). CF is most frequently a result of providing daily care to seriously ill, chronically ill, or a dying family member along with a shared pain experience (Lynch & Lobo, 2012). Typically, the caregiver has a deep sense of empathy for the person, along with the inability to disengage from caregiving resulting in physical, emotional, and spiritual distress. Symptoms develop throughout caring, and they can experience a variety of physical symptoms such as headaches, chest pain, gastrointestinal complaints, and sleep disturbance. Emotional distress, such as depression, apathy, anger, and irritability, can occur. Many complain of moral distress as there is no end in sight of the suffering (Sorenson, Bolick, Wright, & Hamilton, 2017). The risk for CF includes the number of hours, coping ability, age, competing demands.

When examining the experiences of the family caregivers of an AMHD, there are similarities to those who experience CF. The research on this population acknowledges the adverse effect of caring for an AMHD but does not explicitly address CF for this population. The cost of caring for an AMHD can have an adverse physical, emotional, and spiritual impact. Family caregivers of AMHD report higher levels of stress, emotional turmoil, guilt, and complaints of exhaustion and fatigue resulting from the disruptive behaviors and often physical violence of the adolescent. These findings, supported by a systematic mixed study review of family caregivers, found that families experience decreased self-esteem, a negative impact on the family system, stigma, and isolation (Rodriguez-Meirinhos, Antolin-Suarez & Olivia, 2017). Higher levels of strain also resulted from a lack of social supports, feeling that they need to be vigilant and in charge of treatment plans. The chronic nature of mental health disorders contributes to caregiver's stress, and family caregivers reported higher levels of psychological distress, and somatic complaints (Schraeder, Reid & Brown, 2018; Ukamaka et al. 2015).

Caregivers often face financial burdens associated with lost wages from missed work to attend to the needs of the adolescent (Bauer, Sousa-Poza, 2014 & Earle & Heymann, 2012). Family caregivers report having to take time away from work to interact with the school system, law enforcement, and appointments with providers (Ukamaka et al., 2015). The majority of caregivers are single mothers who cannot work due to the demands of the role of caregiver (Moblebatsi, Ndetei, Opondo, 2017; Ukamaka et al., 2015). Family caregivers frequently report that they have limited personal resources (Honey et al., 2015), such as time and money needed for ongoing care necessary for the AMHD. The financial consequences for the family caregiver are that they could be responsible for the continuation of treatment for the adolescent well into their adulthood (Schraeder, Reid & Brown, 2018).

The literature emphasizes the adverse impact on the caregivers' physical, emotional, and spiritual wellbeing, the same conditions as family caregivers who experience CF. The physical, emotional, and spiritual impact on the family caregiver, as described by Meirinhos, Antolin-Suarez & Olivia, (2017) and Schraeder, Reid & Brown (2018), could be addressed as CF. Still, the authors only go as far as detailing them as adverse components of caring. Along with the social-emotional components Moblebatsi, Ndetei, Opondo (2017) & Ukamaka et al. (2015) establish the economic stress that comes from caring for an AMHD. Current practice settings do not address the impact of caregiving for this population, which is similar to the experience of families who have CF.

The family caregiver, which may include parents, siblings, and grandparents, has become a significant part of health care delivery by providing care in the home rather than in an inpatient or institutional setting. The family caregiver is someone who provides regular care or assistance to a friend or family member with a long-term illness or chronic disability (Anderson et al. 2013). Mental health disorders such as anxiety, depression, eating disorders, and disruptive behavioral disorders are considered chronic illnesses. These conditions are prolonged in nature and do not typically resolve spontaneously (National Center for Chronic Disease and Prevention and Health Promotion, 2012). Today one in five adolescents (Office of Adolescent Health, 2016) has a diagnosis of a mental health disorder.

# Needs Assessment

The role of the family is an essential piece to the care of the adolescent, which includes managing the ongoing treatment plan upon discharge and possibly well into adulthood (Schraeder, Reid & Brown, 2017). To assess the impact of CF in this population interviews were conducted with two practitioners who work with adolescents in a RTC and with providers and

staff from three RCTs, one in Sedona, Arizona, and two in Utah. The interviews asked two simple questions, have you heard of CF in the family caregiver and do you have a program to address CF in the family caregiver. Based on the interviews, all had heard of the concept of CF but they do not have a program for family caregivers which screens families or provide interventions for CF for family caregivers with an adolescent in a mental health setting (A. Rencher, personal communication, June 23, 2018; B. McElligott, personal communication, June 24, 2018; M. Bartlett, personal communication, February 11, 2019; J. Fairbanks, personal communication, March 26, 2019, T. Garden, personal communication, March 29, 2019). The practitioners and the staff at the three RTCs acknowledged that families have significant stress caring for their adolescents. They do discuss with families the need to "take care," but they do not have any formal program to screen families for CF or provide interventions.

#### **Literature Review**

A systematic and comprehensive search conducted between September of 2018 and November of 2018 to ask the question are family caregivers who have an AMHD at risk for CF. The following databased were used, Cumulative Index to Nursing and Allied Health Literature (CINHAL), which included CINHAL Complete, MEDLINE, and PsycINFO as a combined search tool. Five search terms were used and included *compassion fatigue*, *family caregiver*, *family caregiver and compassion fatigue*, *family caregiver and adolescent with a mental health disorder*, *and family caregiver with an adolescent with mental health disorder and compassion fatigue*. An initial review of abstracts yielded 39 studies with 21 retained studies all peerreviewed and published between 2010 to 2018. The studies were kept based on the quality of the evidence, rigor of the research, and clinical significance (see Appendix A).

# **Synthesis of Findings**

The review of literature sought to understand the impact of caregiving on the family with an AMHD and if this population were included in family caregivers at risk for CF. The literature emphasizes the adverse impact for the caregivers' physical, emotional, and spiritual wellbeing, the same conditions as family caregivers who experience CF. The physical, emotional, and spiritual effects on the family caregiver, as described by Rodriguez- Meirinhos, Antolin-Suarez & Olivia, (2017) and Schraeder, Reid, & Brown (2018) could be addressed as CF. Still, the authors only go as far as detailing them as adverse components of caring. Along with the social-emotional components, Moblebatsi, Ndetei, & Opondo (2017) and Ukamaka et al. (2015) establish the economic stress that comes from caring for an AMHD.

Parents, siblings, and grandparents of AMHD have the primary role of the family caregiver and have significant challenges when caring for an AMHD, placing them at risk for CF. Ukamaka et al. (2015) study found that families were often under considerable stress as they try to manage the behaviors of an AMHD. Family caregivers reported higher levels of stress, emotional turmoil, and guilt associated with disruptive behaviors and physical violence (McCarthy et al., 2016, Molebasti, Ndetei, & Opondo, 2017, Muralidharan et al., 2016). Family caregivers frequently report being isolated, have less leisure time, and overall dissatisfaction with family life (Muralidharan et al., 2016, Rodriguez-Meirinhos, Antolin-Suarez, Olivia, 2017).

To assess for CF in the family caregiver, the Professional Quality of Life (ProQOL), a tool designed to measure for CF, uses three scales, burnout, secondary traumatic stress (STS), and compassion satisfaction (Stamm, 2016). The survey was designed initially for professionals and used to screen volunteers and family caregivers (Flarity, K., Gentry, J. E., & Mesnikoff, N. 2013; Flarity, K., Nash, K., Jones, W., & Steinbruner, D., 2016; Hila, H., Ben-David, S., & Levy, I. 2016). It was modified to be more inclusive of family caregivers in a study by Lynch &

Lobo with the assistance of Dr. Stamm, the originator of the ProQOL survey (Lynch, S. H., Shuster, G., & Lobo, M. L. 2018 & Stamm, 2016). Studies showed that when both burnout and STS scores were average/moderate or high that this was an indication of CF (Leow, M., Chan, S., Fai Chan, & Moon. (2015); Lynch, S. H., Shuster, G., & Lobo, M. L., 2018; Stamm, 2016).

Research suggests that interventions for family caregivers should include providing programs with multifaceted methods that provide knowledge, coping strategies, and one-on-one support. These have proved to have significant benefits for professionals as well as caregivers (Flarity, Gentry & Mesikoff, 2013; Leow, Chan & Chan, 2015; Potter, DeShields & Rodriguez 2013; Sinclair et al. 2017). The interventions are similar to those suggested for family caregivers of AMHD (Day, Starbucks & Petrakis, 2017; Hibbs, Rhind, Leppanen & Treasure 2015; Honey et al. 2015) peer support programs, self-help, guided self-help, workshops, and knowledge as excellent strategies for helping mitigate the stress of caregiving. In a systematic mixed study review by Rodriguez-Meirinhos, Antolin-Suarez & Oliva (2017) found that parents had a significant need for support to manage conflicts as parental roles change, and the adolescent seeks independence and autonomy. Resources are needed to support families through education and supportive care for the caregiver.

The problem was identified based on the similarities between family caregivers caring for an aging or terminally ill family member and families caring for and AMHD. When presented with the concept of CF, the staff at New Haven acknowledged the need to address the needs of the families. The intended outcome for the project would encompass a program that includes a method to determine if this population of family caregivers is at risk for CF and implement for both staff and caregivers' interventions that include knowledge of CF and tools to reduce the risk.

# **Project Frameworks**

The theoretical framework used for this project is The Neuman Systems Model (NSM) developed by Betty Neuman (Neuman & Fawcett, 2011). The NSM is a holistic, multidimensional approach to the client as a system (Neuman & Fawcett, 2011). According to Neuman, the term client can include individual, family, community, and social issues. The client can also be defined as the "practice setting," and for this project, it will be the RTC. NSM is an open system that interacts with the internal and external environment. NSM describes five interacting variables; physiological, psychological, sociocultural, developmental, and spirituality affected by internal and external stressors (Fawcett & Desanto-Madeya, 2012). NSM defines prevention as a critical intervention and includes primary, secondary, and tertiary interventions. There are five guidelines for the role of the administrator in Neuman's model. The first guideline regards each department as a system, and it is defined by the qualities of the administrator's role. The second role is to facilitate the delivery of primary, secondary, and tertiary prevention, assisting the client in retaining, attaining, or maintaining optimal balance and stability. The third requires an administrator dedicated to the holistic model as well as knowing that each discipline has its understanding and knowledge. The fourth guideline is that the setting is unique to providing care. The fifth guideline focus is on everyone involved in the delivery of services. In respect to the project involving the staff of the RTC was vital to determining how and when to implement the program. It is vital as an administrator to work to maintaining stability for everyone involved (Fawcett & Desanto-Madeya, 2012).

The conceptual framework for the project is Knowledge to Action (KTA). KTA is a dissemination and implementation framework designed to take knowledge from primary research studies and synthesize the knowledge to generate new knowledge tools such as practice

guidelines, decision aids, or care pathways (Straus, Tetroe, & Graham, 2013). KTA utilizes a collaborative process to adapt knowledge at the local level, which for this project will be staff at a RTC. The KTA framework has been a successful model for the implementation of new knowledge and skills in a variety of healthcare settings.

Using the KTA framework, the staff at the RTC, an interprofessional team of therapists, nurses, educators, and support staff, would receive new information on CF. The educational programs serve several purposes, initially to establish a relationship with the team and to inform with the education on CF. By adapting the KTA, on-site training for the staff allows for the ability to identify barriers, develop interventions to reduce barriers, identify anyone who has low compliance with implementing their new program guidelines (Salsberg & Macaulay, 2013). The on-site visits also offer the ability to disseminate new knowledge, define an implementation plan, address barriers, and discuss sustainability (Duhamel, 2017).

NSM adapts the need for education to the client's setting, and this will drive the content by identifying the at-risk family caregiver through the screening tool and by identifying which interventions were more likely to be adapted by the family caregiver. The process should be collaborative. NSM believes that anyone can be a learner, and all that is required is an ability to engage in high levels of critical thinking. The overarching goal is to create a process that can be adapted by the team (Fawcett & Desanto-Madeya, 2012).

# Methods

# Setting

The project introduced the concept of CF to the staff at New Haven, an RTC for adolescent girls with mental health disorders such as depression, anxiety, traumatic stress,

substance abuse, eating disorders, and other challenging emotional disorders (www.newhavenrtc.com, 2017).

New Haven provides residential care at two campuses North and South in southern Utah.

Each campus is comprised of three homes and a school campus. Admission often occurs after the adolescent has spent time in a wilderness program, an inpatient or failed outpatient program.

Residential treatment provides psychological care using a variety of therapies in a structured environment.

# Population

New Haven RTC is a multidisciplinary program that includes licensed therapist, recreational therapist, educators, nurses and support staff. The program provides care for adolescent girls between the ages of 13 to 17. Family caregivers are typically parents but can include siblings, grandparents and aunts and uncles.

# Usual Care

New admissions require one-on-one staff support to evaluate the behaviors and safety. An interprofessional team develops a plan of care that includes individual and group therapies as well as an educational program to meet academic needs. The family plays an integral role in the treatment program. Families participate in therapy sessions that address issues that may contribute to a specific mental health disorder. A component of the treatment plan is family weekends, where the families participate in a variety of activities with other families and their children. The weekends may include camping, on-campus events as well as time off-campus with their child. The design of the program is to provide the adolescent and their family opportunities to function with stability. To do this, the treatment team develops a plan that incorporates fewer restrictions for the adolescent and family before discharge.

#### Intervention

The project included two separate interventions, the first intervention was to educate the staff at New Haven and the second intervention was the implementation of a CF program for the family caregivers who attended an on-campus family weekend.

Staff at the New Haven RTC North Campus participated in the initial one hour in person educational program during a weekly staff meeting in June of 2019 and South Campus in October 2019. The educational program for the staff included the history of CF from the professional to the family caregiver. The causes of CF which include the impact of the relationship between the family member and the family caregiver, the stresses which are often outside the normal family roles. The symptoms of CF which can be physical, emotional and spiritual in nature. The educational program provided interventions to address the physical, emotional and spiritual distress. Interventions include self-help exercise and diet guided self-help such as mediation and peer support. The validated screening tool which is a modified from of the Professional Quality of Life Survey entitled the Family Quality of Life Survey (FQoLS) (See Appendix B).

A staff lead discussion occurred at the end of the educational program to formulate the program that would be offered to families. The staff agreed that the families could attend a group session which would be led by staff therapist. The sessions would include the FQoLS and an educational brochure that would include information on CF and interventions. The educational brochure introduced the concept of CF describing what the caregiver may experience in the way of burnout and secondary traumatic stress. Symptoms of physical, emotional and spiritual distress were described. The brochure also covered interventions to reduce the impact of caregiving. ZENs which included the importance of sleep, exercise, nutrition, and spiritual care.

Along with relaxation and meditation families are provided information on peer support and the benefits of sharing with other family caregivers.

# **Data Collection**

Using the Continuing Professional Development Reaction Questionnaire (CPDRQ), a pretest posttest design was used to assess the staff's commitment to a practice change (See Appendix C). The CPDRQ is a means of measuring a practitioner's response to receiving new knowledge and a subsequent change in practice (Lamont, S., & Brunero, S. 2018; Légaré et al., 2017). According to Légare et al. (2017), a practitioner whose response increased after participating in a CPDRQ for the constructs of intention and a belief about capabilities are more likely to incorporate the practice change. Based on the result, self-reported behavior can be used as a proxy of behavior change.

The questionnaire was distributed in a paper format and collected by the author just before and upon completion of the education intervention on June 26 & 27, 2019, at the North Campus and October 23, 2019, at the South Campus. Once the questionnaires were collected, the data was manually uploaded into Qualtrics, a password-protected site maintained by Northern Arizona University. The surveys data was deidentified and uploaded into Qualtrics to organize the data by the constructs of intention, social influence, beliefs about capabilities, moral norms, and beliefs about consequences.

North Campus, which has three homes implemented the project during a family weekend in July and October of 2019. Families participate in a variety of programs lead by staff therapist. The initial plan was to include families who were on campus for their first visit with their daughter. These families received the FQoLS, staff therapist led discussion on CF, and the brochure. The lead therapist at North Campus also distributed the pamphlet and FQoLS to all

families that were on campus. During group setting, second- and third-time visiting parents were given information on CF but in a less formal manner.

The FQoL survey is a thirty item Likert scale used to measure compassion satisfaction, burnout, and secondary traumatic stress. Moderate to high scores for both burnout and secondary traumatic stress are indicators of CF (Lynch & Lobo,2017; Stamm, 2016). New Haven provided families with a Follow-Up Survey approximately ten days after attending the family weekend. The follow-up survey determines how families received information on CF, their understanding of the impact, and what they have done since acquiring the information on CF.

The Family Quality of Life Survey were distributed and collected by the lead therapists during the family weekend. The Follow-Up Survey were emailed to families by New Haven about ten days following the family weekend in the form of an electronic survey.

# **Data Analysis**

Data for staff participants were analyzed using descriptive statistics, similar to the method developed by Légaré et al. (2017). The data analysis included mean, median, and Wilcoxon signed-rank tests. The use of this non-parametric testing allows for a hypothesis that is not about population parameters and is best suited for comparing two paired groups. The test will calculate the difference between each set of paired data and is best suited to analyze the differences between pre and post-interventions (Parab & Bhalerao, 2010).

The data from Qualtrics was exported into excel to organize the responses based on the question constructs of intention (questions 1 & 7), social influence (questions 2, 6, 9), beliefs about capabilities (questions 3, 5, 11), moral norms (questions 4,10), and beliefs about consequences (questions 8 & 12). Calculations used the formula as defined by Légaré et al.,

(2017), (see Appendix D). Once sorted, it was analyzed using the JMP Pro statistical software (see Table 1)

The lead therapist compiled the Family Quality of Life survey results, using the modified constructs developed for the ProQol tool (Hila, H., Ben-David, S., & Levy, I., 2016; Lynch & Lobo, 2017; Stamm, 2016). The results were hand scored by the family member or staff, allowing for the team to discuss the results with the family member (see Appendix E). The Follow-Up Survey questions results were tabulated by New Haven from an electronic survey sent to families who attended the family weekend (See Table 3).

# **Results**

New Haven RTC staff participated in implementing a new program for family caregivers for CF. The data from the staff participants' CPDRQ and the family caregiver FQoLS and Follow-Up surveys served to evaluate the impact of the project.

The result of the CPDRQ is an indicator of the staffs' intention to change their practice. While there was an increase in responses for all questions, items specifically measuring for intention and beliefs about capabilities were significant. The construct items of intention, a median increase of 4.75 to 5.5, for South Campus a median increase of 4 to 6 for North Campus and beliefs about capabilities the median increase of 3.17 to 3.67 for South Campus and median increase 3 to 5.6 (P < 0.001) were a positive indicator for all participants at New Haven North and South Campus intention to change practice behavior (see Table 1)

The Family Quality of Life Survey suggests that the role of a family caregiver is a risk for CF. Eight of the caregivers scored in the moderate range (score of 23-41) for both burnout and secondary traumatic stress, an indicator of CF (see Table 2). The Follow-Up Survey for families (n=30) suggests that not all families received information on CF. More than half

received information (attended a group or received the brochure) and indicated that they had a new understanding of the impact of CF (see Table 3). There is evidence that families who participated and obtained information on CF had either considered or had implemented one or more of the interventions. The interventions, including having spoken to someone they trust, eating a healthy diet, made sleep a priority and learned to relax and meditate. The families who participated in the program have indications for CF and, after participating in the program, had gained new knowledge and interventions for CF.

Predictive validity was estimated by comparing the intention (median intention construct score) after the CPDRQ activities with the intention score and using a p-value < .05 as statistically significant. Overall, an increase in scores for both campuses for all constructs after the educational program (P < 0.001). There are noticeable increases for the construct of intention (median increase of 4.75 to 5.5 for South Campus and a median increase of 4 to 6 for North Campus) and beliefs about capabilities (the median increase of 3.17 to 3.67 for South Campus and median increase 3 to 5.6). (see Table 1).

The results of the Family Quality of Life Survey included twenty-one respondents, with eighteen reporting a moderate level of burnout and seventeen reporting moderate levels of secondary traumatic stress scales, which are indicators of CF (see Table 2). A total of 38 family participants replied to the Follow Up Family Surveys. Sixteen family participants reported receiving information on CF, two were unsure, and 12 responded no. Those who received information reported they attended a group, received a brochure, or both. Twelve family participants reported that they had a new understanding of CF and its impact. Of those who responded to having received the information, 60.5% reported considering implementing or had implemented one or more of the interventions. Interventions of sharing information with

someone they trusted (50%) reported making sleep a priority, eating a healthy diet, and learned to relax and mediate (37%) (see Table 3).

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The Family Quality of Life Survey suggests that the role of a family caregiver is a risk for CF. Eighteen of the caregivers scored in the moderate range (score of 23-41) for both burnout and secondary traumatic stress, an indicator of CF. The Follow-Up Survey for families (n=30) suggests that not all families received information on CF. More than half (n=17) received information (attended a group or received the brochure) and indicated that they had a new understanding of the impact of CF (n=12). There is evidence that families who participated and received information on CF had either considered or had implemented one or more of the interventions. The interventions including having spoken to someone they trust (n=13), eating a healthy diet (n=11), and made sleep a priority (n=10). The families who participated in the program have indications for CF and, after participating in the program, had gained new knowledge and interventions for CF.

A post-conference was held with the lead therapist from North Campus after the July 2019 implementation. The lead therapist determined that first-time visiting families seemed to be overwhelmed and not ready to attend the CF program. Families who were visiting for a second

or third visit were more receptive to learning about CF based on some informal feedback from families. In January 2020, the program was formally introduced at both campuses with a designated therapist to implement the program.

The cost for implementation included the cost of training of staff and the implementation of the program for families provided by a lead therapist. For staff training, New Haven estimated the cost for thirty staff during a weekly team meeting for a one-hour session at \$3650.00. The cost for the family session estimated at \$54 per hour.

#### **Discussion**

The purpose of this project was to change practice at New Haven RTC to address the incidence of CF for the family caregiver. The project provided the staff at New Haven North and South Campus with education on CF, screening tools, and interventions needed to develop and implement a new program for family caregivers. There were three components for evaluating the project. The CPDRQ from staff participants, the Family Quality of Life Survey to measure CF in the family caregiver, and the Follow-Up survey to measure the family response to the information on CF.

First, it is essential to understand the willingness of the staff to implement a new program — the CPDRQ given to the team as a pre/post measurement of an intention to change. The results of the CPDRQ, comparing the median for both intention and beliefs in capabilities after participating, showed an increase for both constructs in (P < 0.001). The findings are suggestive of the intent to change.

Secondly, it was essential to evaluate families for CF using the results from the Family Quality of Life Survey. Ten family caregivers responded with eight responses having scored in

the moderate range (scores between 23 and 41) for burnout and secondary traumatic stress, the two scales that are suggestive of CF.

Finally, the Follow-Up Survey was essential to determine what information was gained by the families. The survey results (n=30), suggest that not all families received information (n=12) or were sure that they received information (n=2). Families who received information (n=16) only eight reported gaining a new understanding of CF. All who received information indicated they had either considered or implemented one of the interventions. The most saying that they spoke to someone they trust (n=13), eating a healthy diet (n=11), and made sleep a priority (n=10).

# Limitations

The current project has limitations. First, the sample size of families was relatively small and may not be generalizable. Secondly, the project was implemented in a different state from the project developer and not on-site for the entire project; this may have led to some deviation from the planned intervention, such as ensuring that all families received the FQoLS, or participated in a group session. The FQoLS, an adapted form of the ProQol Survey, contains language that does not quite fit with the role of the family caregiver, which may result in some misinterpretation by the person(s) taking the survey.

#### Conclusion

CF arises from a caring relationship for someone with a chronic illness. It can result in physical, emotional, and spiritual distress, and the family caregivers with an AMHD are at risk for CF. Providing family caregivers with AMHD information and interventions on CF can be an effective way to improve the wellbeing of the caregiver. While this project addresses those caring for an adolescent, the information could be potentially useful for caregivers caring for

someone with a mental health disorder of any age. There is more opportunity to study the phenomenon of CF and the family caregiver and overtime, which interventions are most effective.

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Table 1
Continuing Professional Development Reaction
Questionnaire

	North (	Camp	us		
	Pre			Post	
Construct	N		Item Mean	N	Item Mean
Intention		10	4.5	1	0 5.75
Social Influence		10	2.5	1	0 3.83
Beliefs about Capabilities		10	3.2	1	0 5.37
Moral Norms		10	5.55	1	0 6.25
Beliefs about Consequences		10	5.75	1	0 6.35
	South (	Camp	ous		
	Pre			Post	
Construct	N		Item Mean	N	Item Mean
Intention		20	3.9	2	5.95
Social Influence		20	3.2	2	20 3.25
Beliefs about Capabilities		20	3.26	2	5.6
Moral Norms		20	5.075	2	6.075
Beliefs about Consequences		20	5.25	2	6.53

Note. Predictive validity was estimated by comparing the pre-post scores of the CPDRQ using a p-value < .05 as statistically significant.

Wilcoxon signed rank test P value was <0.001

Table 2
Family Quality of Life Survey

	High	Moderate	Low
Compassion Satisfaction (CS) <sup>a</sup>	6	14	1
Burnout <sup>b</sup>		18	3
Secondary Traumatic Stress (STS) <sup>c</sup>	2	17	2

Note. The FQoL Survey was adapted from the Professional Quality of Life Survey <sup>a</sup> CS scores of 22 or less are considered low and scores of 42 or more are high (Alpha scale reliability of 0.88) (Stamm, 2016).

<sup>&</sup>lt;sup>b</sup> Burnout scores between 23 and 41 are considered moderate and score of 22 or less are considered low (Alpha scale reliability of 0.75) (Stamm, 2016).

<sup>&</sup>lt;sup>c</sup> STS scores of 42 or more are considered high, scores between 23 and 41 are considered moderate and score of 42 or more are considered high(Alpha scale reliability of 0.81) (Stamm, 2016).

**Table 3**Family Follow Up Survey

Did you receive information on CF?	Yes	No	Maybe				
mormation on er .	16	12	2				
How did you receive the information?	Group	Brochure	Both				
	8	4	5				
Do you have a new understanding of compassion fatigue is and how it may impact you?	Yes	No	Maybe				
	12	1	6				
Have you shared the	Yes	No					
information on compassion fatigue with family and/or friends?		1.0					
compassion fatigue with family and/or	7	9					
compassion fatigue with family and/or	7 Spoken to someone you trust		Made sleep a priority	Started an exercise program	Reconnected with church, nature, renewed relationship	Learned to relax or Meditate	Participated in a Support Group

Appendix A
Literature Synthesis

	Economic Impact	
Author	Title	-
Anderson et al. (2013)	Adult caregivers in the United States: characteristics and differences in well-being, by caregiver age and caregiving status	BRFFS results loss of work do to time spent caregiving
Bauer, J. M., & Sousa-Poza, A. (2015)	Impacts of Informal Caregiving on Caregiver Employment, Health, and Family	Significant burden financially, missed work days, less productive, loss of pay
Earle, A., & Heymann, J. (2012)	The cost of caregiving: wage loss among caregivers of elderly and disabled adults and children with special needs	Lost wages and earning loss.
Molebatsi, K., Ndetei, D. M., & Opondo, P. R. (2017)	Caregiver burden and correlates among caregivers of children and adolescents with psychiatric morbidity: a descriptive cross sectional study	Lost wages and earning loss do to missed work.
Oruche, U. M., Draucker, C. B., Al-Khattab, H., Cravens, H. A., Lowry, B., & Lindsey, L. M. (2015).	The Challenges for Primary Caregivers of Adolescents With Disruptive Behavior Disorders	Unable to work do to challenges of caregiving.  Mostly women
Author	Physical/Emotional/Spiritual Impact Title	-
Anderson et al. (2013)	Adult caregivers in the United States: characteristics and differences in well-being, by caregiver age and caregiving status	Caregivers report more physical complaints, less satisfied with life, poor health.
Bauer, J. M., & Sousa-Poza, A. (2015)	Impacts of Informal Caregiving on Caregiver Employment, Health, and Family	Negative impact on caregivers physical and psychological health

Coetzee, S. K., & Laschinger, H. K. S. (2018)	Toward a comprehensive, theoretical model of compassion fatigue: An integrative literature review	professional caregivers lack resources and suffer from fatigue, less empathetic, life disruptions
Lynch, S. H., & Lobo, M. L. (2012)  Lynch, S. H., Shuster, G., & Lobo, M. L. (2018)	Compassion fatigue in family caregivers: a Wilsonian concept analysis  The family caregiver experience  – examining the positive and negative aspects of compassion satisfaction and compassion fatigue as caregiving outcomes	CF for family caregiver is similar to professionals Family caregivers experience results in burnout and secondary traumatic stress. Caregivers can provide safe care.
McCarthy, M. J., Smith, R. R., Schellinger, J., Behimer, G., Hargraves, D., Sutter, J., Scherra, K. (2016)  Molebatsi, K., Ndetei, D. M., & Opondo, P. R. (2017)  Muralidharan, A., Lucksted, A.,	Impact of Youth Strengths and Objective Strain on the Experiences of Subjective Strain Among Caregivers of Youth with Behavioral Health Conditions Caregiver burden and correlates among caregivers of children and adolescents with psychiatric morbidity: a descriptive cross sectional study Stigma: a Unique Source of	Caregivers report negative events, negative feelings, and have negative outward behaviors Caregivers report PTSD, depression, anxiety, and increase use of drugs and alcohol Caregivers report stigma
Medoff, D., Fang, L. J., & Dixon, L. (2016)	Distress for Family Members of Individuals with Mental Illness	causing feelings of being less empowered, less confident, poor self- image, isolated, lonely
Oruche, U. M., Draucker, C. B., Al-Khattab, H., Cravens, H. A., Lowry, B., & Lindsey, L. M. (2015).	The Challenges for Primary Caregivers of Adolescents With Disruptive Behavior Disorders	Caregivers feel overwhelmed, lost lesiure time, loss of family connection, loss of pleasurable activities
Perry, B., & Edwards, M. (2015)	A qualitative study of compassion fatigue among family caregivers in long-term care homes	Caregivers report feelings of apathy, frazzled, tired, anxious, physical illness, doubting own personal beliefs, loss of hope

Rodríguez-Meirinhos, A., Antolín-Suárez, L., & Oliva, A. (2018)	Support Needs of Families of Adolescents With Mental Illness: A Systematic Mixed Studies Review	Caregiving is extremely stressful, impacts all family members, disbelief, anxiety,
Schraeder, K. E., Reid, G. J., & Brown, J. B. (2018)	"I Think He Will Have It Throughout His Whole Life": Parent and Youth Perspectives About Childhood Mental Health Problems	Chronic conditions leaves caregivers feeling overwhelmed, over burdened, out of options.
Sinclair, S., Raffin-Bouchal, S., Venturato, L., Mijovic- Kondejewski, J., & Smith- MacDonald, L. (2017).	Compassion fatigue: A meta- narrative review of the healthcare literature	Defines professional caregives as being burned out, overwhelmed, somatic complaints, loss of empathy, spiritual distress
Sorenson, C., Bolick, B., Wright, K., & Hamilton, R. (2017)	An Evolutionary Concept Analysis of Compassion Fatigue.	CF in professional caregivers encompasses emotional stress, loss of empathy, burnout, moral distress
Thorson-Olesen, S. J., Meinertz, N., & Eckert, S. (2019).	Caring for Aging Populations: Examining Compassion Fatigue and Satisfaction.	Informal caregivers are more likely to suffer from CF. Lack of training and lack of respite from caregiving are significant factors.
	Interventions	
Author	Title	-
Baumgarten, H. (June 6, 2019)	Burning up while burning out: Compassion Fatigue awareness & burnout prevention for practitioners	Program of evidence- based interventions recommends sleep, exercise, nutrition, relaxation, peer support
Day, K., Starbuck, R., & Petrakis, M. (2017	Family group intervention in an early psychosis program: A reevaluation of practice after 10 years of service delivery	Education, family support in group setting

Flarity, K., Gentry, J. E., & Mesnikoff, N. (2013	The Effectiveness of an Educational Program on Preventing and Treating Compassion Fatigue in Emergency Nurses	ProQOL survey to measure CF, multifaceted approach, education, peer support, self-care showed improved compassion satifafaction.
Flarity, K., Nash, K., Jones, W., & Steinbruner, D. (2016).	). Intervening to Improve Compassion Fatigue Resiliency in Forensic Nurses	ProQOL survey to measure CF, multifaceted approach, education, peer support, self-care showed improved compassion satifafaction.
Hibbs, R., Rhind, C., Leppanen, J., & Treasure, J. (2015).	Interventions for caregivers of someone with an eating disorder: A meta-analysis	Family support that inlcudes guided self help reduced stress
Hila, H., Ben-David, S., & Levy, I. (2016).	Supplemental Material for Predicting Professional Quality of Life Among Professional and Volunteer Caregivers	ProQOL survey to measure CF was useful for both professional and volunteers
Honey, A., Chesterman, S., Hancock, N., Llewellyn, G., Hazell, P., & Clarke, S. (2015	Knowing What to Do and Being Able to Do It: Influences on Parent Choice and Use of Practices to Support Young People Living with Mental Illness	Education to increase knoweldge and support
Laird, R., & Kuhn, E. (2014).	Family support programs and adolescent mental health: review of evidence.	Family support programs, peer support, emotional support
Leow, M., Chan, S., Fai Chan, & Moon. (2015)	A Pilot Randomized, Controlled Trial of the Effectiveness of a Psychoeducational Intervention on Family Caregivers of Patients With Advanced Cancer	ProQOL survey to measure CF, self care, knowledge led to lower stress and depression
Lynch, S. H., Shuster, G., & Lobo, M. L. (2018)	The family caregiver experience  – examining the positive and negative aspects of compassion satisfaction and compassion fatigue as caregiving outcomes	Modified ProQOL to measure CF in family caregiver
Perry, B., & Edwards, M. (2015)	A qualitative study of compassion fatigue among family caregivers in long-term care homes	Knowledge, social support, self-care

Potter, P., Deshields, T., & Developing a Systemic Program Professional caregivers Rodriguez, S. (2013) for Compassion Fatigue. benefited from edcuation and peer support Rodríguez-Meirinhos, A., Support Needs of Families of Social support, Antolín-Suárez, L., & Oliva, A. Adolescents With Mental Illness: education, support to (2018)manage feelings, and A Systematic Mixed Studies Review stigma

# Appendix B

Family Quality of Life Survey

# FAMILY QUALITY OF LIFE SCALE

#### COMPASSION SATISFACTION AND COMPASSION FATIGUE

When you provide care for people you have direct contact with their lives. As you may have found, your compassion for those you provide care can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a caregiver. Consider each of the following questions about you and your current situation. "Work" refers to the work you perform as a caregiver. Select the number that honestly reflects how frequently you experienced these things in the last 30 days.

I=Neve	r 2=Rarely	3=Sometimes	4=Often	5=Very Often
1.	I am happy.			
2.		e than one person I <i>provide c</i>	are.	
3.		able to provide care for peop		
3. 4. 5. 6. 7.	I feel connected to others.			
5.	I jump or am startled by un	expected sounds.		
6.	I feel invigorated after work	king with those I provide care		
7.	I find it difficult to separate	my personal life from my life	as a caregiver.	
8.	I am not as productive at w provide care.	ork because I am losing sleep	o over traumatic exp	periences of a person I
9.	I think that I might have been	en affected by the traumatic s	tress of those I prov	vide care.
10.	I feel trapped by my job as a	a caregiver.		
11.	Because of my caregiving, I	have felt "on edge" about var	ious things.	
12.	I like my work as a caregive	r.		
11. 12. 13. 14. 15. 16. 17. 18. 19. 20.	I feel depressed because of	the traumatic experiences of	the people I <i>provide</i>	e care.
14.	I feel as though I am experi	encing the trauma of someon	e I have <i>provided ca</i>	re.
15.	I have beliefs that sustain m	e.		
16.	I am pleased with how I am	able to keep up with caregiv	ing techniques and p	protocols.
17.	I am the person I always wa	inted to be.		
18.	My work makes me feel sat	isfied.		
19.	I feel worn out because of i	my work as a <i>caregiver</i> .		
20.	I have happy thoughts and f	eelings about those I provide	care and how I coul	ld help them.
21.	I feel overwhelmed because	e my <i>caregiving</i> load seems ei	ndless.	
21. 22.	I believe I can make a differ	ence through my work.		
_ 23.	I avoid certain activities or a people I <i>provide care</i> .	situations because they remir	nd me of frightening	experiences of the
24.	I am proud of what I can do	to provide care.		
25.	As a result of my caregiving	, I have intrusive, frightening	thoughts.	
26.	I feel "bogged down" by the	system.		
27.	I have thoughts that I am a	"success" as a caregiver.		
24. 25. 26. 27. 28. 29.		s of my work with trauma vi	ctims.	
29.	I am a very caring person.			
30.	I am happy that I chose to d	lo this work.		

Appendix C

# **CPDRQ**

Please answer each of the following questions by indicating the number that best describes your opinion about the behavior indicated . Some of the questions may appear to be similar, but they do address somewhat different aspects of the behavior stated.

I intend to Screen families for compassion fatigue.	Stongly disagree Stongly agree
<ol> <li>To the best of my knowledge, the percentage of my colleagues who screen families for compassion fatigue is:</li> </ol>	0-20% 21-40% 41-60% 61-80% 81-100%
3. I am confident that I could <i>screen families for compassion fatigue</i> if I wanted to.	Stongly disagree Stongly agree  1 2 3 4 5 6 7
4. Screening families for compassion fatigue is the ethical thing to do.	Stongly disagree Stongly agree  1 2 3 4 5 6 7
5. For me, screening families for compassion fatigue would be:	Extremely difficult Extremely easy  1 2 3 4 5 6 7
6. Now think about a co-worker whom you respect as a professional. In your opinion, does he/she screen families for compassion fatigue?	Never Always  1 2 3 4 5 6 7
7. I plan to screen families for compassion fatigue	Strongly disagree Strongly agree  1 2 3 4 5 6 7
Overall, I think that for me screening families for <i>compassion</i> 8. <i>fatigue</i> would be	Useless Useful  1 2 3 4 5 6 7
<ol> <li>Most people who are important to me in my profession screen families for compassion fatigue.</li> </ol>	Stongly disagree Stongly agree  1 2 3 4 5 6 7
10. It is acceptable to to screen families for compassion fatigue.	Stongly disagree Stongly agree  1 2 3 4 5 6 7
11. I have the ability to screen families for compassion fatigue.	Stongly disagree Stongly agree  1 2 3 4 5 6 7
Overall, I think that for me screening families for <i>compassion fatigue</i> would be:	Harmful Beneficial  1 2 3 4 5 6 7

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The CPD Reaction Questionnaire ©2013 Université Laval

# Appendix D

# CPDRQ

Construct scale		ltems <sup>a</sup>	Responses choices	Pre-coded item value <sup>b</sup>	Final item score <sup>c</sup>	Score by construct <sup>d</sup>
Intention	I <sub>1</sub>	I intend to [behavior]	Strongly disagree/agree	1 to 7	1 to 7	(I <sub>1</sub> +I <sub>7</sub> )/2
	17	I plan to [behavior]	Strongly disagree/agree	1 to 7	1 to 7	
Social influence	l <sub>2</sub>	To the best of my knowledge, the percentage of my colleagues who [behavior] is	0–20%	1	1.4	(l <sub>2</sub> +l <sub>6</sub> +l <sub>9</sub> )/3
			21–40%	2	2.8	
			41-60%	3	4.2	
			61–80%	4	5.6	
			81-100%	5	7	
	I <sub>6</sub>	Now think about a co-worker whom you respect as a professional. In your opinion, does he/she [behavior]?	Never/Always	1 to 7	1 to 7	
	l <sub>9</sub>	Most people who are important to me in my profession [behavior]	Strongly disagree/agree	1 to 7	1 to 7	
Beliefs about capabilities	l <sub>3</sub>	I am confident that I could [behavior] if I wanted to.	Strongly disagree/agree	1 to 7	1 to 7	(l <sub>3</sub> +l <sub>5</sub> +l <sub>11</sub> )/
	I <sub>5</sub>	For me, [behavior] would be	Extremely difficult/easy	1 to 7	1 to 7	
	111	I have the ability to [behavior]	Strongly disagree/agree	1 to 7	1 to 7	
Moral norm	14	[Behavior] is the ethical thing to do.	Strongly disagree/agree	1 to 7	1 to 7	(I <sub>4</sub> +I <sub>10</sub> )/2
	I <sub>10</sub>	It is acceptable to [behavior]	Strongly disagree/agree	1 to 7	1 to 7	
Beliefs about consequences	Ig	Overall, I think that for me [behavior] would be	Useless/Useful	1 to 7	1 to 7	(I <sub>8</sub> +I <sub>12</sub> )/2
	I <sub>12</sub>	Overall, I think that for me [behavior] would be	Harmful/ Beneficial	1 to 7	1 to 7	

a Item number (e.g., I<sub>1</sub> = Item 1)

# Appendix E

Family Quality of Life Survey Scoring Sheet

# WHAT IS MY SCORE AND WHAT DOES IT MEAN?

In this section, you will score your test so you understand the interpretation for you. To find your score on each section, total the questions listed on the left and then find your score in the table on the right of the section.

#### Compassion Satisfaction Scale

Copy your rating on each of these questions on to this table and add them up. When you have added then up you can find your score on the table to the right.

3.	
6.	
12.	
16.	_
18.	
20.	
22	
24.	
27.	
30.	_

20.	que
22.	22
24.	
27.	В
30.	23
Total:	42

The sum of my Compassion Satisfaction questions is	And my Compassion Satisfaction level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High

#### **Burnout Scale**

On the burnout scale you will need to take an extra step. Starred items are "reverse scored." If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. For example, question 1. "I am happy" tells us more about

111		
You	Change	the effects
Wrote	to	of helping
	5	when you
2	4	are not
3	3	happy so
4	2	you revers
5		the score

*1.	:	= .	
*4.	:	= [	
	=		
10.			
+15.	=	=	
+17.		=	
19.	_		_
21.			
+29.	=	=	
	al:		

The sum of my Burnout Questions is	And my Burnout level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High

#### Secondary Traumatic Stress Scale

Just like you did on Compassion
Satisfaction, copy your rating on each of
these questions on to this table and add
them up. When you have added then up
you can find your score on the table to
the right.

2.	
5.	
7.	
9.	
13.	
14.	
23.	
25.	
28.	

	_	
Τo	tal:	

The sum of my Secondary Trauma questions is	And my Secondary Traumatic Stress level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High