5-2020

What Kind of Resources Are There for Caregivers of Patients With Mental Illness?

Candice Robertson
California State University, Monterey Bay

Recommended Citation

Robertson, Candice, "What Kind of Resources Are There for Caregivers of Patients With Mental Illness?" (2020). *Capstone Projects and Master's Theses*. 838.
https://digitalcommons.csumb.edu/caps_thes_all/838

What kind of resources are there for caregivers of patients with mental illness?

Candice Robertson

Mental Health Client Action Network- Sarah Leonard

Collaborative Health & Human Services

Department of Health Human Services and Public Policy

California State University Monterey Bay

May 8, 2020

Author Note

Candice Robertson, Department of Health Human Services and Public Policy, California State University Monterey Bay. This research was supported by MhCAN. Correspondence concerning this report should be addressed to Candice Robertson, California State University Monterey Bay, 100 Campus Center, Seaside, CA, 93955. Contact: Carobertson@csumb.edu.

Abstract

The capstone was implemented at Telecare, an agency that serves individuals who are on a psychiatric hold. The capstone's macro-level problem is that caregivers are not receiving the support they need to adequately help their patients. The micro-level was that my agency works with the family so the social workers should be giving out appropriate resources for the caregivers. The capstone consisted of conducting research to assess the different resources that were available for caregivers online. I implemented this by conducting systematic GOOGLE searches and organizing top results by common themes that were in the articles found in the top search results. My expected outcome was to make the social workers *aware of the resources* that were available. The findings from my capstone show that there are not enough scholarly articles that can help caregivers with direct coping skills. Some steps that my agency took to address caregiver burden was to give out appropriate resources and focus on a family uplifting attitude.

Keywords: *Mental Health, Caregivers, Resources for Caregivers,*

I. Agency Description

The Mental Health Client Action Network (Mhcan) mission statement is:

> The Mental Health Client Action Network of Santa Cruz County is a peer-run organization dedicated to providing mutual support and networking, to having a voice in all matters which affect us, to creating programs controlled by peers, to advocating for the rights to choose our own life paths, to educating the public from our own perspective, and to working to eradicate treatment disparities and confronting discrimination. MHCAN provides a place of connection in the tumult of life...” (Mhcan, 2019).

Essentially, the mission is to provide services and advocating for people with severe mental health issues no matter who they are or their background. Mhcan is an outpatient resource center. People can walk in anytime and can stay from open to close. They can get food, clothes, help get housing, have a safe place to sleep, a computer room with internet, have transportation for going places like home or appointments, just a lot of things that people need to live and survive in Santa Cruz, especially since a lot of the people they serve are homeless. They also have peer-support groups every day. Depending on the day, they have witchcraft, knitting, Dungeons and dragons, and more serious groups like anxiety and depression support groups, trauma support, or schizophrenia groups.

Mhcan also contracts peer support to their collaborative partner, Telecare. These peer supports currently work in Telecare’s rehabilitation department. Like Mhcan, Telecare also supports people with severe mental health issues. However, Telecare is more on the clinical side of supporting people with SMI. They are a mental health hospital. They deal with people that are on 5150 (a 3-day psychiatric hold), 5250 (14-day psychiatric hold) and temporary conservatorship and conservatorship. Mhcan peer supports are contracted there because every person that works at Mhcan has a severe mental health issue and a lot of people that work there were once on a psychiatric hold themselves so they can relate to the clients there. Telecare wanted people that can relate and support the clients that are currently there so that is why they turned to Mhcan. In return, Mhcan can do a group there, Shadow Speakers, (which is when two people from Mhcan come and talk about their life stories) and also talk about Mhcan and get more people to come there which helps Mhcan by showing the county that people are utilizing the place and they can use that to get more funding.

II. Communities Served by the Agency

Mhcan serves a wide range of population. The main eligibility rules for them is that the person needs to have a severe mental illness and is 18+ years old. They serve whoever comes through the doors with those two eligibility characteristics. However, one of the most common populations there are homeless because MHCAN gives some shelter when it’s open, gives them a safe space to sleep, and gives them food and clothes. Another common population there are white people since 58.4% of people living in Santa Cruz are white (Santa Cruz County Chamber of Commerce, 2015, para. 2).

During my field practices, I was an intern at the rehab department at Telecare. The population they serve is a little different than MHCAN. The population that Telecare serves are clients that most of the time have a mental illness (some clients do come there for drug related issues) and there is a place for clients under 18. Other than those two things, the demographics are mostly the same.

Since both places serve essentially the same population, the issues of that population are the same. Some of these issues are that there is a lack of affordable housing in Santa Cruz which in turn creates a lot of homelessness. Another issue is that there is still a lot of stigma around people with mental health issues.

III. Problem Description

Too many caregivers of patients with mental illness suffer from caregiver's burden. Currently, there is a large need for resources for caregivers of loved ones with mental health issues. There are about 8.4 million people in caregiver positions currently. However, a lot of these caregivers suffer from "caregiver burden" which is essentially the stress these caregivers feel from taking care of their loved ones (Chadda, 2014, p. 222). Besides being more stressed, other things can also lead to caregiver burden. For example, the loved one is financially dependent on the family or friends and has trouble finding affordable care services in the community (Hunt, Greene, and Whiting, 2016, p. 4, 15). Another factor is that a lot of caregivers do not have a plan in place for someone else to take care of their loved ones if something happens to them so in turn they suffer from emotional burnout and are caretaking much longer than other caregivers for any other illness (Hunt, Greene, and Whiting, 2016, p. 15). Since there is so much stigma around mental health still, caregivers find it hard to vent or talk about their loved ones (Hunt, Greene, and Whiting, 2016, p. 5). Essentially, all these factors add up to caregivers having less time for their needs (Hunt, Greene, and Whiting, 2016, p. 5) Since there are so many causes to caregiver burden, there are also consequences.

Since caregiver burden is caused by so many different things and caregivers are not focusing on themselves, there are consequences because of that. One consequence that is caused by caregiver burden is their lack of attention to their health. Only 1/3 caregivers report having excellent health or very good health which is lower than the average in other caregivers. Also, some have reported that caregiving has actually made it worse (Hunt, Greene, and Whiting, 2016, p. 5). Another consequence of caregiver burden is that since caregivers put their needs behind their loved ones, they are more likely to have higher levels of depression. (American Psychological Association, n.d., para. 2). They are also more prone to feeling lonely and isolated (Chappa, 2014, 223). Figure 1 presents the problem model discussed in this section.

Figure 1: Problem Model

Causes/Contributing Factors	**Problem statement**	**Consequences**
Family member is financially dependent on family or friends	Too many caregivers of patients with mental illness suffer from caregiver's burden	High-emotional stress
Does not have a plan in place in case they can't take care of family member		1/3 caregivers have excellent health
Caregivers find it hard to talk about their loved one's mental health because of stigma		More likely to have higher levels of depression
Have less time for themselves		Loneliness/Isolation

For my capstone, I wanted to bring attention to the lack of resources for caregivers of mental health illness. In doing so, I hoped to reduce the caregiver burden that caregivers feel, more specifically the high emotional stress, them feeling lonely, and them not opening up about their loved ones because of stigma. According to *On Pins & Needles:* Caregivers of adults with mental illness, mention that, "peer support for caregivers can alleviate the isolation and stigma that many family caregivers have expressed in caring for a loved one with mental illness (Hunt, Greene, and Whiting, 2016, p.7). They then go on to list some more policy changes like providing caregivers with education and resources so they have a better idea of their loved one's illness. All of these things are important resources because it doesn't just allow the caregiver to better understand and open up more, but their loved one's can educate themselves as well and be willing to listen to the caregiver and be more understanding about their situation.

IV. Project Description

The capstone was a research project that addressed the research question of "What kind of resources are there for caregivers of patients with mental illness?" This topic was chosen because of a personal experience and a general consensus among caregivers. This topic did not have a lot of data compared to other chronic illnesses. An initial search showed that there were some articles about caretakers and what happened to them mentally and psychically, the caregiver burden (Chadda, 2014, p. 222), and just about how many there were, at least 8.4 million Americans (Hunt et al., 2016, p. 4) but according to scholarly articles regarding this topic, there wasn't a lot about support for the caregivers. There were some articles about how to have self-care but it's hard when a caregiver has to take care of someone almost 24/7.

To find more data about the topic, there was a literature review. Since it was hard to find data on coping skills or support for caregivers, there had to be documentation on what data was found. No matter how much data was found, it led to a bigger question, "Why weren't there a lot of support groups for these caretakers?". The point of the literature review was to document how much resources are out there and if it really focused on the caregiver.

The second step of the literature review was to look at all the google results and scholarly articles that were found, read them, and put them in categories based on what were the most common themes For example, a scholarly article was found using the sentence “Resources for caregivers of mental illness” on google scholar. Once a scholarly article was found, it was documented for the year it was published and if it was free. After reading the scholarly article, it was then documented again and checked off certain boxes in an excel spreadsheet if it included resources for caregivers, causes, consequences, or policy changes. Once documented, the next scholarly article was read. For the literature review, there were about 60 search results and google scholarly articles reviewed. However, a lot of scholarly articles were behind a paywall so more had to be found. Google and Google Scholar were used for this literature review since they were the most easily accessed for the community.

The project was justified because of how many people have mental health illnesses in America today. “1 in 5 (47.6 million) U.S adults experience mental illness each year. 1 in 25 (11.4 million) U.S. adults experience serious mental illness each year” (National Alliance on Mental Health (NAMI), 2019, para. 4). That was so many people at the time, and going back to the other article, there are at least 8.4 million caretakers in America (Hunt et al., 2016, p. 4). These caretakers were spending on average 32 hours a week providing unpaid care. (Nami, 2019, para. 7). Because of these statistics, the primary purpose of this capstone was to document the resources that are available to this population and help the community understand that these caregivers are giving up a lot to help their loved one and are not really getting enough support.

Some benefits that resulted from the research was to bring awareness to the caregivers and how there was not a lot of appreciation or support from family and friends for these caregivers. In return, people that have family members that were caregivers can give them more support in the future. Another benefit of this research was that family members could help the caregivers more which could result in a decrease in high emotional stress and help increase their health for the caregiver (Hunt et al., 2016, p. 5). A benefit for the agency was to be more aware of the resources that are out there for caregivers and make appropriate decisions if a caregiver needed more resources.

V. Project Implementation

Since most of this project relied on conducting research, its implementation plan differed from that of other capstone projects.For this capstone the main components included an extensive literature review analysis. In addition, there was a chart that compared different scholarly articles and google results based on what they mentioned. The literature review and the chart were both started in November 2019 and finished March 2020. After, in March 2020, I showed the social workers the data I found and asked how beneficial this information was to them. The clients could not be approached about this topic because they are sometimes not in the right state of mind and/or it might trigger them to talk about their family.. Resources for this project were finding literature and talking to the social workers about it. I need to use some of the social workers' time to show them what I found and get their opinions so that was another resource. Since this is such a delicate population and the research is into something that isn’t really popular, there were a few challenges. First, it was challenging finding enough data on caregiver support with mental health. There was some data but there it isn’t as much as there should be based on how common it is to have a mental illness. Another challenge was getting time with the participants. There are only 2 social workers there handling the cases of almost 30 people. They are very busy so there had to be a flexible date in the future to talk to them. Table 1 presents the timeline of my implementation for the capstone project.

Table 1. Scope of Work and Timeline

Project description: To research in depth what resources are available for caregivers on simple online searches.

Activities		**Deliverables**	**Timeline/deadlines**
1	Discuss capstone project ideas with mentor	Final capstone project idea approved	Oct-Nov 2019
2	Start looking at what resources there are for caregivers	Make a list of resources for my capstone	Oct-Nov 2019
3	Start my literature review and look at literature from other caregiver groups	Highlight and bookmark references	Nov 2019
4	Finish my literature review	A chart comparing literature reviews depending on certain categories	March 2020
5	Present my findings to the social worker	Get their options on my findings	March 2020
6	Complete reporting requirements	Final agency and capstone reports	April 2020
7	Final preparation for Capstone Festival	Final presentation at Capstone Festival!!	May 2020

Research Methodology and Results

For the literature review, there were 2 different search terms used both on google and google scholar. The first search term used was “Resources for family members with mental illness”. It was first used on google. Table 1 shows the first 10 websites that were listed when using google and each one was documented if there were resources for families. The same search term was used on google scholar. Table 2 shows the first 20 results that were found using google scholar but only 7 out of the 20 were either free or the pdf was available online. These articles were documented for their year of publication, on whether readers needed to pay for them, and if they talked about resources for family members.

Table 1: Results for a google search on "Resources for family members with mental illness"

Table 1	
Google: Resources for family members with mental illness	Resources for families?
https://www.nami.org/find-support/family-members-and-caregivers	Yes
https://www.nami.org/find-support/nami-programs/nami-family-support-group	Yes
https://www.samhsa.gov/families	No
https://www.apa.org/helpcenter/improving-care	No
https://www.mentalhealth.gov/talk/friends-family-members	No
https://www.heretohelp.bc.ca/infosheet/supporting-a-friend-or-family-member-with-a-mental-illness	Yes
https://www.psychiatry.org/patients-families/helping-a-loved-one-cope-with-a-mental-illness	Yes
https://psychcentral.com/lib/15-ways-to-support-a-loved-one-with-serious-mental-illness/	Yes
https://www.nimh.nih.gov/health/find-help/index.shtml	No
https://www.mhanational.org/family-friends	No
Total	5

Table 2: Results for a google scholar search on "Resources for family members with mental illness"

Table 2				
Google Scholar: Resources for family members with mental illness	Title	Year	Have to pay?	Resources for family members?
https://academic.oup.com/schizophreniabulletin/article/8/4/626/1892659	How Families Evaluate Mental Health Professionals, Resources, and Effects of Illness	1982	No	No
https://www.tandfonline.com/doi/pdf/10.1080/01612840305301?needAccess=true	Families Living with Severe Mental Illness: A Literature Review	2003	Yes*	Yes
https://onlinelibrary.wiley.com/doi/pdf/10.1037/h0079695	SUBJECTIVE BURDEN AMONG FAMILY MEMBERS OF MENTALLY ILL ADULTS	1995	Yes	N/A
https://onlinelibrary.wiley.com/doi/abs/10.1037/h0080222	BENEFITS OF SUPPORT GROUPS FOR FAMILIES OF ADULTS WITH SEVERE MENTAL ILLNESS	2010	Yes*	Yes
https://ps.psychiatryonline.org/doi/abs/10.1176/ps.30.5.338	The Family as Partner in the Treatment of Mental Illness	1979	Yes	N/A
https://psycnet.apa.org/buy/1997-06153-004	The family experience of mental illness: Implications for intervention.	1997	Yes	N/A
http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.474.2921&rep=rep1&type=pdf	Adaptive coping among family members of persons with serious mental illness	1995	No	Yes
https://psycnet.apa.org/record/1997-02411-001	The family experience of mental illness: Evidence for resilience.	1996	Yes	N/A

https://www.tandfonline.com/doi/abs/10.3109/09638237.2013.779368	Family members' of persons living with a serious mental illness: Experiences and efforts to cope with stigma	2013	Yes*	Yes
https://psycnet.apa.org/record/1988-23621-001	The family's response to mental illness in a relative.	1987	Yes	N/A
https://link.springer.com/article/10.1176/appi.ap.32.2.87	The Stigma of Families with Mental Illness	2008	Yes	N/A
https://psycnet.apa.org/record/2012-28553-001	Rural experiences with mental illness: Through the eyes of patients and their families.	2012	Yes	N/A
https://academic.oup.com/hsw/article/19/2/132/623031	Resources and Supports for Mothers with Severe Mental Illness	1994	No	Yes
https://link.springer.com/article/10.1007/BF00706488	Economic contribution of families caring for persons with severe and persistent mental illness	1990	Yes	N/A
https://psycnet.apa.org/record/2002-11537-007	Church-based support groups for African American families coping with mental illness: Outreach and outcomes.	2002	Yes	N/A
https://link.springer.com/article/10.1023/A:1018791824546	Self-Help Groups for Families of Persons with Mental Illness: Perceived Benefits of Helpfulness	1999	Yes	N/A
https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.57.3.361	Religiosity, Psychosocial Adjustment, and Subjective Burden of Persons Who Care for Those With Mental Illness	2006	No	Yes
https://onlinelibrary.wiley.com/doi/abs/10.1037/h0087664	Differences Among Families Coping With Serious Mental Illness: A Qualitative Analysis	2000	Yes	N/A
https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2850.2009.01531.x	Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery	2010	Yes	N/A
https://journals.lww.com/intjrehabilres/Abstract/2003/06000/Sources_of_burdens_on_families_of_individuals_with.7.aspx	Sources of burdens on families of individuals with mental illness	2003	Yes	N/A
Total			7	6

The next search term that was used in google and google scholar was “Resources for caregivers of mental illness”. It was also first used on google. Table 3 shows the first 10 results which were then documented if they gave resources for caregivers, if they talked about how caregivers could also get mental health issues, the causes, consequences, and policies. This sentence had more to document since it was more focused on caregivers than family members as a whole. The same sentence was then used on google scholar. Table 4 shows the first 20 articles which were then documented the same as the google results. However, there was also documentation on the year it was published and if it was behind a paywall. Out of the 20 scholarly articles, only 10 were free or the pdf was found online.

Table 3: Results for a google search on "Resources for caregivers of mental illness"

Table 3					
Google: Resources for caregivers of mental illness	Resources for caregivers?	Signs of mental illness or stress in caregivers	Causes?	Consequences?	Policies?
** https://www.nami.org/find-support/family-members-and-caregivers	Yes	Yes	No	No	No
https://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf	No	No	Yes	Yes	Yes
http://www.caregiving.org/wp-content/uploads/2017/12/CircleOfCareReport_Final-Web_December-2017.pdf	Yes	No	Yes	Yes	Yes
https://adaa.org/resources/caregivers	Yes	Yes	No	Yes	No
https://www.apa.org/pi/about/publications/caregivers/practice-settings/intervention/mental-illness	No	No	No	No	No
https://www.caregiver.org/caregiver-health	No	No	Yes	Yes	Yes
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4181176/	Yes	No	No	Yes	Yes
https://www.northshorecare.com/blog/caring-for-mentally-ill-loved-one-caregiver-tips	Yes	No	No	No	No
https://www.mhanational.org/sites/default/files/NAMI%20and%20MHA%20Webinar%20Challenges%20and%20Solutions%20for%20Mental%20Health%20Caregivers.pdf	Yes	Yes	No	Yes	No
https://caregiver.com/topics/mental-health/	Yes	No	No	Yes	Yes
Total	7	3	3	7	5

Table 4: Results for a google scholar search on "Resources for caregivers of mental illness"

Table 4								
Google Scholar: Resources for caregivers of mental illness	Title	Year	Need to Pay?	Resources for caregivers ?	Signs of mental illness or stress in caregivers?	Causes?	Consequences?	Policies ?

https://journals.lww.com/co-psychiatry/Abstract/2005/11000/Caregiver_burden_in_mental_illness__review_of.17.aspx	Caregiver burden in mental illness: review of measurement, findings and interventions in 2004–2005	2005	Yes	N/A	N/A	N/A	N/A	N/A
https://journals.lww.com/psychosomaticmedicine/Abstract/1999/07000/Predictors_of_Burden_and_Infectious_Illness_in.1.aspx	Predictors of Burden and Infectious Illness in Schizophrenia Caregivers	1999	Yes*	Yes*	Yes	Yes	Yes	No
https://link.springer.com/article/10.1007/s00406-011-0215-5	Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics	2011	Yes*	Yes*	Yes	No	Yes	Yes
https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.2004.03287.x	Respite care for caregivers and people with severe mental illness: literature review	2005	Yes	N/A	N/A	N/A	N/A	N/A
https://www.sciencedirect.com/science/article/abs/pii/S0883941711000422	Global Perspective of Burden of Family Caregivers for Persons With Schizophrenia	2011	Yes	N/A	N/A	N/A	N/A	N/A
https://psycnet.apa.org/record/2000-12658-002	Helping elderly caregivers plan for the future care of a relative with mental illness.	2000	Yes	N/A	N/A	N/A	N/A	N/A
https://www.jstor.org/stable/585241?seq=1	Introduction: Caregiving and Caregiver Interventions in Aging and Mental Illness	1999	Yes	N/A	N/A	N/A	N/A	N/A
https://journals.sagepub.com/doi/abs/10.1606/1044-3894.4097	Parents of Children with Mental Illness: Exploring the Caregiver Experience and Caregiver-Focused Interventions	2018	Yes*	Yes	No	Yes	Yes	Yes
https://www.tandfonline.com/doi/abs/10.1080/01612840305301	Families Living with Severe Mental Illness: A Literature Review	2003	Yes*	Yes	Yes	Yes	Yes	Yes
https://www.sciencedirect.com/science/article/abs/pii/S0272735898000762	Factors associated with caregiver burden in mental illness: A critical review of the research literature	1999	Yes	N/A	N/A	N/A	N/A	N/A
https://www.jstor.org/stable/585098?seq=1	The Differential Effects of Social Support on the Psychological Well-Being of Aging Mothers of Adults with Mental Illness or Mental Retardation	1997	Yes*	Yes	Yes	Yes	Yes	Yes
https://academic.oup.com/gerontologist/articl	Aging Parents of Adults With Disabilities: The	1993	Yes*	Yes*	No	Yes	Yes	No

e-abstract/33/4/542/633462	Gratifications and Frustrations of Later-life Caregiving							
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4181176/	Caring for the family caregivers of persons with mental illness	2014	No	Yes	Yes	Yes	Yes	Yes
https://journals.lww.com/jonmd/Abstract/2012/11000/Burden,_Rewards,_and_Coping_The_Ups_and_Downs_of.4.aspx	Burden, Rewards, and Coping—The Ups and Downs of Caregivers of People With Mental Illness	2012	Yes	N/A	N/A	N/A	N/A	N/A
https://onlinelibrary.wiley.com/doi/abs/10.1002/nur.4770170203	Living with mental illness: Effects of professional support and personal control on caregiver burden	1994	Yes	N/A	N/A	N/A	N/A	N/A
https://www.healio.com/psychiatry/journals/jpn/1997-9-35-9/%7B427f047d-ccda-4d4e-b963-a96f0ca43453%7D/the-problems-and-coping-methods-of-caregivers-of-young-adults-with-mental-illness#divReadThis	The Problems and Coping Methods of Caregivers of Young Adults With Mental Illness	1997	Yes	N/A	N/A	N/A	N/A	N/A
https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1545-5300.2003.00091.x	Burden in Schizophrenia Caregivers: Impact of Family Psychoeducation and Awareness of Patient Suicidality	2004	Yes*	Yes*	No	Yes	Yes	No
https://journals.sagepub.com/doi/abs/10.1177/107484070000600403	Conceptual Approaches to Studying Family Caregiving for Persons With Severe Mental Illness	2000	Yes*	Yes*	No	No	Yes	No
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3293083/	Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services	2012	No	No	Yes	No	Yes	No
https://onlinelibrary.wiley.com/doi/abs/10.1037/0002-9432.75.1.40	Integrative Model of Caregiving: How Macro and Micro Factors Affect Caregivers of Adults With Severe and Persistent Mental Illness	2010	Yes	N/A	N/A	N/A	N/A	N/A
Total			10	9	6	7	10	5

Findings

For the first sentence, “Resources for family members with mental illness”, Table 1 shows that out of the first 10 google results, 5 out of the 10 talked about resources or coping skills for family members.

For google scholar results, Table 2 shows that out of the first 20 scholarly articles, 10 of them were published after 2000 and out of those 10, only 4 were published in 2010 and after. The oldest one goes back to 1979. Only 7 out of the 20 were able to be documented since the rest of them were behind paywalls. Out of the 7, 6 of them talked about resources or coping skills for the family.

For the second sentence, “Resources for caregivers of mental illness”, Table shows that out of the first 10 google results, 7 out of the 10 mentioned resources and/or coping skills for caregivers, 3 out of the 10 talked about how caregivers are at an increased risk for depression and anxiety because of caregiving, only 3 out of the 10 talked about what can cause caregiver burden, 7 out of the 10 talked about the consequences of caregiver burden, and 5 out of the 10 talked about policy changes (practitioners should focus more on caregivers, there should be more resources, etc).

For the google scholar, Table 4 shows that out of the 20 that were documented, 13 were published after 2000 and out of those 13, 7 were published after 2010. 10 of the 20 were able to be documented more thoroughly because the rest were behind paywalls. Out of the 10, 9 talked about resources, however, 5 of those talked about them indirectly (for example, they mentioned that caregivers who are more spiritual suffer less from the caregiver burden but did not outright say that being spiritual is a coping skill). Out of the 10, 6 of them talked about how caregivers are at an increased risk for depression and anxiety. 7 out of the 10 documents mention the causes of caregiver burden and all 10 talked about the consequences of caregiver burden. Only 5 out of the 10 talked about policy change.

Conclusions

Based on all the research that was found, it's apparent that there are resources but only to an extent. A lot of websites only really have coping skills which the caregiver has to do on their own time. The academic literature talks about how there should be more resources like social workers focusing on the family unit instead of just the patient but nothing is forcing social workers to change how they help family members. Most of these resources that are given are for the caregivers to do things by themselves like taking a walk or focusing on themselves. There isn't a helpline or any groups for them except for one at NAMI which they only do when there is enough support for that group. Essentially, to relieve caregiver burden, it is up to the caregiver themselves to resolve it, instead of getting help from other people.

VI. Reflection of COVID-19 Pandemic's Impact on Agency and Population Served

Impact of COVID-19 Pandemic on Agency:

Since I was at two different agencies, both of them were impacted differently. The one I was assigned at, Mhcan, closed when this pandemic first started. Telecare, the agency I was currently at, did not close, but a lot of things were changed. The first thing that was changed was the group room. The department I was at is in charge of all the groups and there is a room to do the groups in. However, since the pandemic introduced social distancing, we had to only have a maximum of 4 people in the group room and then either have a group in the media room or the cafeteria. Another change was they stopped visitor hours. People that did not work there were not allowed to come in anymore so the clients there stopped seeing their loved ones. The last one that I was there for was the mandatory taking of temperature before a person started their shift and mandatory mask wearing for all employees.

Impact of COVID-19 on agency clients

The changes made at both agencies affected a large portion of the population. For the first agency, Mhcan, the whole place closed which meant less services so that definitely affected the population that they served. At Telecare, they were still open but the schedule for all the groups were constantly changing daily and they had less visitors which heavily affected the population there as well. Overall though, they were still getting the same services but everything including getting discharged were happening a lot slower.

Impact of COVID-19 on social problem

This pandemic has taken such a big toll on people with mental health issues which in turn is probably not helping caregivers that are already suffering from caregiver burden. Moreover, caregiver burden has probably increased for these caregivers as well because they now have to focus even more of their time on their loved ones during this difficult time.

Impact of COVID-19 on the agency's future

Since I have not been to either agency in almost a month, it is hard to say what they are currently doing that is different from what I saw when I was there. However, something that I do believe will change is how often things are disinfected/cleaned. When this pandemic settles down, there is still going to be COVID-19 so things still need to be cleaned more often. Also, I believe that both agencies will have policies or instructions on what to do if something like this happens again.

VII. Recommendations

Recommendations for the agency

There are a lot of benefits for my agency that came from this research. For example, the social workers at Telecare can start working with the caregivers and give them resources or additional support if they are struggling with caregiver burden. They also can use the knowledge about these resources by changing the way they interact with the whole family unit by not just focusing on the client themselves but with the caregivers as well. Some advice for colleagues would just be aware when interacting with client's family members. They might have been a caregiver for the client at one point in their lives so they might have different views on what they think is right for their loved ones or just react differently to certain things about the client, like letting them come home after the client was put on a psychiatric hold.

Broader social significance

My capstone relates to the border social problem, caregiver burden, by showing people that these caregivers are under-supported and making aware that these caregivers need more resources than just taking a walk or focusing on themselves when they have to dedicate so much time to their loved ones. With this project, I hope that people will be more aware of what a caretaker is going through and possibly help them or support them if they know a caregiver. Also, like mentioned before, my agency can use this data to focus more on the caregiver rather than just the client. Something more than could be done would be actually interview caregivers and see what they think they need to be more supported, like resources or community help and then take that data and work with communities to help set up better resources for these caregivers.

REFERENCES

About Us. (2019). Mental Health Client Action Network. Retrieved May 7, 2020, from http://www.mhcan.org/about.html

American Psychiatric Association. (n.d.). *Helping a Loved One Cope with a Mental Illness.* https://www.psychiatry.org/patients-families/helping-a-loved-one-cope-with-a-mental-illness

American Psychological Association. (n.d.). *Family members of Adults with Serious Mental Illness.* https://www.apa.org/pi/about/publications/caregivers/practice-settings/intervention/mental-illness

American Psychological Association. (n.d.). *Mental and Physical Health Effects of Family Caregiving.* https://www.apa.org/pi/about/publications/caregivers/faq/health-effects

American Psychological Association. (n.d.). *Supporting a Family Member with Serious Mental Illness.* https://www.apa.org/helpcenter/improving-care

Anxiety and Depression Association of America. (n.d.). *Caregiver Mental Health.* https://adaa.org/resources/caregivers

Baronet, A. (1999). Factors Associated with Caregiver Burden in Mental Illness: A critical review of the research literature. *Clinical Psychology Review, 19*(7), 819-841. https://doi.org/10.1016/S0272-7358(98)00076-2

Biegel, D., & Schulz, R. (1999). Introduction: Caregiving and Caregiver Interventions in Aging and Mental Illness. *Family Relations.* Retrieved May 7, 2020, from www.jstor.org/stable/585241

Caregiver. (n.d.). *Mental Health.* https://caregiver.com/topics/mental-health/

Chadda R. K. (2014). Caring for the family caregivers of persons with mental illness. *Indian Journal of Psychiatry*, *56*(3), 221–227. https://doi.org/10.4103/0019-5545.140616

Chan, S, W,. (2011). Global Perspective of Burden of Family Caregivers for Persons with Schizophrenia. *Archives of Psychiatric Nursing, 25*(5), 339-349. https://doi.org/10.1016/j.apnu.2011.03.008

Citron, M., Solomon, P. & Draine, J. (1999). Self-Help Groups for Families of Persons with Mental Illness: Perceived Benefits of Helpfulness. *Community Ment Health J 35***,** 15–30 https://doi.org/10.1023/A:1018791824546

Country Demographics. (2019). Santa Cruz County Chamber of Commerce. Retrieved May 7, 2020 from http://www.santacruzchamber.org/demographics.html

Doornbos, M.(1997). The Problems and Coping Methods of Caregivers of Young Adults With Mental Illness. *Journal of Psychosocial Nursing and Mental Health Service 35*(9) 22-26. https://doi.org/10.3928/0279-3695-19970901-15

Dyck, D.G., Short, R., & Vitaliano, P. P. (1999). Predictors of Burden and Infectious Illness in Schizophrenia Caregivers. *Psychosomatic Medicine.* Retrieved May 7, 2020, from https://journals.lww.com/psychosomaticmedicine/pages/default.aspx

Family Caregiver Alliance. (n.d.). *Caregiver Health.* https://www.caregiver.org/caregiver-health

Franks, D.D. (1990). Economic contribution of families caring for persons with severe and persistent mental illness. *Adm Policy Ment Health 18* **,** 9–18. https://doi.org/10.1007/BF00706488

Greenberg, J., Seltzer, M., & Greenley, J. R. (1993). Aging Parents of Adults With Disabilities: The Gratifications and Frustrations of Later-life Caregiving, *The Gerontologist*, *33*(4) 542–550. https://doi.org/10.1093/geront/33.4.542

Greenberg, J., Seltzer, M., Krauss, M., & Kim, H. (1997). The Differential Effects of Social Support on the Psychological Well-Being of Aging Mothers of Adults with Mental Illness or Mental Retardation. *Family Relations, 46*(4), 383-394. https://doi.org/10.2307/585098

Greene, R., Whiting, C., G., Pašović, M., Diehl, S., Niles-Yokum, K., Caldwell, J., Brister, T., Hart, J., W., Kimball, A., & Wesolowski, H. (2016) *Circle of Care: A guidebook for Mental Health Caregivers.* National Alliance for Caregiving. http://www.caregiving.org/wp-content/uploads/2017/12/CircleOfCareReport_Final-Web_December-2017.pdf

Hatfield, A. B. (1979, May). The Family as Partner in the Treatment of Mental Illness. *Hospital and Community Psychiatry, 30*(5), 338-340. https://doi.org/10.1176/ps.30.5.338

Hatfield, A. B., & Lefley, H. P. (2000). Helping elderly caregivers plan for the future care of a relative with mental illness. *Psychiatric Rehabilitation Journal, 24*(2), 103–107. https://doi.org/10.1037/h0095111

Heller, T., Roccoforte, J. A., Hsieh, K., Cook, J. A., & Pickett, S. A. (1997). Benefits of support groups for families of adults with severe mental illness. *American Journal of Orthopsychiatry, 67*(2), 187–198. https://doi.org/10.1037/h0080222

Here to Help. (n.d.). *Supporting a Friend of Family Member with a Mental Illness.* https://www.heretohelp.bc.ca/infosheet/supporting-a-friend-or-family-member-with-a-mental-illness

Holden, D. F., & Lewine, R. R. J. (1982). How Families Evaluate Mental Health Professionals, Resources, and Effects of Illness. *Schizophrenia Bulletin, 8*(4), 626-633. https://doi.org/10.1093/schbul/8.4.626

Hunt, G. G., Green,. R., & Whiting, C. G. (2016). *On Pins & Needles: Caregivers of Adults with Mental Illness.* National Alliance for Caregiving. http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf

Jeon, Y., Brodaty, H., & Chesterson, J. (2005). Respite care for Caregivers and People with Severe Mental Illness: Literature Review. *Journal of Advanced Nursing, 49*(3). https://doi.org/10.1111/j.1365-2648.2004.03287.x

Johnson, E. D. (2000). Differences among families coping with serious mental illness: A qualitative analysis. *American Journal of Orthopsychiatry, 70*(1), 126–134. https://doi.org/10.1037/h0087664

Karnieli-Miller, O., Perlick, D. A., Nelson, A., Mattias, K., Corrigan P., & Roe, D. (2013) Family members' of persons living with a serious mental illness: Experiences and efforts to cope with stigma *Journal of Mental Health, 22*(3), 254-262. https://doi.org/10.3109/09638237.2013.779368

Larson, J. E., & Corrigan, P. (2008). The Stigma of Families with Mental Illness. *Acad Psychiatry 32,* 87–91. https://doi.org/10.1176/appi.ap.32.2.87

Lefley, H. P. (1987). The family's response to mental illness in a relative. *New Directions for Mental Health Services, 1987*(34), 3–21. https://doi.org/10.1002/yd.23319873403

Mak, W.W.S. (2005), Integrative Model of Caregiving: How Macro and Micro Factors Affect Caregivers of Adults With Severe and Persistent Mental Illness. *American Journal of Orthopsychiatry, 75*, 40-53. https://doi.org/10.1037/0002-9432.75.1.40

Marsh, D. T., & Johnson, D. L. (1997, June). The Family Experience of Mental Illness: Implications for Intervention. *Professional Psychology: Research and Practice.* Retrieved May 7, 2020, from https://psycnet.apa.org/buy/1997-06153-004

Marsh, D. T., Lefley, H. P., Evans-Rhodes, D., Ansell, V. I., Doerzbacher, B. M., LaBarbera, L., & Paluzzi, J. E. (1996). The family experience of mental illness: Evidence for resilience. *Psychiatric Rehabilitation Journal, 20*(2), 3–12. https://doi.org/10.1037/h0095390

McDonell, M.G., Short, R.A., Berry, C.M. and Dyck, D.G. (2003), Burden in Schizophrenia Caregivers: Impact of Family Psychoeducation and Awareness of Patient Suicidality. *Family Process, 42*, 91-103. https://doi.org/10.1111/j.1545-5300.2003.00091.x

Mendenhall, A. N., & Mount, K. (2018). Parents of Children with Mental Illness: Exploring the Caregiver Experience and Caregiver-Focused Interventions. *Families in Society: The*

Journal of Contemporary Social Services 92(2), 183-190. https://doi.org/10.1606/1044-3894.4097

MentalHealth.gov. (n.d.). *Supporting a Friend of Family Member with Mental Health Problems.* https://www.mentalhealth.gov/talk/friends-family-members

Mental Health America (n.d.). *For Family and Friends.* https://www.mhanational.org/family-friends

Möller-Leimkühler, A.M., & Wiesheu, A. (2012). Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. *European Archives of Psychiatry and Clinical Neuroscience*, *262,* 157–166. https://doi.org/10.1007/s00406-011-0215-5

Murray-Swank, A. B., Lucksted, S., Medoff, D. R., Yang, Y., Wohlheiter, K., & Dixon, L. B. (2006, March). Religiosity, Psychosocial Adjustment, and Subjective Burden of Persons Who Care for Those With Mental Illness. *Psychiatric Services, 57*(3), 361-365). https://doi.org/10.1176/appi.ps.57.3.361

National Alliance on Mental Illness. (n.d.). *Family Members and Caregivers.* https://www.nami.org/find-support/family-members-and-caregivers

National Alliance on Mental Illness. (n.d.). *Mental Health By the Numbers*. Retrieved May 7, 2020 from https://www.nami.org/mhstats

National Alliance on Mental Illness. (n.d.). *NAMI Family Support Group.* https://www.nami.org/Support-Education/Support-Groups/NAMI-Family-Support-Group

National Institute of Mental Health. (n.d.). *Help for Mental Illness.* https://www.nimh.nih.gov/health/find-help/index.shtml

Nordby, K., Kjønsberg, K. And Hummelvoll, J.K. (2010). Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery. *Journal of Psychiatric and Mental Health Nursing, 17*, 304-311. doi:10.1111/j.1365-2850.2009.01531.x

Northshore Care Supply. (2020, April 1). *Caring for a Loved One with Mental Illness: Tips Support.* Northshore. https://www.northshorecare.com/blog/caring-for-mentally-ill-loved-one-caregiver-tips

Oyserman, D., Mowbray, C. T., & Zemencuk, J. K. (1994, May). Resources and Supports for Mothers with Severe Mental Illness, *Health & Social Work*, *9*(2), 132–142. https://doi.org/10.1093/hsw/19.2.132

Pickett-Schenk, S. A. (2002). Church-based support groups for African American families coping with mental illness: Outreach and outcomes. *Psychiatric Rehabilitation Journal, 26*(2), 173–180. https://doi.org/10.2975/26.2002.173.180

Reinhard, S.C. (1994), Living with mental illness: Effects of professional support and personal control on caregiver burden. *Research in Nursing & Health*, *17*(2), 79-88. https://doi.org/10.1002/nur.4770170203

Robinson, W. D., Springer, P. R., Bischoff, R., Geske, J., Backer, E., Olson, M., Jarzynka, K., & Swinton, J. (2012). Rural experiences with mental illness: Through the eyes of patients and their families. *Families, Systems, & Health, 30*(4), 308–321. https://doi.org/10.1037/a0030171

Rungreakngkulkij, S., & Gilliss, C. L. (2000). Conceptual Approaches to Studying Family Caregiving for Persons with Severe Mental Illness. *Journal of Family Nursing, 6*(4), 341-366. https://doi.org/10.1177/107484070000600403

Saunders, J. C. (2003). Families Living with Severe Mental Illness: A Literature Review. *Issues in Mental Health Nursing, 24*(2), 175-198 .https://doi.org/10.1080/01612840305301

Schulze, B., & Rössler, W. (2005). Caregiver Burden in Mental Illness: review of measurement, findings, and interventions in 2004-2005. Retrieved May 7, 2020, from https://journals.lww.com/co-psychiatry/Abstract/2005/11000/Caregiver_burden_in_mental_illness__review_of.17.aspx

Solomon, P., & Draine, J. (1995, November). Adaptive Coping Among Family Members of Persons with Serious Mental Illness. *Psychiatric Services, 46*(11), 1156-1160. https://doi.org/10.1176/ps.46.11.1156

Solomon, P., & Draine, J. (1995). Subjective Burden Among Family Members of Mentally Ill Adults. *American Journal of Orthopsychiatry, 65*(3), 419-427. https://doi.org/10.1037/h0079695

Substance Abuse and Mental Health Service Administration. (n.d.). *Behavioral Health is Essential to Health.* https://www.mhanational.org/sites/default/files/NAMI%20and%20MHA%20Webinar%20Challenges%20and%20Solutions%20for%20Mental%20Health%20Caregivers.pdf

Substance Abuse and Mental Health Service Administration. (n.d.). *Resources for Families Coping with Mental and Substance Use Disorders.* https://www.samhsa.gov/families

Tartakovsky, M. (2018, October 8). *15 ways to Support a Loved One with Serious Mental Illness.* Psych Central. https://psychcentral.com/lib/15-ways-to-support-a-loved-one-with-serious-mental-illness/

Tsang, H., Tam, P., Chan, F., & Chang, W., M. (2003, June). Sources of Burdens on Families of Individuals with Mental Illness. *International Journal of Rehabilitation Research.* Retrieved May 7, 2020, from https://journals.lww.com/intjrehabilres/Abstract/2003/06000/Sources_of_burdens_on_families_of_individuals_with.7.aspx

Wong, D. F., Lam, A. Y., Chan, S. K., & Chan, S. F. (2012). Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services. *Health and quality of life outcomes*, *10*(15). https://doi.org/10.1186/1477-7525-10-15