

A Post Institution Society:

Adapting Respite for Caregivers of People with SMI

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Abstract:

Serious mental illnesses, or SMI, are illnesses that are debilitating and impact the activities of daily life (Whitney et al., 2015). Many of these people with SMI require caregiving which places quite a burden on the caregiver, especially since after deinstitutionalization. Respite care models have been found to be effective in other areas so this research will further address how these existing respite care models can be adapted for future SMI respite care. Background research was conducted on the role of desinstitutionalizations in shifting the care of people with SMI from institutions to families. As well as the prevalence of mental illness today, the increase in caregiving, what respite care programs have been effective so far, the current barriers to implementing respite care, and the overall importance as to why respite care should be further adapted for specific SMI respite care. An integrative literature review was conducted using online databases and keywords to fill in the gaps of the lack of best practices and curriculum surrounding SMI respite care. The review will look into if existing respite care models can be used to adapt future respite care for caregivers of people with serious mental illnesses. The results found that the similarities among caregiving across illnesses, needs of caregivers, existing respite care models, and best practices on behavioral crisis care show that SMI respite care can be further adapted and point out the lack of clear best practices on SMI respite care. These findings can lead into further development of these SMI respite care best practices, information dissemination on respite resources, longitudinal studies of respite care, and more needs assessments of SMI caregivers. Some limits of the review were finding articles with just SMI statistics and not AMI (any mental illness). Another limitation is some data found being outside of the US and that the results of the theory are subjective. This research will address the need for

competency in social work practice by finding literature that can contribute to best practices for SMI respite care and the value of service by attempting to reduce the burdens of SMI caregivers.

Introduction

Since the COVID-19 pandemic the amount of caregivers in the US has increased, about one in five people are caregivers (AARP, 2020). While not all the time, physical illnesses tend to be visible to the public eye, making it easier to not have to justify caregiving for someone's loved one. With mental illness there is a different silent battle that both the patient and the caregiver have to face. Like any other chronic illness, some people with mental illnesses need both formal and informal care. While mental illnesses are harder to recognize, so is the caregiving of these individuals. But, like all caregivers, there will be points where a caregiver needs assistance and a break from caregiving to take care of themselves. To be able to take care of their loved ones these caregivers need proper breaks to step back, yet feel like they have proper support and will not be putting their loved one at risk by wanting that break.

This research will assess the needs and burdens of mental illness caregivers and present a research question on how breaks from caregiving can be addressed and the possible benefits for this population. The literature review will assess if respite care models can be used to adapt future respite care for caregivers of people with serious mental illnesses. To do this certain important terms will be defined such as respite care, serious mental illness versus any mental illness (Mental illness, 2021). A background overview will be done on how deinstitutionalization changed the fate of those with mental illnesses by turning to community care (Social work, 1979). As well as the state of mental illness caregiving and the burden this presents with rising rates of mental illness (Mental illness, 2021 & Schroeder et al., 2021). Then, this will be used to look into evaluating current respite programs and why respite care is important to be adapted for SMI. The social problem this research will come to address is the burden that caregivers face (Zauszniewski et al., 2022) and the difficulty of using existing

models (Models of Medical Respite Care, 2022, Brighton, 2016, & Knopf, 2021). Best practices are a vital part of social work program development and the SMI respite care best practices are not easily accessible (National Association, 2008). Doing this will help address the lack of programs for SMI and curriculum surrounding it “Models of Medical Respite Care,” 2022, Brighton, 2016, & Knopf, 2021). An integrative literature review was conducted to do this research using various scientific databases and keyword searches on SMI, respite, and caregivers. The review found that existing respite models can be used to adapt SMI respite care programs. There are some experimental models of SMI respite, peer SMI care programs, best practices for behavioral crisis care, and other models of respite care that can be utilized to develop SMI respite care further (Brighton, 2016, Carter & Mandrell, 2013, Knopf, 2021, Models of medical respite care, 2022, & SAMHSA, 2020). Overall, there is a lack of specific best practices for SMI respite care and furthering this research will help with future program development and reduce the SMI caregiving burden (SAMHSA, 2020).

Defining Terms

Definition of Serious Mental Illness (SMI)

Serious Mental Illness, or SMI, are debilitating mental illnesses, often including disorders such as: schizophrenia, bipolar disorder, major depressive disorder, and schizoaffective disorder (Whitney et al., 2015). These clients require intensive care from caregivers and these caregivers tend to be family and friends. The research will focus more specifically on people with SMI so as to define what research will be done on mental illness and what data is relevant. The anticipated needs for the SMI patient population will be greater in regards to caregiving than the population of people with any mental illness (AMI) with mental illnesses (Mental illness, 2021).

Definition of Respite Care

Respite care is defined as, “temporary relief for caregivers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect” (Whitemore, 2016). Respite care will be referred to throughout this research in contexts of existing models for physical illnesses, dementia, and experimental models for SMI respite care.

Background

The Rise of Respite Care & Family Caregiving After Deinstitutionalization

The first development of the term respite care is unknown from this research. Journals were found that date back to 1979 at the earliest including the term respite care and its increase after deinstitutionalization (Social work, 1979). This journal cited the shift of care going from the institutions to the families, or what is called “community care” here (Social work, 1979). The goal of this care was to prevent more disabilities that would be gained from an institution and long periods of hospitalization (Social work, 1979). The review expected the caregiving burden of the families of these patients to increase after deinstitutionalization and says that respite care should be used to combat this (Social work, 1979). “Crisis houses,” or non-medical short term care is offered as a solution for the benefit of the patient and the caregiver (Social work, 1979). Crisis houses are not specifically cited as a type of respite care, but implies the same purpose of respite care. Overall, there was a want for shorter hospital stays due to institutions being short staffed or causing “iatrogenic effects” which are unintended consequences of the treatment they may receive in the hospital (Social work, 1979). This could be aspects like the patient experiencing consequences due to social isolation or stress contributing to the patient's illness in a negative manner.

As a review from 1994 said, “the emergence of family caregiving was a major unanticipated consequence of deinstitutionalization” (Benson, 1994). After the closing of many of these public institutions patients ended up with their families or homeless (Benson, 1994). While deinstitutionalization has shortened hospital stays for those with mental illnesses, community treatment has not necessarily improved the quality of life for these patients (Benson, 1994). Overall, this community care is lacking resources for families to care for their loved ones with mental illnesses. A frequently used method of community care is medication and often this ends in hospitalization anyway when medicating is unsuccessful (Benson, 1994).

Current Increase in Caregiving

Almost one in five people in the United States currently are caregivers and 61 percent of these caregivers are also working (AARP, 2020). Additionally, there has been a seven percent increase in difficulty coordinating care and a four percent increase in family caregivers rating their own health fair to pay (AARP, 2020). This data originated from the AARP and is from 2020 comparing the data to when it was last conducted in 2015. So this includes data on caregivers after the COVID-19 pandemic started. The more caregivers there are, the more families and caregiving units there will be that need support likely in terms of respite care.

Prevalence of Mental Illness in the U.S.

Between 2005 and 2015 depression rates have increased 18% (Schroeder et al., 2021). Meaning that more and more people are being affected by depression in this country. Although, when the study does not differentiate SMI and AMI it is hard to measure depression in this study against a severe debilitating depression that would be defined as a mental illness that is disabling, also known as an SMI. The Substance Abuse and Mental Health Services Administration (SAMHSA) put out data from 2021 showing the prevalence of mental illnesses. This study also

differentiates between AMI and SMI and represents the data from 2021, but does not compare the data to the past or future years. The study reports that around five percent of the U.S. adult population has an SMI (Mental illness, 2021). When looking at young adults specifically, that is ages 18 to 25 years old, around 11 percent of this population has SMI (Mental illness, 2021). Overall, AMI and SMI are prevalent issues that this country is facing, specifically in the young adult population.

Mental Illness Caregiver Burden

Recent studies have examined how caregivers use personal and social resourcefulness when providing care in times of stress. When caregivers of people with SMI experience financial difficulties 40 percent of them report not using social or personal resources to cope (Zauszniewski et al., 2022). When experiencing anger 30 percent of respondents report not using any personal or social resources at all (Zauszniewski et al., 2022). This is a much higher percentage when comparing the rates to the caregivers of people with other illnesses.

In an Australian study published in 2006, work roles and outside the home reduced stress levels for caregivers were compared across different types of illnesses (Bainbridge et al., 2006). Overall, across all the illnesses that were tested outside work did not affect stress levels negatively or positively (Bainbridge et al., 2006). On the other hand, when the data was split up by disability type it was found that work outside the home reduced stress for caregivers of people with mental disabilities (Bainbridge et al., 2006). The study also discussed how doing studies of how respite care affects stress levels of caregivers may give more accurate results of the stress reduction (Bainbridge et al., 2006). When respite care is used this separates different aspects of the study like how work is also financial income, respite care may not be income, work may provide social interaction, and so on (Bainbridge et al., 2006). Respite could help further the

studies on caregiver burden and it may have a positive effect on the caregivers of people with mental disabilities as work outside the home did.

Effectiveness of Respite Care

Caregivers of people with adult dementia who use adult care were found to have lower rates of stress, anger, and depression with the respite care. In addition, caregivers with access to home and community services were able to avoid institutionalization and reduce nursing home stays (Reinhard, et al., 2008).

A respite care program was developed for caregivers of pediatric oncology patients and their siblings. This program was made up of hospital volunteers and was able to give the caregivers breaks to eat, do laundry, or just have a mental break (Carter & Mandrell, 2013). These respite caregivers were volunteers that underwent training and it started with a one day a week program. For this form of respite care, it was often for young kids under six and for under two hours. After this program, they distributed surveys to the staff, mostly nurses, and 97 percent of them found the respite care was successful (Carter & Mandrell, 2013). This program was based in a clinical setting, during the child's hospitalization so respite care was easier accessed. But, having volunteers help with respite care relieved the burden of both the caregivers and staff. Using volunteers also made the program cost effective (Carter & Mandrell, 2013).

In Massachusetts a program evaluation was done of twelve family support service programs for families of people with mental illnesses and it was found that respite care was the most effective in reducing family care burden (Benson et al., 1996). It was also said that these respite services are productive to help "maintain the individual in their community" (Benson,

1994). As well as “preventing burnout” for the caregiver and reducing the likelihood of abandonment of the mental ill family member (Benson, 1994).

There are some respite care programs that have been developed by peer led groups that have their own experiences with mental illness. There is an example of one of these in North Carolina and the feedback has been positive (Knopf, 2021).

Barriers and Challenges to Implementing Respite Care Currently

Current barriers that have been found with providing respite care to caregivers often has to do with lack of access or knowledge of services (Reinhard, et al., 2008). For a recent study done with Alzheimer’s there were many caregiving families that showed needs, but the majority of them were not using respite care (Reinhard, et al., 2008).

The pediatric oncology respite care program found limitations when it came to hours and availability (Carter & Mandrell, 2013). This pilot program was only offered in a hospital which has its limitations because outside of the hospital care will be needed as well. While this was a good model for pediatric oncology because kids require more care so respite care in a hospital may be necessary as well as at home for this population. In a hospital it is an easier place to start an experimental program for respite care and arrange it in a centralized location. They also found conflicts with types of volunteers and their assigned tasks. Adding the respite caregivers confused the role of some already existing respite volunteers and who is assigned to what role. For example, is the respite caregiver also responsible for fetching items for the patient although that was normally done by different volunteers. So they ended up combining some volunteer roles for a bigger volunteer pool and then were able to more clearly define roles of the respite caregiver position (Carter & Mandrell, 2013).

Importance of Respite Care Being Adapted for SMI

But, overall there is a lack of specific models of respite care for people with SMI. In another community needs assessment done in 1987 the study talked about how respite care focused on disabled kids at first, then Alzheimer's, and this specific study aimed at assessing the community needs of non-Alzheimer's frail elderly people (*Journal of Community Health Nursing*, 1987). This shows how respite care models have been adapted and used for different types of illnesses already, so evidence-based research in the future could further develop best practices for respite care for caregivers of people with SMI as well.

There is already a lack of research and commitment to treating caregivers as clients no matter what the illness is (Reinhard, 2008). Due to SMI being a different illness than what many of the current forms of respite care address, the needs will be different as well. There is not a large amount of respite currently dedicated specifically to SMI. For this reason, this literature review will look into if existing respite care models can be used to adapt future respite care for caregivers of people with serious mental illnesses.

Statement of Problem

Severe Mental Illness, or SMI, are debilitating mental illnesses (Whitney et al., 2015) and these clients require intensive care from caregivers that tend to be family and friends. This adds significantly to the stress of these caretakers, making SMI caregiver stress a relevant problem for the field of social work.

Studies have shown that these caregivers experience more family problems and depression when caring for these people with SMIs. It was also found that when caregiving for more than 20 hours a week there is an even more significant increase in depression for the caregivers (Crowe & Brinkley, 2015).

Purpose of the Study

Gaps in Current Research & Purpose of Research

Respite care for care providers ensures that caregivers get to accomplish tasks that are important to them, but also gives caregivers more opportunities to participate in their community and do what they enjoy (Butler, 1988). In “Respite Care: A Monograph,” it says that respite care not only reduces stress levels, but “reduces dependence of the person with a disability (Butler, 1988).

Along with caregiver burden being the driving force behind this research, SMI programs have not been developed or researched much in the United States. There was a study done in 2015 in Australia, that conducted a several day SMI respite care program to see what effects the break in caregiving would have on the caregivers and it was found to be successful in reducing the burden of caregivers (Brighton et al., 2016). More research is needed on similar programs in general, but also in the United States specifically.

There are similarities of stress and burden for caregivers across different types of illnesses. But, there is a lack of respite care programs developed specifically for caregivers of people with SMI which is an opportunity for this research to see if it is feasible for these existing respite care models to be used for respite care for caregivers of people with serious mental illnesses.

Overview of Integrative Literature Review Methodology

To conduct this research, an integrative literature review was done on existing respite programs and models to see if these models can be applied to people with SMI. Literature reviews are used to explore relevant literature on the topic and give an overview of what is discovered from reviewing the literature (Fink, 2014). More specifically an integrative literature

review will be used which focuses on looking at many pieces of literature with similar research questions and then reports the new findings from integrating the literature all together (Labaree, 2009). As the pieces of work are analyzed, it will be easier to point out gaps in this area of study and room for new research and conclusions on serious mental illness caregivers and respite care. The research will focus specifically on the needs of people with SMI and their caretakers as well as respite care models that are effective for other illnesses.

Various databases were used to conduct this research including: Sage Pub, Google Scholar, JStor, Web of Science, and the OU Libraries online database. Sources included were from peer-reviewed journals and also direct data from organizations such as the National Institute of Health. Articles with data were used primarily from 2015 and later, so as to get relevant information several years before and after the COVID-19 pandemic and to keep the data relevant. Definitions and historical data articles were from older articles due to the fact that the definitions have not changed much over time. When searching, keywords were used such as respite care, illness, serious mental illness (SMI), caregiver, burden, stress, mental illness, mental health, development, needs, and deinstitutionalization. To assess which articles were being used the abstract, results, and conclusion would be read first to see if the findings were applicable to this research. In the abstract, conclusion, and results these keywords would be looked for as well as relevant topics for the research. Some topics included burden of SMI caregivers and the difference of caregiving for other illnesses, existing models of respite care for other illnesses, data on the rates of caregiving, needs of caregivers, and SMI, it was used for research and if it was AMI in was used keeping this in mind how to address the needs. After this, the research was integrated together to draw conclusions on if the existing respite care models can be adapted to fit the needs of SMI respite care. While doing this current practices for people with SMI was

taken into consideration to see how the models can be adapted. If these models are able to be adapted this can fill in the current gaps of respite care when it comes to people with serious mental illnesses. SMI presents itself differently than other illnesses and this research will help address the societal problem of the burden SMI caregiver's face. Since there is not a lot of existing research in this area, this will create a foundation for future research to be done on program development for respite care. Within social work, program development is an important aspect that needs to come with evidence-based research to show that the program is likely to be successful in the future. Overall, this will lead to expanding resources for people with serious mental illnesses and their caregivers.

Integrative Literature Review

Results

Similarities of Difficulties Among Caregivers

When comparing the personal and social resourcefulness among caregivers it was found that across multiple illnesses including: mental illness, amyotrophic lateral sclerosis, cancer, stroke, dementia, traumatic brain injuries, multiple conditions combined, and other conditions that all caregivers tended to use more self-help than seeking assistance (Zauszniewski et al., 2022). This applies when the caregivers "are confronted with feeling anger, anxiety, indecisiveness, or financial distress" (Zauszniewski et al., 2022). Meaning many of these caregivers struggle to seek out and ask for help. In addition caregivers experience the "merging of spaces," which is when domestic spaces and public spaces merge (Milligan, 2005). For example, when a bedroom turns into a site of care like where dialysis is done. This merging of spaces happens for all caregivers when they have to tend to their loved ones needs whether physically or just medically. This confines both these caregivers and the patients to these

domestic spaces (Milligan, 2005). Across the board, caregivers are experiencing similar challenges of being at risk for harm, burnt out from caregiving, and constantly residing in these caregiving spaces. While these challenges may need to be addressed with different specific care methods, broadly, caregivers need help and will likely not seek it out.

Needs of Caregivers & Caregivers As Clients

For the caregivers of pediatric oncology patients when surveyed they ranked respite care as their number one need (Carter & Mandrell, 2013). For caregivers of people with SMI, it was found that the caregivers felt they spent “some time” or “lots of time,” caring for the person with SMI regardless of the actual amount of time spent caregiver (Crowe & Brinkley, 2015). If the needs were assessed of these caregivers of people with SMI, respite care would likely be a need for this group of caregivers as well since the burdens they experience are similar to those of caregivers already receiving respite care.

Caregivers should be treated as “secondary clients” to the patient (Reinhard, 2008). This helps assist the caregivers in times of stress and need. Boosting caregivers competence in their caregiving with psychoeducation reduces the caregivers stress and also reduces errors in medication administration (Reinhard, 2008). Interventions that treat the caregivers as clients in healthcare are lacking (Reinhard, 2008). This is an area where more respite programs can intervene as a form of “therapeutic care” for the caregiver since respite care programs are known to reduce the caregiver strain (*Journal of Community Health Nursing*, 2014 & Brighton et al., 2016). Utilizing respite care programs more for patients with SMI is a way that the caregiver can be treated as a client to help them get a break from caregiving and have an opportunity to take care of themselves and do tasks they may otherwise not have time to do.

Respite Care After Deinstitutionalization

After deinstitutionalization there was supposed to be a shift to a community care model, which is “shift[ing] the responsibility for the care of patients from the institution to the community” (Social work, 1979). The goal was to not have people with disabilities in facilities where the conditions were poor and the staffing was bad (Social work, 1979). Although, since deinstitutionalization was so widespread across the US, community care models needed to be in place, so there was a plan for how all these people that would be discharged from these in-patient facilities would get their care. Since the 1970s studies have been saying that social work services need to be developed to reduce the burden on the family of these disabled individuals that were coming from the institutions being closed (Social work, 1979). There were studies also in the 1970s on giving antipsychotic medications to the discharged patients from the institutions, but it was found to be more effective then when the patient had family support (Social work, 1979). When the effects of deinstitutionalization started there was a call for respite care to reduce the burdens of the families because they overwhelmingly took on the (Social work, 1979). Segal’s review on deinstitutionalization called for the need of short term hospitalization, but preferably crisis houses, that would be nonmedical care and hopefully mitigate the effects of any unintended consequences of long term hospitalization and institutionalization (Social work, 1979). Respite care models were expected to be used for these patients being discharged from the facilities which included more patients than just patients with SMI.

Respite Services Used for People with SMI in Australia Benefits Caregivers

In the study of mental health carers in Australia, they focused on “informal carers” and how the impairments of people with SMI will affect the caregivers (Brighton et al., 2016). They developed a five day program for people with SMI and followed up with surveys for the caregivers of these people to see the effects of the program on the caregivers. All nine of those

surveyed had “negative health effects that they directly associated with their caring responsibilities” (Brighton et al., 2016). During the program they were able to find more leisure time and were able to enjoy hobbies they normally would not have the time for. In addition to this, one participant found that they had time to relax and recuperate from spine surgery and spend time with their husband as they recovered (Brighton et al., 2016).

Models of Medical Respite Care

In the National Institute for Medical Respite Care’s “Models of Medical Respite Care,” they talk about four models of medical respite care, care for people who are experiencing homelessness and cannot recover from illness on the streets (Models of medical respite, 2022). There is the “coordinated care model” which is focused on connection to services and case management for any social needs, medical support, and screening (Models of medical respite, 2022). The “coordinated clinical care model” is the same, but in addition to that provides “some basic onsite medical services” like vital signs and medication storage (Models of medical respite, 2022). The “integrated clinical care model” has the same services as the other two, but can “address acute health needs of program consumers,” meaning that there is contact with onsite clinical staff including care plans and overall more management of conditions (Models of medical respite, 2022). The last and final model, is the “comprehensive clinical care model,” which is able to supply the most amount of medical treatment onsite like rehabilitation, administering antibiotics, and hospice and palliative care (Models of medical respite, 2022). These models are used to supply temporary care to homeless individuals for whatever illnesses they are experiencing that may require extensive care since they often will not have access to insurance or other ways to get care (*Journal of Community Health Nursing*, 2014). The models

are developed from the “Standards for Medical Respite Care Programs,” the models are frequently adapted according to these best practices.

The homeless population often has a lack of resources, or any caregiving at all. But, these models can be adapted and used to address SMI respite care as people with SMI also have health needs that need to be addressed (Models of medical respite 2022). While this research is focused on reducing the burden of SMI primary caregivers with respite care and these homeless individuals lack primary caregivers, these models can still be used since case management is a huge part of the respite care for the homeless. Evidence-based research supports that caregivers need resources to reduce risk to the patient and the limited evidence on serious mental illness respite care specifically supports that respite care is able to do this (Reinhard et al., 2008 & Brighton, 2016). Caregivers experience stress when they do not feel competent in their caregiving and case management can assist in easing this burden (Reinhard et al., 2008). A big portion of all the medical respite care models is case management and this can be used and adapted for respite care for caregivers of people with SMI (Models of medical respite, 2022). In the medical respite care models, this case management looks like insurance navigation, coordination of appointments, connections to doctors, individual needs assessments, care plans, and identifying the patient's eligibility for community services (Models of medical respite, 2022). Assistance with these tasks would likely reduce the burden on the patient and the patient's family. In a review from 1994, it was found that case management is a technique most often used for people with mental illnesses, but case management works best with a formal established system, not when the family is having to take on this role (Benson, 1994). There is also screening for community behavioral health programs that may benefit patients with SMI using this respite care (Models of medical respite, 2022). A health needs assessment was done

on the homeless population looking at what care providers considered to be needs for the homeless population they work with. One of the providers that was interviewed mentioned that the health needs of the homeless are not that much different than needs for those that are housed, the big difference is the barriers to care (*Journal of Community Health Nursing* 2014). With this in mind, the parts of these clinical respite care models that are more focused on direct health care may work well for the population of clients with SMI and their families. The clinical care models have more access to in-house health care that may be needed for the homeless population for physical illnesses and injuries (Models of medical respite, 2022). Although, serious mental illnesses will have different specific needs than the care given here. But, assessing the needs of the SMI caregivers and what care these caregivers are normally providing would enable the physical care aspects of medical respite care to be adapted to a program that can work for SMI. Evidence-based practice for family caregiving cites that the needs of the caregivers should be individually assessed in order to address the needs and provide concrete instructions on care (Reinhard et al., 2008). These needs assessments can be used to add elements to a respite care program for people with SMI.

Behavioral Health Crisis Care

The “National Guidelines for Behavioral Health Crisis Care,” outlines what are considered best practices for crisis care and gives guidelines, tips, and tools on how to do so. Some models of crisis care can be used as models of respite care for mental illness. “Mobile Crisis Team Services,” handle crisis situations with a team that notifies the emergency department, but goes and addresses the situation at the individual’s home without law enforcement, and then follows up with care (SAMHSA, 2020). Elements of this care can be used for SMI respite care such as meeting the patient in their home to make them more

comfortable. Another best practice is to include peers on the team, this could be a good practice for SMI respite care as well to make the patients the most comfortable and have someone that understands them (SAMHSA, 2020). There are also screening and de-escalation techniques that can be utilized in SMI respite care as well (SAMHSA, 2020). Screening can be used to assess risk and de-escalation methods will be important especially if the SMI patient has violent tendencies. One best practice of respite care is using a peer-operated respite care model (SAMHSA, 2020). As mentioned in the mobile crisis peer crisis models can be utilized. Best practices shows no license professionals on site, but available for assessments if needed, and voluntary low cost peer services (SAMHSA, 2020). This can be expanded upon to further develop models of SMI respite care where care is provided by peers instead of medical providers. Additionally, there are existing “peer-run respite” programs where participation is voluntary and peer support is offered 24 hours a day where all the peers have personal experience with mental illness (Knopf, 2021). These programs do not offer medical care and are much cheaper than hospitalization and responses from participants have been overwhelmingly positive (Knopf, 2021).

Pediatric Oncology Respite Care

The pediatric oncology respite care program has a quite different population than adults with SMI, but sets up a good framework for establishing a pilot respite care program (Carter & Mandrell, 2013). This program utilizes volunteers, assesses how feasible in-house respite care, establishes program operations, and evaluates the pilot program (Carter & Mandrell, 2013). All of these elements of respite care can be used to adapt and develop respite care programs for SMI, especially a care model with volunteers.

Discussion

Summary of Findings

Overall, the literature review finds that caregivers are experiencing similar challenges and the needs of caregivers need to be addressed just as much as the needs of the patients (Reinhard, 2008). After deinstitutionalization there was a major switch towards community care that placed an extra burden on families without much support with how to now care for these people with SMI (Social work, 1979). In particular, people with SMI did not have many resources and were medicated and when that did not work then hospitalized (Social work, 1979). While deinstitutionalization reduced hospitalization for people with mental illness, it also did not bring benefit by taking away these families' care (Social work, 1979). The burdens on caregivers of people with SMI are apparent and interventions are needed to address this (Crowe & Brinkley, 2015). When looking at existing models of respite care there are a lot for various illnesses that can establish frameworks for how to develop new respite care programs in future research (Carter & Mandrell, 2013). There are some peer run respite programs that have been successful across the country (Knopf, 2021), as well as a limited number of specific SMI respite programs that were found within the research. The experiential program for SMI respite in Australia was found to be quite effective for caregivers and gave them an opportunity to have a stress free break in their care (Brighton et al., 2016). Additionally, there are extensive models on medical respite care for the homeless that different aspects of care can be taken out of such as an emphasis on case management and overall models for care (Models of medical respite, 2022). There are established best practices to be found surrounding behavioral crisis care, some of these practices including respite care, or ideas that can be used for respite care such as de-escalation techniques, screening, and peer involvement in respite care (Models of medical respite, 2022).

When looking at the existing literature on respite care models, caregivers, and SMI there are a lot of aspects to consider when developing more in depth types of SMI respite care.

One of the primary values in the social work profession is service to help others and address social problems, such as the burden of SMI caregiving in this research (National Association, 2008). The caregiver burden for people with SMI is prevalent (Zauszniewski et al., 2022) and adapting respite care models can address the lack of specific respite care models and programs for caregivers of people with SMI. A program that is modeled around existing programs that work as well as best practices will be most effective in addressing the needs of these caregivers and attempting to reduce their burden of care.

Implications for Social Work Practice

Various respite care programs have been adapted before and can be further adapted to more specifically fit SMI respite care (*Journal of Community Health Nursing*, 1987). Repeating and modifying models from past respite care would be reasonable and feasible due to the overall similar caregiving burden (Zauszniewski et al., 2022). Overall, SMI respite programs and curriculum on how to operate the respite care programs should be more widespread and available. There should be specific best practices developed just for SMI respite care. While there are best practices on behavioral health crises and existing respite care models, a program would be difficult to develop without this further research on SMI respite (Models of medical respite, 2022,). Within the best practices of behavioral health crises, it is hard to find what can be used for respite care models for SMI or find some of the existing respite care best practices (Models of medical respite, 2022, Brighton, 2016, & Knopf, 2021). Being able to easily develop programs from best practices is vital to social work practice and its dedication to competent practice and addressing social problems (National Association, 2008). Therefore, the lack of

best practices for SMI caregiving respite is a detriment to creating programs surrounding this type of respite care.

Limitations of Literature Review

There are various limitations to this integrative literature review and the research conducted. The first being the differentiation between AMI and SMI in this research versus the literature that was reviewed. SMI is specifically referring to serious mental disorders that are debilitating and disrupting the patients daily life (Whitney et al., 2015). While AMI is any mental illness, which would include both SMI and every other mental illness with varying debilitations. This research focuses specifically on SMI respite care, but a lot of the research that was done is on mental illness broadly and not specifically SMI. This makes it hard to identify and address the specific needs of those caregiving for people with SMI. Another limitation is that this research is theoretical in nature. The literature compiled mostly consisted of studies that were conducted and some reviews, but the conclusions that were drawn about the lack of best practices surrounding SMI respite care are still subjective depending on the literature that was reviewed or missed by human error. Additionally, one of the major programs that was talked about the experiential SMI respite program in Australia happens outside of the US (Brighton, 2016). This may limit the studies' applicability to this research when the research on needs and burdens of caregivers has been done within the United States.

Future Directions for Research

As mentioned above, more concrete research needs to be done to develop clear best practices on SMI respite care. As well as longer respite care studies, some of the studies that were done on the caregivers were over a short period of time (Brighton, 2016) and if a longitudinal study covers more of the caregivers life more accurate data will be found on the

caregiving burden (Models of medical respite, 2022). While some needs assessments were found on caregivers and some SMI caregivers, overall there was a lack of needs assessments for this population that would be helpful to develop further knowledge on this population. Needs assessments are important to make sure the correct problems for that caregiving community are being addressed (Reinhard et al., 2008 & *Journal of Community Health Nursing*, 1987). There are opportunities for research on SMI resources and information dissemination for the patients and their families. There was a lot of mention of lack of resources within community caregiving, but other times it was found that the caregivers did not have knowledge of their available resources either (Thornicroft & Bebbington, 1989).

Conclusion

Through the extensive analysis of the available literature on existing respite care, deinstitutionalization, best practices for serious mental illnesses, and caregiver burdens, it can be found that these existing respite care models can be adopted to further develop more specific SMI respite care models. This research will benefit the field of social work broadly by addressing the social problem of caregiver strain from patients with serious mental illness and lead into further research on the continuation and development of SMI respite care programs.

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