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Systematic Review: Coping and Supports of Family Caregivers for Adults with Serious Mental Illness

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Family Caregivers for Adults with Serious Mental Illness

by

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Caring for a loved one with serious mental illness is a challenging role to be in. The purpose of this systematic literature review is to integrate the current literature which values the viewpoint of the caregiver regarding their own strength perspective of discovering what coping skills and support systems they have found to be beneficial. The studies included in the review were peer reviewed empirical, qualitative and quantitative studies, representing several countries and age groups. Inclusionary terms for this study included: "chronic mental illness" or "mental illness", some version of the word caregiver, family, related, adapt, cope and long-term. Exclusionary terms included race and dementia. Common themes of strength found in the research included: educating the caregiver about the illness, the behaviors and prognosis, creating partnerships with the loved one and treatment team, finding acceptance of the illness and life situation, living situation effects, the importance of the caregiver caring for and finding support for themselves, finding a new life purpose and planning for the future. Future research would benefit from further evaluating disseminating educational materials, guidelines for development of support groups, training for peer mentoring and future planning into areas of the world that are more rural or limited in availability of services.

Keywords: serious mental illness, caregiver, coping, support, resiliency, family

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Introduction

Typical stressors associated with caring for and raising a child diminish as they mature and become more independent. However, the responsibilities of caring for a child or relative with serious mental illness (SMI) do not end with a child's passage into adulthood.

What Is Serious Mental Illness?

An article by Wang, Demler and Kessler (2002) uses current public law to define serious mental illness as:

> the presence of any DSM mental disorder, substance use disorder, or developmental disorder that leads to "substantial interference" with "one or more major life activities." The diagnostic component of this definition was operationalized in the NCS with CIDI diagnoses of 3 broad classes of 12-month DSM-III-R disorders: mood disorders (major depression, dysthymia, bipolar disorder), anxiety disorders (panic disorder, generalized anxiety disorder, phobias, posttraumatic stress disorder), and nonaffective psychoses (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, and psychotic disorder not otherwise specified). (p. 92-93)

With the growing knowledge and changing diagnostic criteria pertaining to mental illness diagnosis, the term used by professionals to describe this collection of diagnosis has also changed several times in recent decades. The currently accepted term has changed with usage and definition among professionals. Common terms used previously included: chronic mental illness (CMI), serious and persistent mental illness (SPMI) and serious

mental illness (SMI). In 1992, the United States Secretary of Health and Human services

officially defined SMI as:

>Adults with a serious mental illness are persons: (1) age 18 and over, (2) who
>
>currently or at any time during the past year, (3) have a diagnosable mental,
>
>behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria
>
>specified within the Diagnostic and Statistical Manual of Mental Disorders (DSM)-III-
>
>R, (4) that has resulted in functional impairment which substantially interferes with
>
>or limits one or more major life activities…All of these disorders have episodic,
>
>recurrent, or persistent features; however, they vary in terms of severity and
>
>disabling effects. (Insel, 2013, para. 3)

For the purpose of consistency throughout this research, the term 'serious mental illness'

or SMI will be used, regardless of the term used by the publishing research.

Prevalence

According to the 2013 National Survey on Drug Use and Health: Mental Health,

approximately 10 million, or 4.2% of the adult population in the United States live with a

serious mental illness (Substance Abuse and Mental Health Services Administration, 2014).

NAMI also estimates that only 40% of Americans with any kind of mental illness seek out

professional intervention, and similar numbers are found to be true in European countries

(WHO, 2004). Although not all countries report their statistics for SMI, in a survey

conducted by the World Health Organization in 2006, many countries did participate in a

survey regarding SMI. It was reported that, "in developing countries, between 76-85% of

serious cases of mental illness did not receive any treatment within the prior year" (WHO,

2006, para. 5). This deficiency of treatment may be due to cultural stigmas or the lack of

health care available for these individuals. However, developing countries are not unique

in their stigmatization of SMI. Though the exact number of individuals with SMI not

receiving any formal care is not known, estimates range from 50-80% (Marshall &

Salomon, 2004). What we do know is that more individuals and families living with SMI

are making their way without any form of professional help. Without formal assistance, the

vast majority of persons with SMI are either trying to manage it alone, or depend on the

assistance of someone who cares for them.

Need for Care

Serious mental illness, "disorders have episodic, recurrent, or persistent features;

however, they vary in terms of severity and disabling effects" (Insel, 2013, para. 3). Not all

individuals with SMI require someone to care for them full-time throughout their lives.

Medication and therapies can make significant improvements in quality of life for many

individuals, but many millions do require support, some or all of the time, for the entirety

of their lives. Individuals supporting a family member with an SMI find themselves in a

challenging role. The caregivers are dealing with a loved one that is an adult, who in many

ways can make rational decisions, and who have the right to self-determination. However,

these same adults are also in need of a great amount of patient support. Serious mental

illness may produce difficulties with a number of daily living skills such as basic self-care,

managing insurance and medical care, managing living expenses/bills, maintaining gainful

employment, and maintaining friendships and social supports. They may reside with their

family members or live separately, but regardless, they have need for support with social,

financial and a variety of other physical and emotional needs (Tessler & Gamache, 2000).

Life expectancy is shorter for persons with SMI. Based on several American studies, life expectancy for someone with SMI is estimated to be between "49 and 60 years" (Insel, 2011, para. 1) on average somewhere between 14 and 32 years earlier than the average individual without SMI (Insel, 2011). According to the University of Oxford (2014), the shorter life expectancy is due to:

High-risk behaviours are common in psychiatric patients, especially drug and alcohol abuse, and they are more likely to die by suicide. The stigma surrounding mental health may mean people aren't treated as well for physical health problems when they do see a doctor. (Para. 11)

Even with this shorter lifespan, if a parent is caring for an individual with SMI, care will likely span most or all of a parent's lifetime. In a 2009 survey by the National Alliance for Caregiving, it was determined that 28.5% of the U.S. population is caregiving for another adult (relative or friend) in some capacity. Estimates suggest 60 – 70% of individuals with SMI reside with a family member and greater numbers--up to 90%--remain in close proximity of family members to access support (Lefley, 1996).

Burdens in the Role of Caregiving

While some individuals with SMI may try to function on their own, others rely on their families to help them function with daily life issues. The family members who do take on the role of caregiver for this population will encounter a unique set of stressors and burdens. In fact, Schulz and Sherwood (2008) state:

Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in

multiple life domains such as work and family relationships, and frequently requires

high levels of vigilance. There is often no end for the responsibility of caring for this

child or loved one. (p. 105)

Although each person's experience of SMI is unique, and there is a wide continuum

of symptoms and severity that can be experienced by individuals with these disabilities,

there is nearly universal agreement that combinations of psychological and

pharmacological treatments can improve the quality of life to varying degrees (Carey &

Carey, 1999). While these treatments are an essential part of living well with SMI, they are

not sufficient. What is needed is "some combination of medication, psychotherapy and

lifestyle choices along with community supports to facilitate robust recovery" (NAMI, 2013,

p. 2). For such an extensive set of conditions to occur, family support is often needed.

The role of caregiver for the loved one with SMI is often a lifelong and daunting

position and may feel at times like a thankless job. Those in this role may feel they are

unable to share this burden with others due to social stigmas, guilt and shame (Lefley,

1996). Many caregivers have experienced moments or perhaps years of their lives where

they feel overwhelmed and ill-equipped to deal with the needs of their loved ones

(American Psychological Association, 2014). The burden of caregiving for one's child or

relative with SMI can come with feelings of resentment, isolation, grief, shame, blame, being

trapped and overwhelmed, and a loss of personal priorities (Thompson & Doll, 1982;

Malone, 1993).

Finding Coping Skills and Supports That are Effective

Research has shown that some are able to handle the burden of care better than

others (Hatfield & Lefley, 1987). For example, Zegwaard et al. observed, "Caregivers who

are more confident are more successful in handling difficult situations" (Zegwaard, Aarsten, Cuijpers & Grypdonck, 2011, p. 2254). For these people, evidence demonstrates that taking on the role of lifelong caregiver may be intimidating, but does not appear to result in a life that feels overwhelming and burdensome (Hatfield & Lefley, 1987; Herman & Reynolds, 1992).

There are coping skills and social supports that may be common to individuals who are able to adapt to this role (Herman & Reynolds, 1992; Schulz & Sherwood, 2008). Some researchers have found that these caretakers are able to have acceptance of life circumstances, reasonable expectation of quality of life, and for some, even a joyful outlook (Herman & Reynolds, 1992; Schulz & Sherwood, 2008).

Resilience refers to the ability to rebound from adversity and prevail over the circumstances of our lives. As with any catastrophic event, SMI offers families an opportunity to change in constructive ways and to strengthen family bonds (Marsh, Lefley, Evans-Rhodes, Ansell, Doerzbacher, LaBarbera, & Paluzzi, 1997, p. 4). Just what these coping skills and supports are that allow caregivers to feel confidence, competence and resiliency with this life journey, will be explored within this research. Some terms used in this study may be seen as ambiguous and therefore may benefit from clarification for the purposes of this study. Coping skills are defined as, "The specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events" (MacArthur Foundation, 1998, para. 1). Support strategies are defined as seeking the assistance of individuals, groups or organizations as a means of assistance and psychological encouragement during ongoing life challenges (Mental Health Commission of Canada, 2012). And finally, life satisfaction, for the purposes of this study is defined as an

individual's perspectives of the quality of their life circumstances and the anticipation of

maintenance, improvement or decay of their quality of life circumstances moving forward

(Essays, UK, 2013 and Psychology Dictionary, 2014).

The purpose of this paper is to present a systematic review of the literature on

effective or beneficial coping strategies and supports for individuals who act as caregivers

for their relatives who have SMI.

Methods

This research is formatted as a systematic literature review. A systematic literature

review is an exhaustive synthesis of literature, using current quality research as relevant

evidence to analyze and answer a research question. An estimated 6 percent of the world's

population has SMI, and family and friends are trying hard to support these individuals.

But, their journey is not easy. Practical research and insight, which can be obtained by this

research, can offer relief and well-being to individuals who will be struggling with their

role as caregivers. If caregivers, therapists, social workers, or any health or mental health

professional can disseminate information and guidance about the most effective coping

skills and support strategies to those who need it most, this research will have made a

significant change for the betterment of many people's lives.

The following electronic databases were used to obtain sources for this literature

review: Social Work Abstracts, PsycNET, SocINDEX, Family Studies Abstracts, Pilots and

SAMHSA. The database searches were conducted using EBSCOhost, Summon and CLICnet

databases, through the University of St. Thomas library network.

The search terms for this systematic literature review included the following, which

had to all appear either in the title, article, abstract or key word index for each article:

- "chronic mental illness" or "mental illness"

- Some version of the word "caregiver" was included in the title or article (for example: caregiver, caregivers, caregiving). Criterion used to search in the database was, "careg*" (the "*" after the word stem is a symbol used in bolean search method which indicates any variation of the word with the stem provided).

- Either "family" or "related"

- One of the following terms was included: cope, coping, support or some version of the word "adapt" (specified by adapt* in the search engine)

- "long-term"

Words of exclusion from the search included:

- dementia

- race

The exclusion terms were included due to the large number of extraneous articles with these terms that were outside of the targeted research subject.

All articles included in this systematic literature review were required to be empirical in nature and peer-reviewed. All articles include data gathered from one or multiple related caregivers through means such as observation, case notes, survey or interviews, regarding specific factors they have found to be advantageous to their ability to obtain or maintain positive life satisfaction. Studies included research from countries around the world but must have been translated into English to be included in this review.

Research Synthesis

Using the inclusion and exclusion criteria, 54 articles were found in the database search. Of the articles found, many were literature reviews or not empirical articles, and

could not be used to further the current research. One of the articles written in the

Netherlands was not translated into English and could therefore not be included. Several

articles focused exclusively on caregivers of individuals with developmental disabilities or

physical illnesses and were therefore excluded from this research. Some of the articles

were excluded because they mentioned caregivers but were focused on the perspective or

experience of the individual with SMI and not the experience of the caregiver. One of the

articles was a professional article documenting experiences of caregivers through the eyes

of professionals, but no actual caregivers contributed to or were interviewed through the

research process. One source led to a response to the editor of a professional journal in

regards to needs of caregivers and did not meet the empirical criteria for inclusion as

research. Finally, one article was excluded because it was a manual of an intervention

method for caregivers' support group and not a study.

The final results following implementation of exclusionary criteria left 14 articles,

which were relevant to the current research question and therefore reviewed in this

systematic literature review (see Table 1). The determination of "effective" was based on

the findings, and is grounded in the perception of the caregiver in their level of adaptability

to life circumstances and life satisfaction. Studies include qualitative, quantitative and

multi-modal designs, which include empirical findings. Qualitative designs were utilized by

43% of the current studies, quantitative methods were used by 21% and the remaining

36% used a combination of qualitative and quantitative data in their research.

All caregivers included in these studies were related in some way (through blood

relation or by law) to the adult with SMI whom they were caring for. Caregivers from the

included research were at many different places in life, from ages in their middle 30's to

middle 80's, although the majority of the research focused on individuals from mid-life to

elderly (50-80 years range). While the majority of caregivers participating in the research

were parents, study participants also included spouses, siblings and adult children.

Table 1
Studies Included in Systematic Review

Author(year)	Focus	Comparison Group	Country	Sample	Study Type
Aschbrenner (2007)	Long-term impact of parenting child w/bipolar, later in life	Yes	United States	139, age avg 64	qualitative and quantitative
Aschbrenner et. al. (2009)	Parenting a child w/bipolar in later life	Yes	United States	145, age mid 60s	qualitative and quantitative
Aschbrenner et. al. (2010)	Subjective burden and personal gains of older parents of adults with SMI	Yes	United States	111, age avg 63	qualitative and quantitative
Barker et. al. (2012)	Daily stress and cortisol patterns of parent carers of adults with SMI	Yes	United States	61, age avg 58	qualitative and quantitative
Cohen & Thomas (1996)	Needs of carers of people with long-term mental illness	No	Whales	36, age 40-60	qualitative and quantitative
Greenberg et. al. (1993)	Effects of subjective burden on maternal health –mothers caring for adult children w/schizophrenia	No	United States	90, age 45-82	quantitative
Hanzawa et. al. (2013)	Psychological impact on caregivers traumatized by violent behaviors of family members with schizophrenia	No	Korea	165, age mean 40 SD 10 years	qualitative
Huang et. al. (2009)	Experiences of long-term carers in Taiwanese culture (schizophrenia)	No	Taiwan	10, age 42-75	qualitative
Lefley (2010)	Treating difficult cases, family support group for serious mental illness (schizophrenia)	No	United States	4, 2 siblings & 2 parents	qualitative
MacNeil & Jaggers (2013)	Strength based intervention for long-term caregivers (SMI)	No	United States	10, age 58-80	quantitative
Muhlbauer (2008)	Caregiver perceptions and needs regarding symptom attenuation in SMI	No	United States	35, age 40-76	qualitative
Obloy & Hutcheson (2002)	Planned lifetime assistance network: a new service model with promising results (mental illness or mental disability)	No	United States	42, age 50-80	quantitative
Ward & Cavahagh (1997)	Self perceived needs of carers for dep. with long-term problems (including MI)	No	Scotland	103 (14 carers for MI relatives/friends)	qualitative
Winefield et. al. (1998)	Responses to support groups for family caregivers in schizophrenia: who benefits from what?	No	Australia	8, 7 parents and one spouse	qualitative

As stated in the inclusion criteria, research reviewed was limited to articles that

were written in or translated into English. A number of different countries and cultures

were included in this literature review. Although 64% of articles were obtained from

research in the United States, several other countries were represented in the research,

including: Australia, Korea, Scotland, Taiwan and Whales. One other notable variance in

many of the included studies was the clarification of whether the caregiver was living with

or apart from the loved one with SMI.

Some studies included a comparison group, to control for individuals who are in

similar life stages, but not in the caregiving role. This comparison group allowed a

reasonable comparative analysis to peers' life satisfaction and struggles. The studies

encompassed many life factors. Strict comparisons between participant and control

members were difficult, as individuals differed in terms of their life circumstances or

perceptions or reactions to their own life circumstances.

This set of research studies, then, takes into account a wide variety of individuals

living in various cultures and life stages and offers insight into what coping skills and

support strategies have been found to be effective for related long-term caregivers of

individuals with SMI. The studies included in this literature review clearly reveal patterns

present in successful, healthy caregivers. The most important factors included: caregiver

education; strong and clearly defined partnerships with medical providers; caregiver

acceptance of the illness; a good fit regarding living arrangements; and caregiver self-care.

Importance of Caregivers' Education about Serious Mental Illness

Psychoeducation. The more caregivers understand about SMI the more effective

they feel they can be in their support of loved ones (Aschbrenner, 2007; Lefley, 2010). As

caregivers are able to access adequate psychoeducation, they feel they are more effective in

their role, and they perceive themselves as being better supported and having greater

coping capabilities (Aschbrenner, 2007; Aschbrenner et al., 2010; Lefley, 2010; Huang,

Hung, Sun, Lin & Chen, 2009; Winefield, Barlow & Harvey, 1998). Caregivers report that

psychoeducation is such an important piece to finding acceptance in their role as caregiver;

yet, it is commonly perceived as a significant deficit area because appropriate mental

health information for caregivers seems difficult to access (Ward & Cavanagh, 1997;

Winefield et al., 1998).

Families want to know about SMI, medications, side effects, what to expect, how to

act and how to react (Muhlbauer, 2008; Greenberg, Greenley, McKee, Brown & Griffin-

Francell, 1993; Cohen & Thomas, 1996; Winefield et al., 1998). Serious mental illness can

present differently in each individual, but there are commonalities. Educating caregivers is

a significant step to, "understanding and appreciation of families' current experiences with

a member who has SPMI" (Muhlbauer, 2008, p. 100). Education about SMI can empower a

caregiver; it can reduce negative components including feelings of distress and perceived

stigma, and increase their own ability to cope with symptoms and repercussions of their

loved one's illness (Huang et al., 2009; Muhlbauer, 2008; Lefley, 2010).

Reducing fear and building competence. Greenberg and colleagues (1993) found

that a family members' physical health can be greatly effected by chronic anxiety, which is

triggered by long term fear and stress which has gone untreated or addressed.

Understanding the course of SMI and how to best support someone in their struggle with

SMI, understanding what can be changed and what cannot, are all essential pieces of

attainable information for caregivers. Education of caregivers releases the fear,

responsibility and shame, which can be experienced in coping with SMI, and builds much

needed confidence and competence (Greenberg et al., 1993; Muhlbauer, 2008; Lefley,

2010). MacNeil and Jaggers, 2013, found that caregivers who are able to identify their own strengths and who are able to see the benefits to what they are doing with regard to their loved one with SMI will feel more confident and will have more resiliency in coping with the challenges.

Creating Partnerships

It is difficult to find the delicate and respectful balance in the dialectic between a caregiver's monitoring and facilitating care, and taking over for a person one loves and cares about, and for whom the caregiver may be legally responsible. Muhlbauer (2008) reported that caregivers are confused about when they should step forward to make decisions for their family member with SMI, and when they should allow their loved ones to maintain the lead in their choices around care and support.

Medical professionals may be going through a similar dilemma with the caregiver and the patient in not knowing to whom to communicate information. Medical professionals may not know that their patient with SMI is unable to understand or remember what they are told (or they may not have legal autonomy to make their own medical decisions) and that the caregiver should also know about information coming from the doctors (Huang et al., 2013). Sometimes the medical professionals do not readily communicate to caregivers because the caregiver is not the patient and the patient is an adult. This variance of role of responsibility is different than is typically seen in medical offices. This alteration of the caregiving role can bring guilt to the caregiver; guilt over feeling they may have to supersede the patients' wishes (Muhlbauer, 2008; Lefley, 2010).

Some studies reported family members felt as though they needed to act as the intermediary between professionals and their loved one and among professionals

themselves. They felt handicapped or burdened because professionals rarely

communicated with each other, expecting the caregivers to fill in the information gaps

repeatedly (Huang et al., 2009; Hanzawa, Bae, Bae, Chae, Tanaka, Nakane, Ohta, Zhao,

Iizuka, & Nakane, 2013).

The literature demonstrates that caring for an adult who is in need of help can be

psychologically challenging. Having full legal rights to make decisions for another adult

may cause conflict when both parties don't agree (Huang et al., 2009). When dealing with

SMI, no professional would argue that these caregivers are taking on a selfless role that

comes at a price. Those willing and able to take on the role of familial caregiver know their

loved one better than any medical professional or any paid caregiver ever could.

Developing and maintaining an open communication with the patient and clinicians is

essential for decreasing anxiety and frustrations of the caregiver.

Acceptance of Illness and Associated Behaviors

As outlined in several studies, individuals with SMI appear to make impulsive

decisions and may act on arbitrary thoughts. They can think more rationally and minimize

symptoms of their illness when they are taking their medications, but frequently choose to

stop medication compliance (Huang et al., 2009; Obloy & Hutcheson, 2002; Hanzawa,

2013). Caring for individuals like this can lead to caregivers' daily life being unpredictable,

stressful, and overwhelming. These circumstances can strain the relationship with the

loved one, increase instability of the individual with SMI, and cause physical and mental

instability in the caregiver (Barker, Greenberg, Seltzer & Almeida, 2012; Obloy &

Hutcheson, 2002; Mulbauer, 2010; Lefley, 2010; Aschbrenner et al., 2010).

Behaviors such as shopping sprees, impulsive sexuality, severing supportive relationships with family and friends and stopping needed medications are difficult to understand and difficult to witness (Aschbrenner, 2007). Beyond intellectually understanding comes acceptance of the reality of living with someone with SMI and acceptance of life circumstances. In order to begin this process, caregivers must have some understanding of the difference between behaviors that are intentional and ones that result as a demonstration of the mental illness of their loved one (Muhlbauer, 2010). Associated behaviors of SMI may be perceived as laziness or an exhibition of being intentionally uncooperative, but are truly manifested symptoms of SMI. If caregivers are unable to change the way they themselves think about these collateral symptoms as part of the SMI, stress and tension increases in relationships (Muhlbauer, 2010; Lefley, 2010; Barker, 2012).

Studies have found that competition for control over need of care, finances, behaviors and daily decisions between the caregiver and the loved one produces conflict and anxiety in relationships and increases the perceived burden and daily stress on the caregiver (Obloy & Hutcheson, 2002; Muhlbauer, 2010). Caregivers function better and with lower stress levels if they can put aside resenting or fighting the behavioral symptoms, and instead, find acceptance within themselves, set appropriate and respectful boundaries, and provide assistance to their loved one when needed (Muhlbauer, 2010; Barker, 2012; Obloy & Hutcheson, 2002).

Living with or Apart from Loved One

There are both positive and negative aspects for caregivers to live either with or apart from their loved one. In deciding whether the caregiver and loved one should live

together researchers note that it is important to consider: medical and psychological

stability; ability to maintain a home and personal finances; personal awareness of needs;

safety for themselves and others; and cultural expectations (Obloy & Hutcheson, 2002;

Huang et al., 2009).

Equally as important as what the person with SMI can handle, the physical and

psychological well-being of the caregiver needs to be considered carefully (Aschbrenner,

2007; Aschbrenner, 2009; Greenberg, 2009; Muhlbauer, 2008). For example, according to

Aschbrenner (2007) older parents who had an adult child with SMI living in the home with

them reported higher levels of stress and greater difficulties with their own psychological

and physical health (p. 128). However, Greeenberg (2009) reported that in their study,

parents whose children were living with them did report to have higher subjective burden,

but reported to be in better physical health than the parents who were living separately

from their loved ones with mental illness (p. 209).

The current set of studies does not appear to recommend whether living with or

living separate from the person being cared for is preferred. This lack of recommendation

is because there are so many aspects which vary in each individual situation. Many factors

need consideration, such as: the perspective of the caregiver, benefits found from living

with the person needing a caregiver included things such as greater control over finances

(no need to support or subsidize two households) and greater emotional bonding. Later in

life the adults with SMI may offer greater support back to their parents with whom they

live (Greenberg et. al., 1993; Aschbrenner, 2010). Benefits to living separately included

things such as greater autonomy for both parties, more time and ability to pursue personal

interests and maintain personal health, decreased fear and decreased chances of personal

harm, and daily levels of anxiety related to SMI is less due to ability to have physical

separation from the person experiencing the SMI (Greenberg et al., 1993).

Being an Effective Caregiver without Forgetting One's Own Needs

Learning how to best take care of and empower a loved one with SMI, without giving

up personal priorities and identity, is an important piece to the puzzle of feeling

accomplished as a caregiver.

Many families emerge from coping with the challenges of caregiving with a renewed

sense of resiliency and personal strength. This may be especially true for older

parents, who may have adapted to caregiving challenges over time by acquiring the

resources and skills needed to cope effectively with their child's mental illness.

(Aschbrenner et al., 2010, p. 609)

These resiliencies are more evident in those who have shown the ability to find a

balance between their own needs and those of their loved one, without sacrificing either

one. Several studies in this review address resiliency and touch on the point of caregivers

who have maintained autonomy showing greater resiliency, acceptance and life satisfaction

(Aschbrenner, 2007; Aschbrenner et al., 2009; Aschbrenner et al., 2010; Lefley, 2010).

Support groups. Support groups can offer many things to caregivers. Though not

intentionally, many caregivers may become isolated from friends, other family members

and their community (Aschbrenner et al., 2007; Cohen & Thomas, 1996; Huang et al.,

2009). The general public may not understand the struggles of a caregiver of an adult with

SMI. Support groups can open up a family to new opportunities for friendship and social

and emotional support with individuals who are aware and understanding of their life

challenges (Greenberg et al., 1993; Huang et al., 2009).

Many things other than friendship can also be obtained with involvement in support groups. Education and knowledge may come from participation in these groups (Lefley, 2010). Education goes beyond what is read in textbooks; members learn from other members' experiences and from their mistakes (Lefley, 2010; Huang et al., 2009; Aschbrenner et al., 2010). Research respondents reported that information and testimonies were more accurate to real life and more validating than what can be found in books or learned from professionals (Lefley, 2010). There is often a true connection with those who are going through and sharing similar life experiences (Greenberg et al., 1993; Winefield et al., 1998). Interactions between group members are empowering. Support groups allow for processing of thoughts and feelings, gaining perspective of opinions and events, grounding of thoughts and beliefs and insight and developing of coping strategies (Lefley, 2010; Huang et al., 2009; Winefield et al., 1998).

Work-life balance. Many individuals with SMI find it difficult or impossible to maintain employment and so turn to their caregivers for financial help (Aschbrenner, 2007; Aschbrenner et al., 2009; Cohen & Thomas 1996). A much larger percentage of caregivers for adults with SMI are unemployed as compared to their typical peers of a similar age who are not caregivers (Aschbrenner, 2007; Cohen & Thomas, 1996). But, for many caregivers, there is no choice in the matter; they have to work to support themselves and their family. The process of balancing the responsibilities of work and home life is significantly more capricious than for those who do not have the additional role of caregiver (Aschbrenner, 2007; Greenberg et al., 1993).

Working while caregiving can be problematic but is not an entirely impossible task. What is required is finding balance and flexibility. As an employee, the caregivers must be

able to have open communication with employers. They must also have the ability to

maintain flexible schedules including options for family medical leave, sick leave, and

vacation time. They also need understanding from coworkers (Aschbrenner, 2007;

Greenberg et al., 1993; Huang et al., 2009).

      The caregiver's mental and physical needs. Although not all factors are within

their locus of control, many factors are shown to contribute to the degree to which

caregivers are able to attend to their own physical and mental well-being. These include:

gender; IQ; education; pre-existing conditions; social supports; family size; and household

income (Aschbrenner et al., 2009). From the included studies, one notes that caregivers

identify some similar barriers to successfully attending to their own mental and physical

needs. These included their own perceptions of: (1) level of burden; (2) financial priorities

or limitations; and (3) support from others (Aschbrenner et al., 2009; Aschbrenner et al.,

2010; Barker et al., 2012; Cohen & Thomas, 1996; Greenberg et al., 1993).

      Caregivers' own perception of their level of burden is the most widely reported

barrier to their own mental and physical health (Aschbrenner et al., 2010; Barker et al.,

2012; Cohen & Thomas, 1996; Greenberg et al., 1993). There seems to be a difference

between individuals who are able to see themselves as a partner in the process of

caregiving, rather than the person burdened with sole responsibility for the care of their

loved one. Caregivers with the former perspective are more resilient and have increased

psychological well-being throughout their time in this role (Muhlbauer, 2010; Aschbrenner

et al., 2010). Barker (2012) studied levels of cortisol in parents who were caregivers of

adults with SMI and compared their stress to their peers who were not caregivers. Cortisol

is a hormone released in the body when an individual is experiencing stress. Not

surprisingly, this study reported that caregiving parents typically experience much higher

levels of stress across time than their peers who are not caregivers.

Also highly reported in the included studies was physical and mental problems

resulting from issues of financial hardship and personal neglect -- caregivers putting the

loved one's physical and mental health needs above their own (Aschbrenner, 2007;

Aschbrenner et al., 2010; Barker et al., 2012; Greenberg et al., 1993). Higher anxiety

associated with trying to find balance between the role of caregiver and role of an

employee can lead to chronic stress and lead to negative effects on mental and physical

health (Aschbrenner, 2007).

Only one of the studies included in this review (Greenberg et al., 1993) reported that

reciprocity of care was found to be of great benefit and significantly comforting to

caregivers later in life. This benefit was found to decrease the perception of burden in later

years for the caregiver. The probability of reaping care for the caregiver was almost

exclusively a benefit for caregivers who cohabitated with their loved ones. Many individual

life characteristics affecting caregivers may lead to varying levels of vulnerability for them

and should be addressed and supported throughout their life stages, as to not leave them

depleted and vulnerable throughout their time in the caregiving role (Aschbrenner, 2007;

Aschbrenner et al., 2009; Greenberg et al., 1993).

Life purpose and growth. Through facing life challenges and being resilient when

faced with adversity, caregivers may realize personal growth and a feeling of life purpose

that they may never have believed possible without this specific challenge (Aschbrenner,

2007; Aschbrenner et al., 2010). Caregivers at times may feel overwhelmingly stressed and

out of their element, but that does not mean that the life journey of a caregiver is a completely negative one.

Caregivers may learn to be a friend and companion to their loved one with SMI (Aschbrenner, 2010). Family and friend relationships often grow stronger through the caregiving process, values come into play between caregiver and the loved one, and each tends to gain greater understanding of each other's needs and wants as they create a closer bond (Aschbrenner, 2010). "Caregiving gives rise to positive outcomes, such as a greater sense of purpose in life or feelings of personal growth" (Aschbrenner, 2007, p. 13). This outcome also increases sense of resiliency, self worth and coping skills in the caregiver (Aschbrenner et al., 2010; Huang et al., 2009).

Caregivers who have a religious faith can find strength and purpose through their faith, or sometimes through a sense of obligation. During periods of time when caregivers feel overwhelmed or confused they may turn to religion to find answers and direction (Huang et al., 2009). Faith or religion allows some caregivers to come to terms—find purpose or a sense of direction—with the responsibilities of their role (Huang et al., 2009). Religion may play a role in feeling as though enduring through difficult times is a purposeful and meaningful experience that will be rewarded through karma, or through following religious doctrine of taking care of those in need (Aschbrenner, 2007; Huang et al., 2009; Lefley, 2010). Caregivers find their purpose in different ways, but developing a sense of growth and purpose contributes to life satisfaction in their role.

Security of ongoing care. Care and support encompasses so many things, such as financial responsibilities, companionship, health and welfare management. But caretakers age; for many they are not going to be able to handle the job anymore, and passing this big

job on to another individual may not be realistic. So caregivers worry about what will

happen if they can no longer do their job (Aschbrenner, 2007; Aschbrenner et al., 2009;

Aschbrenner et al., 2010; Greenberg et al., 1993; Huang et al., 2009; Muhlbauer, 2008;

Obloy & Hutcheson, 2002).

There are programs and services available to help caregivers plan for the future of

their loved one (Obloy & Hutcheson, 2002).   But, even if services are not available,

planning ahead can be very helpful to the caregiver and to the individual with SMI.

Planning for the future can make great differences for caregivers today, "parents and

siblings appear to experience less stress, greater peace of mind, freedom to plan for

retirement, and improved family relationships...more stable living situations, fewer crises

(Obloy & Hutcheson, 2002, p. 411).

Discussion

This research focused on identifying what coping skills and support strategies have

been found to be effective for long-term related caregivers of individuals with SMI. It is

evident that all over the world, regardless of culture, socioeconomic status or age,

caregivers experience similar frustrations but more importantly are finding similar coping

skills and support strategies to be helpful.

The findings of this systematic literature review demonstrate that education and

communication with and between clinicians are important to caregivers. More than

anything else, caregivers consistently stated that they wanted more ongoing education and

communication with doctors and other professionals. Health and mental clinicians should

strive to ensure case coordination; family reports should not be expected to be the sole

source of communication between clinicians. Education and communication go hand in

hand. Caregivers are often the most knowledgeable individuals about their loved ones'

daily successes and barriers. Caregivers want to know what to expect, how to help and

how and when to let their loved ones be independent in their own life decisions.

Communication with caregivers is essential; although the caregiver is not the "patient,"

they are part of the team and wish to be included and valued for their unique insight.

Education and communication offers caregivers a sense of confidence and competence in

moving forward. Future research could consider how to most efficiently provide

information among interested parties. Electronic mental health records or standardizing

systems of care coordination are areas for consideration for streamlining communication.

Acceptance of SMI is often a difficult process. Often, it is not what they had

anticipated for themselves or their loved ones. However, through acceptance of the reality

of their loved one's SMI, many caregivers report significant decrease in their anxiety and

increase in their success in moving on with their lives and finding joy and peace in their

lives. This research highlighted that for many caregivers support groups were very helpful

with finding acceptance of the diagnosis and life circumstances.

Caregivers are able to find normalization of their experiences and have access to

other experiences and resources. Support groups were also demonstrated to provide

instant access to socialization with peers who understand and are willing and able to listen

to them. When all is said and done, many caregivers can look back with pride and forward

with positive anticipation of what life has yet to offer -- but not until they can find

acceptance within themselves about their role as a caregiver and about their loved one's

illness. Future research might explore the benefits of introducing support groups into

regions where mental health services are not as widely available or as readily accepted.

Peer support and education may offer a support network in areas where stigmatization of SMI is more prevalent as a barrier to services.

Caregivers may lose sight of their own wants and needs in taking care of a loved one with SMI. This research has confirmed that isolating and cutting oneself off from friends and family, neglecting one's own health and goals or moving away from personal priorities depletes a person. Humans need support and goals to strive for. Individuals need encouragement, reinforcement and companionship. There are times when caregivers are solely focused on coping with urgent mental health issues, but that reactive state cannot be maintained across time without cost to the caregiver; and subsequently cost to the person with SMI. The research demonstrates that in order to thrive, caregivers must find things in life that give them purpose and joy, and they must have social support opportunities. Future research could study the benefits of offering 1:1 caregiver support. This are of study would examine the benefits of caregivers who have found effective coping skills and supports in their own lives, mentoring new caregivers.

Finally, research demonstrates significant benefit for caregivers and their loved ones planning for the future. What is going to happen when the caregiver is gone or unable to physically or mentally care for their loved one? Findings from this study demonstrate the benefit of taking the time to make plans for the future decreases current stress. Caregivers should make plans for financial, physical and emotional support for when they are unable to continue with their role. This plan of action results in significantly calming fear and stress. There are services available to help with this planning for the future, which is comforting for caregivers and the individuals needing the care. This is an education piece. Educating the caregiver, the patient, and other family members as to what the

anticipated plan of care is moving forward. Future research would benefit from creating

and disseminating materials to a wider audience of caregivers. Since these programs

currently tend to be more widely available in larger communities, researchers should reach

out to more rural areas and study the perceived benefits of these consumers.

Of the caregivers who find their job and their life circumstances daunting and

overwhelming, some may be afraid to ask for help; they may feel they have tried everything

possible already. Some may feel resentment or guilt about not feeling capable or maybe

about not wanting to be a caregiver at all. Others may just feel that it is their burden to

carry on and do so alone. No matter the resolve of the caregiver, this is an extremely

challenging role. Parents and relatives are functioning in an important and needed way,

but for many, they would benefit from the social worker's educated insight and support

that may be able to greatly improve their confidence, competence, and quality of life.

Useful future research might play a role in creating materials targeted specifically toward

caregivers and researching their benefits. Current educational materials offer information

on patient issues and helping them—also needed—but very little offers insight specifically

designed to educate and prepare caregivers in the personal journey that lies ahead of them.

Social workers will have the capability to use this information to empower clients

who are in desperate need of hope. Social workers have the role of guiding, educating, and

supporting clients through their caregiving journey and can feel empowered by their

commitment to follow the National Association of Social Workers' guidelines to "promote

and facilitate evaluation and research to contribute to the development of knowledge"

(NASW, 2008) by reviewing and summarizing this body of work regarding resilient

caregivers and what caregivers perceive as helpful in building resiliency. Using this

literature review, social workers can more confidently provide insight and suggest skill sets and supports that have been demonstrated to be helpful with great numbers of caregivers learning to cope and thrive in challenging life circumstances from all over the globe.

Limitations

With the search terms used for this systematic literature review, 54 articles were originally gathered, but the final sample included 14 articles. Although the discovery in this research was significant, it would have benefited if the sample size could have had a larger representation. Also, the number of authors of research was somewhat limited. The included research revealed the limited number of authors in multiple research studies. So few articles with a limited variety of authors may have limited the research findings through restricted variability. Finally, although there was variation in the age of the subjects among the studies, the majority of findings reported were from subjects who were mid to late life. This imbalance of age of caregivers may reflect special issues or perspectives related to being in mid to late ages as caregivers, and may not equally represent younger aged caregivers.

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