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Parents with Serious Mental Illness Served by Peer Support Specialists

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Abstract

Parents with a mental illness, especially single mothers, who are caring for their children are particularly vulnerable to social isolation, stress, financial hardship, and lack of resources. Prevention and strengths-based interventions are needed for mothers with serious mental illness and their children. Current mental health interventions tend to focus on the individual without respect to family context and do not address parenting needs or support for both the parent and child. The literature indicates mothers with a mental illness and their children should be considered a high-risk group in need of more intensive and more frequent mental health supports. One alternative for more frequent mental health support is through the peer support specialist model. Although the peer support specialist model is a nationally recognized evidence-based practice, research is limited on identifying the program and service needs of parents with mental illness from a peer support specialist perspective. This study implemented an exploratory investigation to identify life stressors and specialized programs and service needs for parents with mental illness from a peer support specialist perspective. Results of this study identified support groups for parents with mental illness and for youth/young adults with a parent with a mental illness as the highest level of need. Results also found a need for peer support specialists to be paired with individuals based on mutual characteristics of parental status and identification of having a parent with a mental illness.

Keywords: parents with mental illness, children of parents with mental illness, peer support specialists

Introduction:

Parents with Serious Mental Illness Served by Peer Support Specialists

Families affected by parental mental illness are vulnerable to social isolation, financial hardship, and marital discord as well as increased risks for their children (Beardslee, Versage, & Gladstone, 1998; Reupert & Maybery, 2007). Many children raised by a parent with mental illness (MI) are at risk for developing psychological programs in adulthood and may present with psychiatric problems, disrupted attachment, and socio-economic disadvantage (McCormack, White, & Cuenca, 2016; Reupert & Maybery, 2007).

Maternal mental health is linked to child development, level of parent-child interaction, developmental delays, and child abuse and neglect (Dickstein et al., 1998). Mothers with serious mental illness (SMI) face multiple challenges when dealing with reproductive issues, parenting assistance, and custody loss, often without family support (Nicholson & Blanch, 1994). Children of mothers with SMI are also likely to be involved with multiple service agencies, including both mental health and child welfare (Hinden, Biebel, Nicholson, & Mehnert, 2005). However, despite the prevalence of maternal SMI and the risk of adverse outcomes for both mother and child, very few intervention programs designed specifically for parents with SMI and their children exist (Hinden, Biebel, Nicholson, & Mehnert, 2005).

Analyses of the National Comorbidity Survey data indicate 68% of women meeting the criteria for a psychiatric disorder over their lifetime are mothers (Nicholson, Biebel, Williams, & Katz-Leavy, 2004). The onset of many psychiatric disorders occurs during childbearing years, contributing to impairment of the affected mothers (Lagan, Knights, Barton, & Boyce, 2009). In recent years, the population of parents who have SMI has increased (Bassett, Lampe, & Lloyd, 1999). With the advent of improved services and medications, a shift from the medical model of practice to a psychosocial basis of practice, increased consumer advocacy, expansion of community-based care, and decreased reliance on psychiatric hospitalization, more women with SMI have chosen to become parents (Bassett et al., 1999). This, however, has not encouraged or motivated the mental health system to address parenting as an important issue for individuals with SMI, particularly women. Even as community programs have expanded and are focusing on recovery-oriented services, including interventions that focus on psychosocial rehabilitation that address work-related skills and employment, parenting skills are still not being addressed (Nicholson & Blanch, 1994).

Perspectives of Mothers with SMI

When discussing mental health treatment satisfaction with mothers with SMI, Diaz-Caneja and Johnson (2004) found most of the mothers are satisfied with their individual mental health treatment; however, they were not satisfied with the level of knowledge or concern for their personal lives (Diaz-Caneja & Johnson, 2004). Mental health professionals were described as failing to acknowledge the day-to-day practical difficulties women face as parents while simultaneously trying to adhere to treatment regimens. According to Diaz-Caneja and Johnson (2004), lack of child care, sick children, and feeling slow to respond to their children due to the medication's side effects were identified as barriers. Mental health professionals have ignored these issues and often label mothers as non-compliant because of missed appointments. The mothers provided suggestions for improvements that included home support, long term support, groups for mothers/parents with SMI, support for their children that include activities outside of their home, and family friendly facility environments.

In other studies, women with SMI have identified motherhood as a central force (a) keeping them involved with treatment, (b) a key outlet for expression of feelings of care and concern, and (c) a valued, normative social role (Benders-Hadi, Barber, & Alexander, 2013; Carpenter-Song, Holcombe, Torrey, Hipolito, & Peterson, 2014; Montgomery, Tompkins, Forchuk, & French, 2006; Oyserman, Mowbray, Meares, & Firminger, 2000). In a study by Benders-Hadi et al. (2013), 24 mothers in an inpatient large state psychiatric hospital in suburban New York were interviewed to develop an understanding of the characteristics and needs of this population. More than half reported being the primary caretaker of their children. Survey and focus group data revealed how important the role of motherhood was in giving purpose to their lives and helping them remain on track with treatment recommendations. Most of the mothers in this study reported that they did not feel their mental illness had any effect on their ability to be a mother, while others indicated stigma played a role in the presumption that people with SMI will inevitably be bad parents.

In an ethnographic pilot study, Carpenter-Song, Holcombe, Torrey, Hipolito, and Peterson (2014) interviewed three urban, low-income, African-American mothers diagnosed with SMI over the course of a year to document their lived experiences. A small sample size was used in order to achieve an in-depth case study. The findings indicated that the mothers had little to no involvement from the biological fathers. All three of the women rarely discussed their illness and viewed treatment with ambivalence. Most of the discussion involved struggles with everyday life including violence, loss, lack of safety, and financial insecurity. All three women experienced physical and sexual trauma and faced daily strains of financial insecurity. One woman attributed her depression and drug addiction to her traumatic childhood and took medication to combat anxiety attacks brought on by the stresses in her life. Family life was the main focus for the women. These women noted being a mother and the everyday work, worry, and joys of raising children brought meaning to their lives. The women took an active role in their children's upbringing and strived to be a better mother in order for their children to have a better life than they did. All of the women were raising their children with little support from others. Faith in God was a constant source of solace and strength for all of the women in the study (Carpenter-Song et al., 2014). This study highlights the need for family-centered supports, especially when the family has history of violence, deep poverty, and isolation (Carpenter-Song et al., 2014).

Service providers may have yet to realize that the importance of the mother's relationship with their children is a major motivating factor for mothers with SMI (Bassett et al., 1999; Blegen, Hummelvoll, & Severinsson, 2012; Diaz-Caneja & Johnson, 2004). When interviewed, the vast majority of mothers in this study expressed strong positive views about motherhood (Diaz-Caneja & Johnson, 2004). Mothers with SMI indicated that although the struggle with their mental illness depleted their energy and took up their attention, their children's needs for them as mothers were perceived as a powerful motivation to continue the struggle (Blegen, Hummelvoll, & Severinsson, 2012). However, in treatment situations, mothers were obliged to prioritize their mental illness instead of the children's needs for proximity, attachment, and good mental health (Blegen, Hummelvoll, & Severinsson, 2012). This led the mothers trying to balance their own emotional difficulties, needs, and the demands of the treatment against their children's needs in each specific situation (Blegen, Hummelvoll, & Severinsson). Six mothers described having children as a central incentive to recover and remain well, and obtaining the goal of maintaining parental responsibilities motivated the mothers to participate in treatment to prevent relapse (Diaz-Caneja & Johnson).

Although mothers with SMI have identified their children as a central incentive to seek treatment and continue participation in treatment, prevention and strengths based interventions are rare for parents with SMI and their children (Hinden, Biebel, Nicholson, & Mehnert, 2005). Very few programs and services exist that include early intervention and prevention strategies targeted to children of parents with SMI (Craig, 2004; Nicholson & Biebel, 2002). Most training programs for parents, particularly mothers with SMI, target families where the child is either in danger of being placed in foster care or the child is displaying behavior problems (Hinden et al., 2005). Services and interventions designed to help with parenting are more often found in the child welfare sector and are predominantly deficit-based and only made available when children are judged to be "high-risk" for out of home placement (Hinden et al., 2005). Mental health interventions tend to focus on the individual without respect to gender, family context and do not address parenting needs or support for both mother and child (Hinden et al., 2005). In addition, when intervention efforts focus on either the child or the mother outside the home environment, difficulties are likely to arise (Oyserman, Mowbray, & Zemencuk, 1994). Because inpatient psychiatric treatment of a mother disrupts her marital and family relationships, interventions logically should focus on strengthening the family and preventing hospitalization (Oyserman et al., 1994).

Evidence-Based Interventions for Mothers with SMI and their Children

Through a qualitative study of programs for parents with SMI and their children, Nicholson et al. (2007) found that parents with SMI are likely to benefit from multimodal programs that utilize a variety of therapeutic approaches that address various aspects of the individual rather than narrowly defined interventions that address issues of access to essential resources and necessary parenting and illness management skills. In addition, the fact that outcomes for children and families depend on multiple factors suggests there are likely to be many opportunities for improving the well-being and functioning children living with parents with SMI (Nicholson et al.). However, according to Nicholson et al., these opportunities are often missed. Whereas the need is great, there are no evidence-based practices to improve outcomes for these families (Nicholson et al.). Very few empirically tested parenting programs for women with mental illness and their children have been conducted (Nicholson et al., 2007). However, examining existing interventions is increasingly recognized as an important, complementary strategy for establishing evidence-based practices (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Hinden, Biebel, Nicholson, & Mehnert, 2005).

The rationale for the development of an evidence base regarding effective programs for parents with SMI and their children is compelling (Nicholson et al., 2007). Although there has been progress in developing specific intervention strategies to prevent the development of psychopathology in children whose parents have serious mental illness, no programs or interventions for parents with serious mental illness and their children have been rigorously tested (Nicholson et al., 2007). According to Reupert and Maybery (2007), policymakers, researchers, and practitioners need to consider not only the child or the parent with mental illness, but recognize that families affected by parental mental illness require a multifaceted approach that acknowledges all stakeholders, including the child, the parent, the family, the agencies, and society as a whole. This includes cross training of mental health and child protection workers, including a family focus in identification, intervention, and prevention (Reupert & Maybery, 2007). Nicholson et al. (2001) pointed out that many service organizations are fragmented and uncoordinated when it comes to family mental health strategies. Programs tend to focus on the client without considering the client's environment or contextual demands. In addition, program eligibility generally either serves the adult or child with the mental illness, but not the family as a whole (Nicholson et al., 2001).

Family Focused Care

Addressing workers' attitudes, knowledge, and skills in family-focused care can provide a basis from which workers can engage effectively with parents with mental illness and their families (Maybery & Reupert, 2006). It is acknowledged, however, that this basis exists within a larger hierarchy of health care delivery. Foster, O'Brien, and Korhonen (2012) provide a family-focused framework for practice as a 'bottom-up' approach, with the recognition it exists within the context of an overall organizational approach to care. The key element of family-focused care is a philosophy of care, incorporated into practice, which recognizes the uniqueness of each consumer and family member. The family is viewed as a complete entity that includes supporting families in their natural caregiving environments (Foster, O'Brien, & Korhonen, 2012). Family-focused care aims to improve outcomes for the parent with mental illness, reduce the subjective and objective burden of care for families, and provide a preventative and supportive framework for children.

Multiple studies recommend that families affected by parental mental illness receive various foci interventions that acknowledge all stakeholders (Oyserman, Mowbray, & Zemencuk, 1994; Nicholson & Henry, 2003; Nicholson, 2007; Reupert & Maybery, 2007; Nicholson, Albert, Gershenson, Williams, & Biebel, 2009). The scarcity of high-specificity interventions in contrast to the high prevalence rate indicate most parents with mental illness and their families are either served by less parent-specific interventions or meet their needs by "stringing together" an uncoordinated and nonspecific array of services (Hinden et al., 2006 p. 36). Steps need to be taken in order to develop a broad array of parent and child-specific intervention strategies that provide a detailed framework for a family focused approach. An initial first step should include a focus on the enhancement of existing evidence-based services that have been proven effective.

Peer Support for Mothers with SMI and their Children

A model of care that has received much attention in the past decade is the evidence-based peer support specialist model (Bond et al., 2001; Mowbray, Moxley, Jasper, & Howell, 1997; Salzer, 2010; Salzer & Mental Health Association of Southeastern Pennsylvania, 2002; Salzer & Shear, 2002; Salzer, 2013). Peer support specialists are persons with mental health conditions who have completed specific training that enables them to enhance a person's wellness and recovery by providing peer support (National Coalition for Mental Health Recovery, 2014). Peer support specialists (PSS) can work in a variety of locations, including peer support centers, crisis stabilization units, respite programs, psychiatric hospitals, and community day rehabilitation programs (National Coalition for Mental Health Recovery, 2014). Peer support can be provided as a one on one service or in a group setting where consumers can share together in an open forum (National Coalition for Mental Health Recovery, 2014).

The effectiveness of peer support is well documented in numerous studies (Bologna & Pulice, 2011; Bouchard,

Montreuil, & Gros, 2010; Davidson, Bellamy, Guy, & Miller, 2012; Gillard, Edwards, Gibson, Owen, & Wright, 2013; Walker & Bryant, 2013). In 2007, Dennis Smith, Director of the Centers for Medicare and Medicaid Services, explained in a letter to all state Medicaid agency directors that peer support service is an evidence-based mental health model of care that consists of qualified peer support providers who assist individuals in their recovery from mental illness and substance use disorders. As a direct result, state Medicaid agencies started allowing reimbursement for peer support services, which provided the opportunity for certified Peer Specialist (CPS) training programs to be developed around the country (Katz & Salzer, 2007).
Because of its documented effectiveness, certified peer support specialists are a growing behavioral workforce that is essential in recovery-oriented environments (Salzer, 2010). The concept of Family and Youth Peer Support Specialist training and certification is an emerging concept and strategy for supporting parents with a child with a serious emotional disturbance (SED) as well as young adults with mental illness (Center for Health Care Strategies, 2013). The National Federation of Families for Children's Mental Health and family run organizations have been strong proponents of the benefits of family and youth peer support for many years, advocating for the recognition and funding of these services through state and federal dollars, and their inclusion and sustainability as part of the broader array of children's services funded through Medicaid (Center for Health Care Strategies, 2013). Specific steps have been taken to develop a national certification process to train parents who have a child with SED as parent peer providers (The National Federation of Families for Children's Mental Health, 2014). In 2009 and 2010, The National Federation of Families for Children's Mental Health collaborated with family organizations, researchers, and treatment providers to collect and organize information about the role of parent support services in Systems of Care and other settings (The National Federation of Families for Children's Mental Health, 2014). As a result, the Certification Commission for Family Support was created within the National Federation of Families for Children's Mental Health. The Certified Parent Support Provider certification defines the uniform standards and title of parents helping other parents who have children (ages birth to 26) experiencing emotional, behavioral health, substance use, intellectual disabilities, or mental health concerns. The Certified Parent Support Provider program is a unique step in developing and implementing specialized peer support services that focus on specific populations. This specific certification program, however, has not been expanded to include PSS certification for parents diagnosed with a mental illness.

Although it has been concluded that while peer support services appear to have become an addition to mental health services, and peer support is considered an important component of mental health care, peer support is under-researched as a service aimed at specific subsets of individuals with mental illness. Multiple studies identify the need for parent peer support programs as a key service for parents with mental illness (Bassett et al., 1999; Diaz-Caneja & Johnson, 2004; Perera, Short, & Ferncacher, 2014; Nicholson, Biebel, Hinden, Henry, & Stier, 2001). This knowledge, however, has not led to the development of specialized peer support services that link peer support specialists who are parents with other parents with mental illness in need of support. It is not known whether being a parent is an important demographic element when pairing peer specialists with consumers in need of peer support services. It is also not yet known what the essential components would be when delivering a peer support program to parents with SMI who are caring for their children.

The purpose of this study is to survey peer support specialist's perspectives of specific life stressors and program and service needs for parents with a mental illness who receive services from peer support specialists. This study examines the most frequently identified life stressors and the level of importance for specialized program and services for parents with a mental illness from a peer support specialist perspective. This information may provide background information to help determine whether the parental status of peer support specialists is important demographic information in determining the types of life stressors and program and service needs for parents with mental illness.

Method

Procedure

Survey methodology was used to collect demographic information and perception-related information. Two methods were used to obtain participant data after IRB approval. The first method utilized an email distribution list asking participants to complete the survey by clicking a link within the body of the email. An informational email with the survey link was sent to the Alabama Department of Mental Health's Director of Consumer Relations for approval. The Director of Consumer Relations sent the mass distribution email to the 133 existing mental health peer support specialists who are currently trained and certified. Participants were asked in the email to participate in a voluntary, self-directed online survey. Participants were informed it should take approximately 10 to 15 minutes to complete the survey. Once the participant clicked on the link included at the bottom of the email invitation, the participant was taken to the Information Page for participation in the study. On the informational page participants were made aware that their participation was completely voluntary and all data collected will be anonymous. Participants were made aware that they could quit the survey at any time with no consequences to them or their relationship to the Alabama Department of Mental Health, their employer, or Auburn University. No identifying information (name, address, or telephone number) was collected. If the participant agreed to participate after reading the Informed Consent information, the participant clicked on the "Agree to Participate" link and was taken to the first page of the survey. For follow up to non-respondents, a reminder mass distribution email was re-sent to the certified peer support specialists via the Director of Consumer Relations. Certified peer support specialists were encouraged to participate in the survey if they had not already done so on day 10 after the survey was launched. The second follow up occurred on day 15 and the third and last follow up occurred on day 20 from the date of the original email. The follow up emails included a thank you statement for those who had completed the survey and an encouraging reminder for those who had not completed the survey. After the conclusion of 30 days, the researcher closed the survey. A total of 26 participants responded to the email requests for participation.

The second method to obtain participant data included distributing a paper version of the survey during regularly scheduled in-person training for certified peer support specialists. The first author read the information letter and invitation script in person to the certified peer support specialists participating in the required peer specialist quarterly continuing education training in Clanton, Alabama, at the Alabama Power Conference Center. The researcher asked that anyone who had not already taken the online version of the survey and who wished to volunteer to participate to raise their hand to receive a paper version of the survey. Of the 72 attendees, 25 volunteered to participate. A manila envelope at the front of the room was provided for participants to insert their completed survey form. Of the 133 existing certified peer support specialists in Alabama, a total of 51 certified peer support specialists completed the survey, yielding a 39% response rate. Eight forms were incomplete and provided no usable information. Therefore, usable data was collected from 44 participants, which resulted in a 33% return rate.

Participants

Participants for this study were individuals with mental illness who currently serve as peer support specialists in Alabama. Participants were males and females who were at least 19 years of age and employed part-time or full-time as a certified peer support specialist. A total of 133 certified peer support specialists were recruited to participate. These 133 comprised the population of peer support specialists trained and certified as a peer support specialist at the present time in Alabama.

Instrumentation

Participants in this study were invited to complete a survey form developed by the first author to collect demographic information and information related to the perceptions of the peer support specialist. Survey questions included (1) general demographic information, such as gender, race, and age group, (2) the number of consumers who received peer support services within the previous two weeks, (3) the amount of time spent with an individual providing peer support service, (4) whether peer support services are being provided to consumers who are parents or non-parents, (5) the number of consumers who are parents served per week, including the number of single mothers and fathers currently caring for their children, (6) type(s) of life stressor(s) for consumers who are parents and for consumers who are not parents, (7) and types of specialized services/programs needed, but not available for consumers currently receiving peer support. Open-ended questions included (1) ways that consumers are identified to receive peer support services, (2) barriers to receiving peer support service, (3) the greatest service/program need for consumers who are parents, and (4) the most underserved group of individuals with serious mental illness needing peer support services and supports. All open-ended questions provided space on the survey form for participants to write their responses. Sample survey questions include 1.) What do you consider to be the NUMBER ONE greatest service/program need for other consumers who are parents? (Please identify only one specific service/program) 2.) On a scale of 1 to 10, with 10 being the highest need and 1 being the lowest need, how would you rank the service need for the following specialized services? 3.) For parents with serious mental illness, what are the most common type(s) of life stressor(s) for which you provide the most peer support service? 4.) In your opinion, how important would it be to have specialized peer support for peer support specialists who are parents of a child with mental illness assisting other parents with a child with a mental illness?

The level of need for specialized services was assessed using a Likert-type scale with values ranging from 1 to 10, with 10 indicating the highest need and 1 indicating the lowest need. The types of services being assessed included (1) parents with mental illness support groups, (2) peer meet-up groups for socializing and recreation activities, (3) support groups for children of a parent with mental illness.

Responses to determine the importance of specialized peer support services were measured using a three-point Likert-type scale, with values ranging from one to three with one being not important, two being somewhat important, and three being very important. Types of specialized peer support services included (1) peer support based on age, (2) peer support based on parental status, (3) peer support based on having one or more children with a mental illness, and (4) peer support based on having a parent with a mental illness.

Instrument validity was established by a panel of experts which included the Consumer Relations Director for the Alabama Department of Mental Health, the Coordinator of Adult Mental Illness Services for the Alabama Department of Mental Health, two community mental health executive directors, and a researcher. The panel of experts established content validity to assure that the instrument was clear and understandable and items were representative of items to identify life stressors and program and service needs.

Results

Demographics

Of the 44 included in the analyses, 26 (59%) were female, 17 (38.6%) were male, and one did not indicate a gender identity. The most noted age group was 46-55 (n=17; 39%). Five individuals (11%) ranged from 25-35 years of age and 14 (32%) were age 56 or older. For race, 25 (57%) were White and 17 (38.6%) were African-American. For marital status, 15 (34%) were divorced, which ranked the highest. Thirteen (30%) were legally married and 11 (25%) never married. For parental status, 31 (71%) were parents and 13 (29%) were not parents. The majority of parents had either one (23%) or two (25%) children and only one (2%) had five or more children. The demographic data are reflected in Table 1.

Table 1 *Demographic Characteristics of Peer Support Specialists*

Variables	(n)	Percent
Gender		
Male	17	39
Female	26	59
Race		

White	25	57
African American	17	39
Others	2	4
Age		
18-24	0	0
25-35	5	11
36-45	8	18
46-55	17	39
56+	14	32
Marital Status		
Legally Married	13	30
Divorced	15	34
Never Married	11	25
Others	4	11
Parental Status		
Parent	31	71
Non-Parent	13	29

The employment status of the participants was almost evenly distributed with 21 (48%) working full-time and 23 (52%) working part-time. For those working part time, participant hours worked per week were evenly distributed and represented a wide range of hours (2-30) worked. For current place of employment, the majority of participants (n=21) worked for a public community mental health center (48%) and 16 (36%) indicated "other". Places of employment for "other" included group homes, non-profit organizations, and urgent care clinics. For type of programs the participant served, 14 (32%) indicated residential, 12 (27%) outpatient, and 10 (23%) community day treatment. Twenty-two (50%) also indicated the "other" category. Some of the program examples indicated for the "other" category included intensive outpatient, crisis hotline, and homeless outreach. Employment data are reflected in Table 2.

Table 2 *Employment Characteristics of Peer Support Specialists*

Variables	(n)	Percent
Employment Status		
Part-time	23	52
Full-time	21	48
Place of Employment		
	21	48

Community mental health center	16	36
Other		
Types of Programs Served		
Residential	14	32
Outpatient	12	27
Community day treatment	10	23
Other	22	50

The number of consumers served by the participants within the past two weeks ranged from 0 to 150 and was equally distributed. The average amount of time spent providing services to a consumer ranged from 0-10 minutes (n=3; 7%) to more than two hours (n=11; 25%). The majority of participants (n=30; 73%) spent between 30 minutes to more than two hours with an individual providing peer support services. Of the 44 participants, 36 (82%) stated that they provided peer support services to parents with a mental illness, and five (11%) stated the parental status was unknown. Of the parents served, 14 (32%) participants stated they served single mothers currently caring for their children and 11 (25%) stated unknown. Fourteen (32%) stated that they served single fathers currently caring for their children and 10 (23%) stated unknown. Parental status of consumers served by peer support specialists are reflected in Table 3.

Table 3 *Parental Status of Consumers Served by Peer Support Specialists*

Variables	(n)	Percent
Parental Status of Consumers Served		
Parents Served - Yes	36	82
Parents Served - Unknown	5	11
Single Mothers		
Single Mothers Served - Yes	14	32
Single Mothers Served - Unknown	11	25
Single Fathers		
Single Fathers Served - Yes	14	32
Single Fathers Served - Unknown	10	23

Level of Need for Specialized Services and Programs

The category of highest need was support groups/programs for children of a parent with a mental illness with a mean of 8.76 and standard deviation of 2.07; the maximum score was 10 and the minimum score was 2. The category with the second highest need was support groups for parents with a mental illness with a mean of 8.55 and standard deviation of 2.13; the maximum score 10 and the minimum score was 3. The categories with the lowest need both had a mean of 8.0. These categories were peer groups for socializing and recreation (SD=2.63) and money management/financial planning classes (SD=2.40); the maximum score for both groups was 10 and the minimum score was 1. The level of need data are reflected in Table 4.

Table 4 *Level of Need for Specialized Services and Programs*

Variables	N	Mean*	Standard Deviation
Support groups/programs for children of a parent with a mental illness	38	8.76	2.07
Support groups for parents with a mental illness	38	8.55	2.13
Peer groups for socializing and recreation	38	8.0	2.63
Money management and financial planning	38	8.0	2.40

* Minimum score two and maximum score 10.

Most Frequently Identified Life Stressors for Parents with Mental Illness

The life stressors listed most often for parents included housing (n=26; 59%), depression (n=22; 50%), anxiousness (n=21; 48%), feelings of hopelessness (n=20; 45%), and employment issues (n=19; 43%). For life stressors specific to parents, parenting skills (n=14; 32%), concerns about their children (n=12; 27%), and custody issues (n=12; 27%) were not listed as the most common life stressors. Life stressors are reflected in Table 5.

Table 5 *Most Common Life Stressors for both Parents with a Mental Illness*

Types of Life Stressors	(n)	Percent
Housing	26	59

Depression	22	50
Anxiousness	21	48
Feelings of hopelessness	20	45
Employment issues	19	43
Parenting skills	14	32
Concerns about their children	12	27
Custody issues	12	27

Level of Importance for Specialized Services Needed

The specialized service ranked as the highest need was family support groups for parents and their children, with 16 (36%) participants ranking it first. For parenting classes, 19 (43%) participants ranked this service as the lowest need compared to conflict management classes and family support groups. The level of importance for three specific specialized services is reflected in Table 6.

Table 6 *Level of Importance for Specialized Services Needed but Not Available*

Types of Services and Programs	Highest Importance (n)	Highest Importance Percent	Lowest Importance (n)	Lowest Importance Percent
Conflict management	12	35	9	21
Parenting classes	6	18	19	43
Family support groups for parents and their children	16	46	6	14

Level of Importance for Specialized Peer Support Services

Specialized peer support consumer preferences based on characteristics of the peer support specialist included

(1) parents assisting other parents with a mental illness, (2) adolescents/young adults of a parent with a mental illness assisting other adolescents/young adults of a parent with a mental illness, (3) parents of a child with a mental illness assisting other parents of a child with a mental illness, and (4) mutual age of the peer specialist and consumer being served. Of the four peer support consumer preferences, mutual age of the peer specialist and consumer being served received the lowest number of ratings, with 22 (50%) participants rating the service as very important. Twenty-eight (62%) participants rated parents assisting other parents with a mental illness as very important. A close second, 27 (61%) of the participants rated adolescents/young adults of a parent with a mental illness assisting other adolescents/young adults of a parent with a mental illness as very important. For parents of a child with a mental illness assisting other parents of a child with a mental illness, 25 (57%) rated this service as very important. Very few participants (0 to 3; 7%), rated any of the specialized services as not important. The level of importance for specialized peer support consumer preferences is reflected in Table 7.

Table 7 *Level of Importance for Peer Support Consumer Preferences*

Mutual Characteristic of the Peer Specialist and Consumer being Served	Very Important (n)	Very Important Percent	Somewhat Important (n)	Somewhat Important Percent	Not Im (n
Parent with a mental illness	28	64	9	24	
Adolescent/young adult of a parent with a mental illness	27	61	11	29	
Parent of a child with a mental illness	25	57	10	23	
Age	22	50	13	34	

Barriers to Receiving Peer Support Service

This research question provided participants the opportunity to write their response to identify the biggest barriers to receiving peer support service. The main themes included lack of knowledge about peer services (n=7; 16%), lack of funds/non-billable service (n=7; 16%), lack of professional support (n=6; 11%), lack of time to serve consumers due to the limited number of peer specialists available (n=5; 9%), lack of employment opportunities for peer specialists (n=3; 7%), lack of transportation (n=2; 5%), lack of consumer willingness to receive peer services (n=2; 5%), and lack of access to peer services (n=2; 5%). The most common barriers to receiving peer support service are reflected in Table 8.

Table 8 *Most Common Barriers to Receiving Peer Support Service*

Group	(n)	Percent
Lack of knowledge about peer services	7	16
Lack of funds/non-billable service	7	16
Lack of professional support	6	11
Lack of time due to limited number of peer specialists	5	9
Lack of employment opportunities for peer specialists	3	7
Lack of transportation	2	5
Lack of consumer willingness to receive peer support services	2	5
Lack of access to peer support services	2	5

Discussion

Implications of the Findings

In this study, demographic factors were assessed for Peer Support Specialists currently employed full-time or part-time in Alabama. For gender and race, participants reflected the demographic characteristics of the overall population in Alabama, but were divorced at a higher rate (34%) than the general population (11%) in Alabama. For parental status, 71 percent were parents. This finding correlates with previous research which indicated 68 percent of women with a serious mental illness are mothers and 57 percent of men with a serious mental illness are fathers (Nicholson, Biebel, Katz-Leavy, & Williams, 2004).

In regards to employment, participants worked in a variety of settings including residential, outpatient treatment, community day treatment, and psychiatric hospitals and served individuals in both a one on one service and in a group setting. The location, types of programs served, and the number of individuals served reflect the finding of previous research (National Coalition for Mental Health Recovery, 2014).

Because it was unknown whether parents were currently being served by peer support specialists, it was important to determine a baseline for the number of parents currently receiving peer support service. Participants were asked to indicate the number of mothers and fathers served within the past two weeks in order to have a reasonable time frame for recollection. Of the 44 participants, thirty six (82%) stated that they provided peer support services to parents with a mental illness. Because it is now known parents are being served by a majority of peer support specialists, this information provides a framework for future in-depth studies relating specifically to parents currently receiving or needing peer support services.

The level of need was assessed using a Likert-type scale with 1 indicating the lowest need and 10 the highest need. Of the six different categories of specialized services and programs, participants rated support groups/programs for children of a parent with mental illness the highest with a mean of 8.76. This finding validates the need for specialized programs and services for children of a parent with mental illness as indicated in previous research. Adult children described growing up with a parent with a serious mental illness as being uncertain of what will happen next, struggling to connect, feeling different from other children, and feeling lonely (Foster, 2010). The findings from Riebschleger (2004) also emphasized the need for increased family-based services that include psychoeducation and emotional support. An additional study provided feedback from parents diagnosed with a mental illness regarding psychoeducational program content for their children. The parents recommended including learning about mental illness as a disease or real illness, including symptoms, medications needed to manage the illness, and the ability to be active in recovery. Parents also emphasized the need for their children to be aware of when to ask for help, be knowledgeable about inaccurate stigmatized beliefs, how to respond to stigma situations, and how to develop positive coping skills (Riebschleger, Onaga, Tableman, & Bybee, 2014).

Support groups for parents with a mental illness received the second highest level of need for specialized programs and services with a mean of 8.55. Because participants were individuals with a mental illness, with a large majority being a parent, this finding also validates previous research indicating the need for programs for parents with mental illness that allow parents with a mental illness to meet and share information with other parents with a mental illness (Bassett et al., 1999). As indicated by Maybery and Reupert (2006), parents with mental illness need a venue to receive support from their peers in order to alleviate current barriers identified by mental health professionals when responding to individuals with mental illness and their children. In addition, single mothers with mental illness may not have the family support they need, which in turn, may require them to seek social support and understanding from peers (Perera, Short, & Fernbacher, 2014). Nicholson, Biebel, Hinden, Henry, & Stier (2001) recommended peer supports for parents because parents with mental illness may have issues, concerns, and fears when it comes to parenting. Providing peer support groups, parent peer specialists, and parenting training can help alleviate many of the issues parents currently face alone without any supports. Nicholson, Biebel, Hinden, Henry, & Stier (2001) also recommend a 24 hour warm lines for parents to call when an issue or crisis arises, along with web chat rooms, Facebook pages, Twitter, and case management via text.

The most frequently identified internal life stressors for parents included depression, anxiety, and feelings of hopelessness. The internal feelings of depression, anxiety, and feelings of hopelessness are discussed in previous research where mothers with mental illness expressed distress, lack of confidence, and feeling ostracized due to the stigma of mental illness (Bassett et al., 1999).

For external life stressors, housing and employment issues are the most common for parents with mental illness. Both housing and employment are basic life needs that are necessary for personal safety, security, and continued recovery. For children of a parent with a mental illness, the main cause of maladaptation is not necessarily parental mental illness. The risk for problems in adaptation is more often associated with diminished family financial resources and increased familial stress (Tebes et al., 2001). Therefore, housing and employment are life stressors that must be addressed for individuals with a mental illness and their families in order to avoid increased internal stressors, adjustment problems, and vulnerability within the family.

The level of importance for three specific services, conflict management, parenting classes, and family support groups for parents and their children, were ranked from 1 being the lowest importance to 3 being the highest importance. Family support groups for parents and their children ranked as being the most important (n=16; 46%) and parenting skills ranked as being the least important (n=19; 43%). The ranking of family support groups as the highest importance also correlates with the findings in research question number 2, which identified support groups for children and parents as the highest need.

The level of importance placed on parenting skills may be associated with the fact that the majority of participants, who are both consumers and parents, may not view parenting skills as a need for either those they serve or themselves. Because they have similar characteristics to those they serve, it may be difficult to be unbiased or objective when determining the importance of services. The term parenting skills may be viewed negatively by parents with mental illness as it may indicate a lack of ability to be an effective parent. This possibility needs to be explored further as research indicates parents with mental illness often feel ridiculed and viewed as permanently flawed and incapable of being an adequate parent (Fox, 1999). In addition, parenting skills may not in fact be needed to the level other services are needed because it could be an assumed need based on professional bias.

The question as to whether peer support services need to be developed based on specific mutual characteristics of the peer support specialist and consumer being served has been raised in recent years. It was unknown as to whether peer support specialists themselves viewed common mutual characteristics as an important factor when pairing someone for peer support services. This research question addresses whether peer support specialists view certain mutual characteristics as very important, somewhat important, or not important. Of the six identified mutual characteristics, peer support specialists ranked each one as very important over 50 percent of the time. The mutual characteristic receiving very important the most frequently was a parent with mental illness assisting others parents with a mental illness (n=28; 64%), with adolescents/young adults of a parent with mental illness assisting other adolescents/young adults of a parent with mental illness as a close second (n=27; 61%). These findings indicate a need for peer support specialists to be paired with individuals based on mutual characteristics of parental status as much as possible or feasible. The findings also indicate a need to develop specialized support programs for youth/young adults who have a parent with a mental illness. Currently, mental health services are provided to the individual with the mental illness and fail to address the needs of the whole family. This finding further validates the need for additional research to be advanced in order for specific services to be developed for the youth/young adults of parents with a mental illness.

In regards to the biggest barriers to receive peer support service, the main themes included lack of knowledge about peer services, lack of funds/non-billable service, lack of time to serve consumers due to the limited number of peer specialists available, lack of professional support, lack of employment opportunities for peer specialists, lack of transportation, lack of consumer willingness to receive peer services, and lack of access to peer services. Based on the main themes identified by the participants, it is evident more outreach and education is needed to inform individuals with mental illness about peer support services. Without adequate information and knowledge about peer support services, the effectiveness of the program becomes greatly diminished. In addition, the lack of funding greatly reduces the availability of peer support specialists and impacts the time spent with individuals needing peer support services. Policy change needs to occur at the state Medicaid level to incorporate peer support services as a billable service in order for peer support services to be available to an individual when needed.

Another theme that needs attention is the perceived lack of professional support. Training and advocacy efforts that emphasize the value of peer support services must target professionals in all systems and domains. Because stigma by mental health professionals is documented through research in numerous countries (Courtis, Lauber, Costa, & Cattapan-Ludewig, 2008; Hugo, 2001; Lauber, Nordt, Braunschweig, & Rossler, 2006; Lepping, Steinert, Gebhardt, & Rottgers, 2004; Rao, Pillay, Abraham, & Luty, 2009), it is imperative that leaders in the mental health field develop mechanisms to alleviate professional bias towards coworkers diagnosed with a mental illness. Peer support specialists need to be able to work in an environment where they feel valued as a colleague and not separated or isolated from other employees based on stigma or social hierarchies.

Limitations

The results of the current study are not without limitations. One limitation was the sample size even though a 33% return rate is notable. The sample was limited to peer support specialists currently certified in Alabama who are either employed full or part-time. Results from this study may have been different if peer support specialists from other states or countries were included in this study along with peer support specialists who are not currently employed. In addition, participants chose to answer the questions on the survey based on self-selection. Individuals who did not participate in this study may have produced different results. Because the sample size for participants was small, additional data analyses could not be conducted in order to compare the viewpoints of parents and non-parents or other subgroups.

A second limitation to the study included the accuracy of the data. Although the study was administered online and in-person, the results from the participants' responses depended upon honest answers. Participants also could have answered the questions in a way that would be viewed as pleasing to the researcher. Also, participants may have had selective memory and were unable to remember all of their interactions with individuals they served. For the participants who took the survey in-person, fatigue could have played a factor due to the participants completing the survey immediately after participating in training during the morning hours and eating lunch. In addition, the results were dependent upon whether the respondents understood the questions and that the questions reflected the life stressors and program and service needs of individuals with mental illness. Lastly, bias could have played a part due to the fact the participants also had a mental illness and were asked to determine the needs of individuals with a mental illness that they served. Participants also may have self-selected to participate based on the topic of the survey, which could have skewed the results.

A third limitation to the study included time constraints. The study was open for a period of one month and the results reflected the perceptions of the participants at a particular point in time. Additional research is needed at different points in time to address this limitation. Lastly, the questions on the survey were limited in order for the survey to be completed within a reasonable time frame. All possible answers were not accounted for which adds rigidity to the survey instrument. Additional questions regarding parents with a mental illness and their children need to be explored further and different methods of asking the questions need to be developed.

Recommendations for Future Research and Practice

The research for this study focused on certified peer support specialists currently employed full or part-time in Alabama. The focus of this study was to obtain demographic and perception related information to determine the life stressors and program and service needs of both parents and non-parents with a mental illness from a peer support specialist perspective.

The study was designed so it could be replicated with other peer support specialists in other environments. Although the peer support specialist program is a nationally recognized evidence-based practice, the research is very limited on identifying the program and service needs of parents and non-parents with mental illness from a peer support specialist perspective, therefore, additional research is needed to obtain the perspectives, ideas, suggestions, and opinions of peer support specialists as it relates to parenting needs of individuals with mental illness and their children. Peer support specialists provide unique insight because they are peers with a mental illness who also function as a service provider. Findings from this research study indicate that peer support specialists spend more time with an individual with a mental illness than traditional service providers. This allows both the peer support specialist and the individual receiving service to develop rapport, trust, and a sense of comradery that parents with mental illness have reported as difficult to develop with traditional mental health providers (Diaz-Caneja & Johnson, 2004; Fox, 2009; Montgomery et al., 2006)

The results of this study also identified parental status of the peer support specialist as an important demographic factor when pairing parents with mental illness with peer support specialists. Therefore, a peer support provider program specific to parents and children of parents with a mental illness is both needed and warranted. The results of this study also identified additional barriers, life stressors, and groups who need peer support services. Additional research is needed to explore these findings in greater detail in order to develop specific methods to address these concerns. With a continued focus on identifying the needs of parents and non-parents with a mental illness, researchers, practitioners, and administrators will gain additional insight into the issues surrounding individuals with mental illness and develop innovative mental health services that should be incorporated into the current mental health service delivery system.

Recommendations and Conclusions

Given the findings of this study, the following recommendations are summarized below.

1. Medicaid and private insurance payment models need to be restructured to support both the individual with a mental illness and their immediate family. Based on the findings of this study, participants rated support services for children of parents with mental illness as the highest need and highest level of importance over other types of specialized programs and services. The current payment structure for Medicaid and other types of insurance reimbursement does not allow for the entire family unit to receive services and supports. Children of parents with mental illness are rarely identified as needing additional supports and services. This is in spite of the fact that numerous studies indicate otherwise (Aldridge, 2006; Aldridge & Becker, 2003; Hinden, Biebel, Nicholson, & Mehnert, 2005; Mowbray, Bybee, Oyserman, Allen-Meares, MacFarlane, & Hart-Johnson, 2004). Family support should be a reimbursable service for mother, child, spouse, parents, and siblings. Although individualized treatment may take into account the parent's treatment needs, it rarely addresses other issues important to her or him, including their children and how they are adapting to their parent's illness, how well they are coping, worries about custody or ridicule from neighbors, financial worries, lack of emotional support, inadequate housing, and lack of transportation. Therefore, family services must be incorporated into the current billing structure for mental health treatment.

2. Medicaid and private insurance payment models need to be restructured to ensure peer support models are a billable service. Based on the findings of this study, participants stated lack of funding for peer support services is a main barrier to receiving peer support services. The Peer Support Specialist Service Model is an evidence-based practice that has been proven effective in multiple studies. As with the Assertive Community Treatment Model, which is billable through the Medicaid Rehabilitation option and focuses on consistent, caring, person-centered relationships that have positive effects upon outcomes and quality of life, the Peer Support Specialist Service Model must also be included as a billable service. As stated in previous research, the Centers for Medicare and Medicaid Services recognized peer support service as an evidence-based mental health model of care that consists of qualified peer support providers who assist individuals in their recovery from mental illness and substance use disorders. As a direct result, state Medicaid agencies started allowing reimbursement for peer support services, which provided the opportunity for certified Peer Specialist (CPS) training programs to be developed around the country (Katz & Salzer, 2007). However, this reimbursement option is currently not mandatory or required in state Medicaid plans. Without the ability for providers to bill for peer support services, it will remain difficult for individuals with mental illness, which includes parents with mental illness, to access peer support service as part of their continuum of care.

3. Current treatment models should be reevaluated and enhanced to address the specific needs of parents with mental illness and their children. The findings of this study indicate a need for additional programs and support services for parents with mental illness and their children. Although current treatment models like Assertive Community Treatment have been proven to be very effective keeping individuals out of the hospital and stable in the community, priority populations have not included individuals who are the sole caretaker for their

children (White & McGrew, 2013). Priority populations for these services are typically single males with a recurring history of inpatient hospitalization. However, the family unit is highly vulnerable and in need of additional attention from mental health providers (White & McGrew, 2013). Mental health services currently focus solely on the individual with a mental illness, but fail to recognize the importance of proactively addressing the psychological, emotional, and cognitive impacts of mental illness on immediate family members. Children and youth are especially vulnerable to the impacts of mental illness on the parent because the child is dependent on the parent for stability, support, and emotional and physical care. Therefore, children and youth of a parent with a mental illness, and in particular, children living with a single parent with a mental illness, must be included in the list of those considered a high priority for access to mental health services and supports. As stated by Nicholson et al. (2001), current standardized programs, services, interventions, and treatment protocols must be studied and revised to overcome system-induced barriers to service utilization and treatment effectiveness. As services are coordinated, service professionals must review inter-agency agreements, MOUs, and vendor contracts to include language and expectations for family-centered, strengths-based care for parents with mental illness and their children. Replication of effective models and innovative programs including psychosocial rehabilitation strategies, Assertive Community Treatment (ACT) teams, expansion of Programs for Assertive Community Treatment (PACT), and peer support specialists, should be applied to the domain of parenting (Nicholson et al., 2001).

4. Specialized peer support programs need to be developed for parents with mental illness, with emphasis on single mothers caring for their children. Participants in this study rated support groups/programs for parents and their children as the highest need. Parents with a mental illness, especially single mothers who are caring for their children, are particularly vulnerable to social isolation, stress, financial hardship, and lack of resources (Reupert & Maybery, 2007; Beardslee, Versage, & Gladstone, 1998). Because of these vulnerabilities, single mothers with a mental illness and their children should be considered a high-risk group in need of more intensive and more frequent mental health supports. This high-risk group needs to have access to peer support service, which should be considered an essential service in their mental health care continuum. Multiple studies have reiterated the need for parent and child specific interventions that are part of a wide array of family-focused modalities (Nicholson et al., 2007; Hinden, Biebel, Nicholson, & Mehnert, 2005; Riebschleger, 2004; Mowbray, 1995). Therefore, peer support services for parents and their children is one specific intervention that should be included in a family-oriented model of mental health care.

5. Self-analysis of pre-existing stigmas and bias must be brought to the forefront for discussion for those in training to become mental health professionals and for those currently practicing in the mental health/rehabilitation field. Education on gender differences and parenting needs should also be integrated within rehabilitation and counseling courses. Participants in this study rated lack of professional support as a main barrier to receiving peer support services. Therefore, professionals at every level, including administrators and practitioners, need ongoing professional education that includes information that addresses stigma and bias within the counseling/mental health field. There is also a specific need for increased awareness on the topic of parenting, because it is a significant treatment and rehabilitation issue for women with mental illness (Diaz-Caneja & Johnson, 2004). In addition, the mental health profession remains steeped in the Medical Model, where the individual is automatically placed in a devalued group that society often considers worth much less than someone without a disability (Smart, 2009). The Medical Model ignores the individual's role function and environmental demands and automatically assumes the person with a mental illness cannot equally contribute to society or be a functioning and successful parent who can live a meaningful life (Smart, 2009). The mental health professional must move from a Medical Model mentality to a Social/Empowerment Model of disability.

6. Technology (i.e. text messages, Facebook, online support groups, webchats) should be utilized to expand and enhance support services for mothers/parents with mental illness and their children, which includes training for families on technology utilization. Because this study emphasized the need for additional programs and supports for parents with mental illness and their children, additional tools should be developed that are cost-efficient and easily accessible. Some of the most inexpensive but effective resources are now connected to

technology. Social media strategies like peer networking, blogs, on-line support groups, twitter, and text messaging are quickly becoming common tools for communication with family, friends, co-workers, and other professional groups. Not only is it necessary to develop in-person support groups for parents and their children, it is also necessary to develop alternate means of support so parents and their children can access from home or away from the treatment center. Having the alternate means of support increases the likelihood that the support services will be accessed and utilized (Foster, O'Brien, & Korhonen, 2012; Diaz-Caneja & Johnson, 2004).

7. Additional research is needed in order to increase the knowledge base for effective interventions and support services for parents with mental illness and their children. Currently, there is a lack of research into the needs of parents with mental illness and their children from a peer support specialist perspective. In addition, there are few studies that adequately research effective interventions and support services for parents with mental illness and their children (Nicholson et al., 2007). Researchers in the field of mental health must acknowledge the need for the development of evidence-based practices for this population group (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Hinden, Biebel, Nicholson, & Mehnert, 2005). In order for mental health professionals to have access to evidence-based practices for parents with mental illness and their children, there must be a recognized need and desire for additional research that identifies what type of services and supports are most effective.

8. Agencies must provide parents with mental illness and their families with the training and support needed to be effective advocates for systems change. Advocacy has been the cornerstone for change in the public mental health system in this country. Conditions and services have been significantly improved because of advocacy and litigation of concerned individuals who would no longer accept injustice. With the strategic efforts of engaged advocates, a low priority can quickly become one of the highest priorities. Unless parents with mental illness and their children demand services to meet their needs, it is unlikely change will happen quickly, if ever. Therefore, there must be continued advocacy from various fronts that demand parents and children receive equal treatment that meets their specific needs.

Conclusion

This study examined the perceived program and service needs for parents with serious mental illness from certified peer support specialists' perspectives. Results of this study indicated that peer support specialists are currently serving parents with a mental illness in Alabama. Participants rated support groups/programs for children of a parent with mental illness and support groups for parents with a mental illness as the two programs with the highest levels of need. The most frequently identified internal life stressors for parents with a serious mental illness included depression, anxiety, feelings of hopelessness. The most frequently identified external life stressors included the need for housing and employment. Results of the study also found pairing individuals based on mutual characteristics of parental status and the identification of having a parent with a mental illness as very important. The biggest barriers to receiving peer support services included lack of knowledge, funding, time, and professional support.

The results of this research on identifying the life stressors and program and service needs for parents with a serious mental illness from a peer support provider perspective indicates that specific programs are warranted that are currently not available. Some of these programs include support groups for parents with mental illness and support groups for youth/young adults with a parent with a mental illness. Future research is needed to explore parenting needs in depth from a peer support specialist perspective and to further investigate the specific service barriers identified, which prevent individuals from receiving the benefits of peer support service.

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