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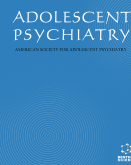
The Sibling Support Demonstration Project: A Pilot Study Assessing Feasibility, Preliminary Effectiveness, and Participant Satisfaction

BENTHAM SCIENCE

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Abstract: ***Background***: The hospitalization of a child on an inpatient psychiatric unit is traumatic for the entire family, but few services address the needs of their siblings and caregivers.

Objective: This pilot study aimed to demonstrate the feasibility and potential benefits of implementing psycho-educational and support groups for caregivers and siblings of children and adolescents admitted to psychiatric units. The primary aim of this intervention was to increase sibling resiliency and reduce trauma experienced by families.

Method: A total of 145 siblings and 196 caregivers participated in the intervention. Siblings participated in a structured support group that enabled them to share their stories and learn coping skills. Caregivers were provided with a psycho-education curriculum in a group facilitated by a parent mentor. At the end of each session, participants completed surveys which included questions on demographics, satisfaction, knowledge learned, and anticipated changes in behavior as the result of participating in the intervention.

Results: Feasibility was demonstrated through successful recruitment, high rates of survey completion, and overall participant satisfaction. Caregivers reported gaining useful parenting strategies to better support the siblings, an increased understanding of the impact of mental illness on siblings, a reduction in feelings of isolation, and improved access to resources. Siblings reported feeling relieved and better understood, learning new coping skills, and finding validation and support through sharing their experiences in a group setting.

Conclusion: This study supports the feasibility and importance of providing sibling and caregiver support and psycho-education to enhance resiliency and reduce trauma among family members of psychiatrically hospitalized children and adolescents.

1. INTRODUCTION

Mental health disorders in a child or adolescent can impact the entire family. Young people with mental health needs often create a high burden of stress on their families, which, in turn, can further intensify the level of stress in the home environment (Maurin *et al*., 1990). A psychiatric hospitalization of a child can also be especially challenging, and potentially traumatic, for other children in the home. Unfortunately, inpatient child psychiatry units and residential programs do not

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routinely address the needs of the siblings of the identified patient in a uniform or systematic way.

Children and youth experience varied and complex reactions to the experience of having a sibling with a mental health disorder. They often describe a sense that they have "lost" their sibling to the illness (Sin, 2012) and may mourn the "normal" relationship they shared prior to onset of illness (Lukens, 2004). Children often describe a lack of understanding of their sibling's illness and a perceived lack of education about the illness and prognosis (Abrams, 2009; Amaresha, 2014). Siblings often take on caregiving responsibilities in the home, hoping to ease their perception of the burden placed upon their parents (Sin, 2008). Because of embarrassment, fear of rejection, or family pressure, siblings may try to keep their brother or sister's mental health disorder a secret from their teachers and friends, thereby exacerbating a sense of loneliness and isolation (Sin, 2012; Abrams, 2009).

Siblings also report conflicting emotions of resentment and guilt, feeling that their ill sibling garners more of their parents' time and attention, while simultaneously feeling guilty about their own perceived lack of understanding and empathy (Lukens, 2004; Sin, 2012). With the increased pressures and levels of stress within the household and family, siblings may experience adverse effects on their own mental health. A recent systematic review indicated that siblings of children with mental health disorders are two to four times more likely to have diagnosed psychopathology of their own when compared with a control population (Ma, 2015).

There is a limited literature on specific interventions for siblings of children with mental health disorders. Lobato and Kao (2002) conducted an intervention that consisted of six weekly 90-minute group sessions for both parents and siblings that sought to improve sibling knowledge, develop emotional coping strategies, and balance individual sibling needs. The authors found that after six weekly 90-minute group sessions, siblings (of children with autism, developmental delay or chronic medical conditions) demonstrated increased levels of understanding of their sibling's disorder with fewer behavior problems themselves and higher reported rates of connectedness. Granat et al. (2012) measured change in children's under-

standing of their sibling's disability after participation in a sibling support group. They found that prior to participation in the sibling group, less than half of all siblings were able to name their brother/sister's disorder, whereas after participation, 90% were able to identify their sibling's condition.

A growing body of research suggests that interventions that support the families of children with chronic medical illnesses or disabilities confer benefits for parents, the identified patient, and for siblings (McCubbin & Huang, 1989; Cavallo, 2009). Families have become more involved in child mental health care and parent support groups for children with disabilities can now be found in most communities (Robbins et al., 2008). Peer mentorship models have been widely used in several areas of health advocacy and education including breastfeeding, immunizations, and cancer survivorship (Cupples, 2011; Amin, 2014). Advocacy organizations for children with mental health disorders, such as the National Association for Mental Illness (NAMI) and the Parent Professional Advocacy League (PPAL) are increasingly relying on the role of mentorship by lay members of the community who have had the experience of navigating the mental health system. A national survey of parents and children with emotional and behavioral disorders found that 72% of respondents endorsed emotional support to be the most helpful aspect of family support services (Friesen & Koroloff, 1990). One study showed that parents of children with emotional disorders who attended support groups used more types of services and were more involved in community advocacy and with other parents than parents who did not attend a support group (Koroloff & Friesen 1991). In a qualitative study, parents who attended a support group on an inpatient adolescent unit discussed the impact of having a child with mental health needs on parents, siblings and families and expressed that they felt less isolated, had learned to support each other and felt that doctors were more approachable (Slowik, Wilson, & Loh, 2004).

In response to the unmet needs of siblings and families, the first author developed the Sibling Support Demonstration Project at the Eunice Kennedy Shriver Center of the University of Massachusetts Medical School. The project provided psycho-educational groups for caregivers and support groups for siblings of children and adoles-

cents admitted to locked inpatient psychiatric units. The project was piloted at the Cambridge Health Alliance/Cambridge Hospital from November 2011 to July 2013. The project has continued beyond the pilot phase at Cambridge Health Alliance and remains as an ongoing program.

The goals of the project were to: 1) Increase sibling resiliency and reduce the trauma that is commonly experienced by siblings of children and adolescents during psychiatric hospitalization; 2) Build skills, competency and confidence among parents; 3) Help restore family stability once the hospitalized patient returns home, minimizing rates of re-hospitalization; 4) Build capacity among medical practitioners, thereby influencing the delivery of family-centered mental health care in hospital settings.

The purpose of this paper is threefold: to describe the Sibling Support Demonstration Project, report on its feasibility and acceptability, and review preliminary measures of efficacy for both siblings and parents.

2. METHODS

2.1. Project Overview

When patients were admitted to the inpatient psychiatric unit at the Cambridge Health Alliance (CHA) /Cambridge Hospital, their family members were invited to participate in a psychoeducational group for caregivers and/or a support group for siblings. The caregiver psychoeducation group focused on: increasing understanding of the emotional and psychological impact on siblings of having a brother or sister with mental illness; decreasing caregivers' feelings of isolation; reviewing parenting strategies geared toward improving siblings' resiliency; introducing resources and strategies to access resources; and providing education on the sibling experience from a lifespan perspective. Areas of focus in the sibling support group included: increasing knowledge and understanding about the hospitalization experience; reviewing functional coping skills; increasing siblings' recognition that they should not have to keep secrets about frightening things happening in their families; reducing the siblings' feelings of isolation, and reinforcing that caring adults are available to help siblings.

2.2. Recruitment

The pilot phase of this study was conducted at a single site, CHA Cambridge Hospital, a community teaching hospital affiliated with Harvard Medical School, and part of the Cambridge Health Alliance in Cambridge, Massachusetts. The Cambridge Hospital is known as one of the primary safety net hospitals in the region.

Potential participants were identified from among the families of patients admitted to the hospital's two pediatric psychiatry inpatient units, the Child Assessment Unit (CAU) and the Adolescent Assessment Unit (AAU). The CAU is a 13 bed locked unit that provides care for children ages 3 to 12 years. The AAU is a 14 bed locked unit that cares for children ages 13 to 18 (19 years if youth are still in high school). Patients are admitted to these units directly from the emergency room at CHA Cambridge Hospital, as well as from other hospitals and psychiatric emergency service teams from throughout Massachusetts and the rest of New England. The average length of stay on the units is approximately 8 days and 9 days, for the CAU and AAU, respectively.

Between November 2011 and July 2013, a member of the clinical staff (MD, RN, or social worker) from one of the respective units would review a recruitment flyer about the Sibling Support Demonstration Project with the parent or guardian of every child admitted to the CAU and AAU. Every family who identified the presence of at least one sibling in the home of the patient was invited to participate in the study. Because of low recruitment during the first month of the study, the research team decided to augment the recruitment strategy by contacting the families of admitted patients through telephone calls, using an IRB-approved phone script. The phone calls were initially made by one of the child and adolescent psychiatrists on the study team, but this method also yielded few participants. The next approach was for a trained parent mentor, also a member of the study team, to conduct the recruitment calls; this method was significantly more successful because the parent mentor was able to provide support and empathize with the experience of having a child admitted for psychiatric hospitalization, in addition to providing details about how to participate in the study.

During the study period, over 1,200 families were contacted by a member of the study team through recruitment telephone calls. Ultimately, almost all study participants were recruited by phone outreach directly from a parent mentor on the study team. Typically, multiple phone calls were made in order to reach one of the caregivers in the home, assess the presence of siblings in the home, and provide information about the nature of the groups.

2.3. Screening and Eligibility

Participation in the sibling support group and psychoeducational group for caregivers was open to all families of patients admitted to the CAU and AAU. During the recruitment phone calls, caregivers were invited to bring any identified sibling to the group who met the following criteria: children ages 5 to 18 years growing up in the identified patient's home, including step-siblings and cousins of the patient as well as any foster children residing in the home, and children who were fluent in English. Children with a history of significant behavioral problems or other circumstances that precluded meaningful engagement in the group were excluded. Specifically, children were not invited to attend the group if they were nonverbal, had extreme oppositional behavior, or had a severe cognitive impairment. Caregivers had to be sufficiently proficient in English to participate in the group. The psychoeducational group was open to all caregivers including parents, guardians, grandparents, foster parents, aunts and uncles who were either in the patient's home or were an active part of their upbringing at the time.

2.4. Group Logistics

The caregiver psycho-educational group and sibling support group each took place during visiting hours on the inpatient units, so that families of hospitalized children did not need to make a separate trip to participate. To maximize participation and accommodate the schedules of siblings in school and parents at work, programming was offered two nights per week, from 5:30pm-7:00pm and 4:00pm-5:30pm. Food and beverages were served to participants as a part of the project to help minimize family stress around meal time.

Since patients were admitted and discharged from the hospital at different times, the groups were designed to accommodate both newcomers and more established participants. The groups were structured as "drop-in" sessions with the goal that each sibling and caregiver would participate in a minimum of one session. The caregiver group and sibling group met in nearby rooms at the same time, so that caregivers were able to participate in the educational program while siblings were actively involved in the sibling intervention. All sessions were held on-site at CHA Cambridge Hospital.

2.5. Ethical Approval & Informed Consent

The study was reviewed and approved by the Institutional Review Board at Cambridge Health Alliance, an affiliate of Harvard Medical School. Parental consent was obtained for youth under the age of 18, and children under the age of 18 provided their assent at the beginning of each group. Youth who were age 18 provided their own consent. Group facilitators reminded participants that what they shared was confidential, and that participation was voluntary. Participants were reminded that the group might be tape-recorded in order to identify themes that emerged. If a participant expressed discomfort with audio recording, the tape recorder was not used.

2.6. Psychoeducational Group for Caregivers

Caregiver groups were facilitated by a trained parent mentor, serving a maximum of twelve caregivers in each group. Caregivers received the brochure *Supporting Siblings of Children With Mental Health Needs* which was developed by the first author and a list of local resources geared to supporting siblings and parents, and stabilizing families. The class was didactic in nature; caregivers learned about the needs of typically developing siblings, the importance of supporting siblings, and strategies to support siblings at home. Strategies included validating the siblings' experience, giving siblings language to talk about the events leading up to the psychiatric hospitalization, and spending one-on-one time with the siblings. Any remaining time was spent in an open-discussion format, addressing specific sibling issues raised by participants. Caregivers were invited to attend the psycho-educational group as often as they liked, during and following the patient's hospitalization, though most participants (97%) only attended once.

2.7. Sibling Support Group

Sibling support groups were co-facilitated by various trainees who self-selected to join the study team (including residents in psychiatry, child fellows, psychology post-docs, and social work interns) as well as two clinical staff, an expressive arts therapist and a licensed clinical social worker. The groups included a maximum of twelve siblings per session.

The curriculum comprised a selection of activities, two of which were adapted from the Sibshop model (Meyer & Vadasy, 2007), and were appropriate for mixed age groups. Sibshops are workshops for siblings of children with disabilities that are designed to provide peer support and education within a recreational context. The sibling support groups facilitated siblings' opportunities to develop connections with peers who shared the experience of a brother/sister's psychiatric hospitalization, gain insight into the brother/sister's disability, develop coping strategies to manage their challenging family lives, and increase their comfort level with the hospitalization experience.

Since the age range for the siblings extended from age 5 to age 18, the sibling group co-leaders used their discretion to divide the group into age-appropriate cohorts when younger siblings and teen siblings participated on the same night, enabling us to provide appropriate peer groups. Similarly, although the group leaders used the same activities with the different age groups, they engaged the adolescent siblings in more sophisticated, in-depth discussions about the topic areas. Thus, the groups were tailored to meet the needs of younger siblings and adolescent siblings. Occasionally, mixed age siblings within the same family wanted to participate in the same group and in those cases, the older siblings often assumed a mentoring role with the younger siblings.

After a review of group rules, siblings decorated name tags and ate pizza. This was followed by the Starburst Candy Activity, an adapted version of the M&M Game from the *SibShop*™ program (Meyer & Vadasy, 2007). Siblings were given a small number of candies that were linked with color-coded questions. If a sibling picked a red candy, for example, the question was "What makes you happy about your brother/sister?" Each sibling in the room was given an opportunity to answer, and a discussion would ensue. A total of seven questions were asked: "What makes you mad about your brother/sister?" "What do you do when you're upset, and what makes you feel better?" "What do you tell other people about your brother/sister?" "Has your brother/sister ever had a temper tantrum in public?" "Why is your brother/sister at the CAU/AAU?" and "If you could change one thing about your life, what would it be?".

"Dear Dude", another activity adapted from the *Sibshop*™ curriculum (originally titled "Dear Aunt Blabby"), was used multiple times with siblings, but since the Dear Dude activity involved higher level reading and was more appropriate for older siblings, it was not used consistently, unlike the Starburst Candy Activity in which every sibling participated. (Meyer & Vadasy, 2007). The Dear Dude activity involved participants reading and responding verbally to sample letters about sibling dynamics. Siblings were also given access to art supplies so they could draw or doodle if they chose to do so during the group.

To wrap up the sibling group, the facilitators hung two pieces of paper on opposing walls, each of which posed one question: "What Was Your Favorite Part About Today's Session?" and "What Would You Change About Today's Session?" Each sibling was given post-it notes to write down their responses and attach to the corresponding paper. If siblings were unable to write their responses, the facilitators scribed for them. Before departing, siblings were offered a certificate of participation and the artwork/materials they produced in the group.

2.8. Measures

In addition to collecting the siblings' responses to the questions in the Starburst Candy Activity, both the siblings and caregivers were given questionnaires at the end of their respective groups. The questionnaires consisted of semi-structured items as well as open-ended items such as asking how they felt before and after the groups and what they learned in the groups.

The caregiver questionnaire elicited information on caregiver demographic characteristics, prior experience they had with attending groups aimed to support siblings, what caregivers learned or intended to change as a result of participating in the group, what types of post-hospitalization serv-

ices would be helpful, and how satisfied caregivers were with the groups. The sibling questionnaire elicited information on the demographic and household composition of the families that attended, whether the sibling had a supportive adult to talk to, whether and what was helpful to the sibling about the group, and whether and what changes the sibling experienced as a result of participating in the group.

2.9. Data Analysis

Subject responses to the surveys and group activities were entered into an online database using SurveyMonkey, which also was used to conduct basic descriptive statistical analysis of quantitative data. Means and frequencies were calculated for quantitative data obtained from the sibling and caregiver surveys. Survey data were studied within each type of participant group (sibling *vs.* caregiver) and in a cross sectional analysis by demographic group (gender, age, education level and primary language).

Qualitative data gathered both through the surveys and through the group discussions with siblings and caregivers were analyzed using a grounded thematic analysis. All responses to a single question were reviewed and categorized based on themes by single study team member, who was blinded to the subject's identity. The thematic coding was split across multiple study team members. The themes were reviewed by a 5-member panel of the larger study team, who identified the most common re-occurring narratives to present.

3. RESULTS

3.1. Recruitment and Enrollment

During this pilot study, 1,290 families were contacted by a trained parent mentor through recruitment telephone calls. 341 subjects were successfully recruited, representing 196 caregivers and 145 siblings. The vast majority of enrolled participants were able to complete all of the study measures, including attending the entire group, participating in the activities, and completing research and feedback measures at the end of the group. Specifically, 100% of the caregivers and 96% of the siblings completed the study questionnaires. The majority of participants attended the

groups once, with 92% of siblings attending once and 97% of caregivers attending once; the small percentage of remaining participants attended multiple times.

3.2. Caregiver Study Sample

Caregiver demographic data are outlined below in Table **1**. Nearly half (47%) of the caregivers who attended the groups had either a college or graduate school level of education. The vast majority (92.3%) of the caregivers reported that English was the primary language spoken at home. Only 11.2% of caregiver participants report ever having attended any kind of workshop, group or therapy focusing on siblings.

Table 1. Caregiver demographics.

Caregiver Demographics	% (n)
Primary language of caregiver	
English	92.3 (181)
Spanish	4.1 (8)
Portuguese	2.0 (4)
Haitian Creole	0.5 (1)
Other	1.0 (2)
Caregiver educational level	
High school or less	23.5 (46)
Some college, associate, or technical degree	25.0 (49)
Undergraduate (bachelor's) degree	23.5 (46)
Graduate degree	23.5 (46)
Other/declined to answer	4.5 (9)
Prior experience with groups/therapy on sibling support	
Yes	11.2 (22)
No	83.2 (163)
Not sure	4.1 (8)
No response	1.5 (3)

Note. N=196.

As shown in Table **2**, the overall perception of the program was extremely positive: 88.3% of the caregivers indicated being "very satisfied" (highest rank) with the group. The majority of caregivers felt the group was very helpful, and the groups seemed to foster a safe and secure environment:

88.8% of caregivers reported feeling very comfortable sharing their stories in the group setting. Ninety-seven percent (97%) of caregivers reported they would recommend the caregiver group to others.

Table 2.   Caregiver perceptions.

Caregiver Perceptions	% (n)
Satisfaction	
Not at all satisfied	0 (0)
A little satisfied	0 (0)
Somewhat satisfied	11.2 (22)
Very satisfied	88.3 (173)
No response	0.5(1)
Group helpfulness	
Not at all helpful	0 (0)
A little helpful	2.0 (4)
Somewhat helpful	28.6 (56)
Very helpful	67.9 (135)
No response	1.5 (1)
Level of comfort sharing in the group	
Not at all comfortable	0 (0)
A little comfortable	0 (0)
Somewhat comfortable	10.2 (20)
Very comfortable	88.8 (174)
No response	1.0 (2)
Would recommend the program to other families	
Yes	97.0 (190)
No	9 (0)
Maybe	2.0 (4)
No response	1.0 (2)

Note. N=196.

3.3. Caregiver Qualitative Outcome Data

3.3.1. Psychoeducation

In response to the question asking caregivers to list two to three things they learned at the session, caregivers indicated that they gained useful parenting strategies and techniques through participation in this group. Caregivers reported changes they intended to make as the result of participating in the program, including spending more one-on-one time with siblings and validating their experiences, creating more structure and regular routines at home, and improving communication with everyone in the family. Caregivers also described coming to a realization that the entire family is affected by a child's hospitalization. Responses included, "My son is affected by this, too, not just me"; "I learned that my daughter's issues are probably having more impact on my son than I realized, and that we should consider strategies that were discussed to help him"; that they are now "more aware of the impact outbursts have," and that in the future they plan on "being more cognizant of sibling issues".

Caregivers also reported having learned about numerous resources they were previously unaware of, and stated their intention to seek out these resources. Several caregivers indicated in their responses that there are many more resources available than they thought. Caregivers indicated an intention to explore the online resources they were given for sibling support and to become more involved in ongoing support groups.

3.3.2. Emotional Support

In their responses to the question asking what they had learned, the caregivers also indicated that the emotional support provided by the group was significant for them. Many described realizing that "we are not alone," and "other parents have similar issues". The combination of emotional support and resources seemed to provide motivation and hope to parents at a time when many felt deeply demoralized. One parent stated, "I learned how much the parents need each other." Caregivers described feeling more confident about supporting the siblings, that "I am doing some things right!", and that they now feel "it can change, things will get better."

3.3.3. Need for more services

Caregivers made numerous suggestions for the types of services that would be helpful for their families after their child was discharged from the hospital. Foremost among the suggestions was the need for more support groups both for parents and for siblings. Many requested forming an online support community with chat rooms, information pages with resources, and FAQs. Other caregivers

requested a call-in number and group activities. In addition to these comments, a number of caregivers focused on increasing the accessibility of resources, requesting assistance accessing available resources through an educational advocate or mentor, and in-home therapy or other services.

3.4. Sibling Study Sample

Sibling demographic and satisfaction data are reported below in Table **3**. The groups were divided nearly evenly by gender. While the median age of siblings was 11 years (SD 2.8), the largest cohort of siblings served were adolescents between the ages of 12-18.

Table 3.   Sibling demographics and perceptions.

Sibling Demographics and Perceptions	% (n)
Gender	
Males	49.0 (68)
Females	51.0 (72)
Age	
Early childhood (5-8 years)	26.4 (37)
Middle childhood (9-11 years)	34.3 (48)
Adolescence (12-18 years)*	39.3 (55)
Previously talked with an adult about brother's or sister's problems	
Yes	50.0 (70)
No	32.1 (45)
Not sure	17.1 (24)
No response	0.7 (1)
Would recommend group to other kids	
Yes	67.9 (95)
No	3.6 (5)
Maybe	27.8 (39)
No response	0.7 (1)

Notes. N=140. *One participant was 19 years old.

The majority of the siblings (67.9%) reported that they would recommend the group to others; anecdotal reports from sibling group leaders about younger siblings indicated that some answered "maybe" or "no" for the question about recommending the group to others not because they were not satisfied with the group, but because they did not fully understand the question (*i.e.* they did not know other children with a sibling with mental health disorders). Half of the siblings reported either never having talked about their sibling with a supportive adult (32.1%) or being unsure whether they ever had (17.1%).

3.5. Sibling Qualitative Results

Qualitative data were available from the siblings' responses to the Starburst Candy Activity and the open-ended items on the survey which revealed several themes: the complexity of the sibling relationship, the shame associated with the patient's mental health disorder, and coping strategies. The same themes emerged among siblings irrespective of their age, though responses from adolescents tended to be more sophisticated than the responses from younger siblings. The youngest siblings were more likely to respond with drawings and group leaders provided scaffolding to put words to their experiences, while adolescents were able to engage in more nuanced verbal discussions and reflection and were able to provide more coherent narratives. For example, a six year old girl shared in the group that her hospitalized brother "fights, yells at me" while a 13 year old girl shared that her hospitalized sister "gets really angry. It's unpredictable. When it's just the two of us, it's good, but when it's all four of us, it goes wrong. She hates being coddled. She gets lots of attention." Regarding the use of games in mixed-aged groups, one 16 year old girl confirmed the suitability of the activities in a mixed age group in this way: "For me personally I definitely could have handled just jumping into the questions, but for younger kids (including my younger sister), I think the little games/activities are helpful for getting them comfortable and speaking openly.

Complexity of the sibling relationship. The first two questions of the Starburst Candy Activity asked siblings about their hospitalized sibling. The first question asked what made the participant happy about their hospitalized sibling, which served to build rapport among the siblings and help them identify strengths in their potentially strained sibling relationship. Most of the siblings were able to identify positive characteristics or strengths in their relationship. By establishing these positive aspects, group leaders validated the siblings in their experience that this relationship was complex and neither all good nor all bad. This

further helped them with future questions about behavior as it contextualized that their sibling's behavior was often situational. Examples of their responses include: "When she's not worrying about everything, just laughing and smiling" and "He is a really nice brother. He is a good sharer. He is always there for me when I need him."

The second question, "What makes you mad about your brother/sister?" was asked to help underscore and validate the complexity of the sibling relationship, and gave the siblings an opportunity to express themselves. Most responded with statements about behavioral issues they have dealt with in the home, and several endorsed being victims of physical aggression. Examples include: "My brother threatened to beat my mom. He calls me bad names and curses. He hits me," and "When he has his episodes because it's scary," and "She swears, punches mom in the stomach, kicks the dog. I get so angry with her for being so mean."

Shame and Stigma. The Starburst Candy Activity posed two questions that asked the siblings about what they would like to change in their life, and how they explain their sibling's hospitalization to others. The siblings' answers revealed the discomfort and shame they often feel regarding their sibling's mental health disorder. Very few siblings reported feeling comfortable telling friends or others the truth about the situation. Most explained that they felt it was a "secret" or shameful to share with others. The participants reported a wide range of reasons why their sibling was currently admitted to the hospital, including "he's at mom's house (my parents don't want others to know he's in the hospital)", "I tell them he's home sick. My parents told me what to say. I wish I could tell my best friend because I trust him," "My mom said not to talk about it," "My mom tells me to lie," "Nothing. Because people don't understand," "He's with my nana," and "That she's struggling with depression."

In the final portion of the activity, siblings were asked, "If they could change one thing in their life, what would it be?" Many expressed a desire for the improvement of their sibling's health and behavior, a reduction in family's suffering, and a desire for the sibling to be cured. In addition, several expressed a desire to obtain additional material or financial means such as having more money, giving a parent a car, living in a mansion. Many ex-

pressed a fantasy, for example, being a wizard, the ability to fly, or being invisible.

Coping Strategies. Siblings were also asked the question "What do you do when you're upset and what makes you feel better?" The responses revealed that most siblings could identify some degree of healthy coping strategies, including talking to someone about how they were feeling (often a friend, older sibling or parent) and using healthy forms of distraction, such as reading a book, playing a game or sport, listening to music, or playing with a pet. Several children endorsed more isolative coping styles such as going to their room to be alone. A few children endorsed more maladaptive coping measures such as yelling, slamming doors, or hitting their sibling or other objects. Group leaders discussed the use of more functional coping skills with siblings, to reinforce and encourage healthier interactions within their families. These coping mechanisms included deep breathing, journaling, and walking away from the conflict.

Emotional Support. Siblings responded to survey questions that asked them what was most helpful about the group, how they felt before and after participating in the group, and what was their favorite part about the group. Their responses suggested positive reactions to the intervention. The strongest theme that emerged from their responses was that siblings felt relieved after having the opportunity to talk about their feelings around their brother's or sister's mental health disorder. Many reported feeling unsure or nervous before the group, saying that they felt "shy" or "anxious." Afterwards, participants reported feeling "lighter," "relaxed," "relieved because I let out my feelings and like all these emotions have been lifted off," "like I don't have a lot of things to myself anymore," "comfortable," "happy to express myself," and "I feel that I can talk with my parents more."

When asked to identify what was most helpful about the group, most siblings mentioned the opportunity to talk and being asked questions, with responses such as "talking with people with similar situations," "Being able to say anything you want," "helping me get a lot of things off my chest," and being able "to express our feelings." The siblings who participated in the groups often reported feeling happy or relieved to meet other young people who understood their situations, because they, too, had a brother or sister with a men-

tal health disorder. This helped them feel less alone; as one participant wrote, "I felt it let me know I wasn't the only person with a brother/sister with a problem." There are indications that some siblings began to internalize the messages of the group: that they were not to blame for their brother or sister's illness. Many reported leaving the group feeling "happier", "relieved," "calmed down," "much better about myself" and "[feeling] good that I'm not the only one with problems and bad situations." These responses suggest that some siblings began to internalize the messages of the group: that they were not to blame for their brother or sister's illness.

Another theme that emerged from the siblings' comments is that not only was the emotional support perceived to be helpful, but learning about their brother or sister's situation and discussing coping strategies was important. Numerous participants after the group reported feeling "knowledgeable," "like the advice I got will help me in advance", and "more comfortable with my brother".

These young people, whose families are often in crisis, described the group as a contrast to their everyday situations: a safe, calm place where they could relax and even have fun.

Many siblings reported feeling "scared," "worried," before the group, but described the group as "a safe environment" and reported after the group feeling "sad because I have to leave," or even "scared because I'm leaving a safe place."

4. DISCUSSION

In conceptualizing this project, the first author brought together best practices to create an innovative intervention. First, the program emphasized involving parents/caregivers in efforts to support siblings, as opposed to a traditional sibling support group model in which parents drop off the siblings and are not part of the intervention. Second, it provided trained parent mentors with lived experience to work directly with family members. Parent mentors carry significant credibility among families of children with mental health needs; utilizing parent mentors to conduct phone recruitment and facilitate the caregiver group revealed that many parents felt more comfortable talking to a parent mentor about the impact of mental illness on fam-

ily members than with a clinician. Third, trainees were offered the opportunity to lead sibling support groups using a structured curriculum. The trainees reported that leading the sibling groups gave them critical insights into the impact of mental illness on typically-developing siblings, reinforced the importance of providing family-centered mental health care, and provided an overall sense of hopefulness about the field of mental health. Fourth, we created a schedule that accommodated the needs of families who were in a state of crisis; programming was offered in the early evening (after school and work), families were provided dinner to minimize their stress, and childcare concerns were mitigated when all eligible members of the family were able to attend.

The results of this pilot study suggest that implementation of the Sibling Support Demonstration Project was feasible and was perceived positively by the participants. The study team developed an effective method for recruitment of caregivers and siblings of children and adolescents admitted to an inpatient psychiatric unit. Siblings engaged in a structured support group with their peers, and group leaders elicited striking narratives about the experience of having a brother or sister with a major mental health disorder. Similarly, caregivers were able to successfully engage in the psycho-educational groups and demonstrated increased knowledge about the siblings' experience and emotional needs. Both groups of study subjects reported high levels of satisfaction with the project and indicated important skills and lessons learned.

In a previous qualitative study, parents who attended a support group for parents, siblings, and families on an inpatient adolescent unit expressed greater connectedness to one another and felt that physicians were more approachable (Slowik, Wilson, & Loh, 2004). Results from caregivers of our pilot study indicated similar findings, including less isolation and greater knowledge about area resources. Overall, caregivers indicated that they would recommend the psychoeducational group to others and found that the group provided a safe and supportive environment while increasing their knowledge about how to care for the siblings of children with mental health disorders. Caregivers reported finding comfort and strength in sharing their experience with others, recognizing that they, too, need support. The majority of the caregivers

who participated in the study indicated that they did not have prior experience with sibling interventions, highlighting the potential need for greater sibling support interventions in the area of child/adolescent mental health.

Past studies have shown that siblings of children and adolescents with mental health disorders can often feel embarrassed, guilty, and/or isolated as a result of their experience. Siblings in our study reported that the group provided a safe place where they could meet other people who understood what they were going through. Our results also suggest that the siblings who participated in the group found it helpful, with 67.9% of siblings reporting that they would recommend the group to others.

The results of this pilot project suggest that it may be a useful model to employ in inpatient settings, and that participants found it beneficial. Caregivers reported increased competency and confidence in managing their families' lives with a child or adolescent who has been hospitalized. Siblings had the opportunity to share their stories and were introduced to coping skills. We were not able to assess whether we met the ambitious goal of restoring family stability once the hospitalized patient returned home, although this is another area of research to pursue.

While the findings from this pilot study show promise regarding the effectiveness of this project, it is important to acknowledge several limitations to put the findings in context. First, survey questions asked participants to report retrospectively about how they felt at the beginning and toward the end of the intervention. Although this method was implemented to maximize the response rate and minimize respondent burden, it is wholly dependent on a subjective report, as respondents may not accurately recall their behaviors or attitudes at the beginning of the group. There was no comparison group for this pilot study, and thus it is possible the observed outcomes as reported by caregivers or siblings may be due to other factors beyond their participation in this project. Some limitations of the study intervention and data collection include a potential lack of fidelity to the structured Starburst Candy Activity, as facilitators were given discretion to modify the activity depending on the size and composition of the group as well as timing restrictions. In addition, in the youngest set

of siblings, it is possible that they did not fully understand what was being asked in some of the post-group survey questions. The groups were also conducted in English, limiting generalizability to non-English speaking populations.

CONCLUSION

In summary, this paper reviews the successful implementation of the Sibling Support Demonstration Project which indicates that it is feasible to implement on an inpatient psychiatric unit, and was deemed acceptable by the participants. Specific indicators of feasibility included recruitment, participation, survey completion, and overall participant satisfaction. Both caregivers and siblings reported high levels of satisfaction with the project and indicated they learned some important lessons and skills. This pilot intervention demonstrated that the groups successfully provided support to the siblings that participated. Further, the parent groups improved caregivers' understanding of the sibling experience, acquisition of new parenting strategies to better support siblings, and access to resources. Further research is warranted to evaluate whether this program can reduce siblings' trauma and increase their resiliency. Next steps could include evaluating outcomes between those that participated vs. those that did not participate in the groups, a randomized controlled trial, refinement of existing tools, conducting an evaluation of group facilitator experiences, and creating culturally sensitive translations of the intervention to reach a broader range of participants.

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HUMAN AND ANIMAL RIGHTS

The manuscript indicates that this was an IRB-approved research study involving human subjects, both adults and children, and that the study was approved by the IRB at Cambridge Health Alliance.

CONFLICT OF INTEREST

The author declares no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

REFERENCES

Abrams, M. S. (2009). The well sibling: challenges and possibilities. *American Journal of Psychotherapy*, *63*(4), 305-317.

Amaresha, A., Venkatasubramanian, G., & Muraldhar, D. (2014). Needs of siblings of persons with psychosis: a systematic descriptive review. *Clin Psychopharm and Neuroscience*, 12(2), 111-123.

Amin, A. L., Neuner, J., Duthie, E. A., Finn, V. R., & Kong, A. L. (2014). A one-to-one mentoring support service for breast cancer survivors. *WMJ: Official Publication of the State Medical Society of Wisconsin*, *113*(5), 185-189.

Cavallo, S., Feldman, D. E., Swaine, B., & Meshefedjian, G. (2009). Is parental coping associated with the level of function in children with physical disabilities? *Child: Care, Health and Development*, *35*(1), 33-40.

Cupples, M. E., Stewart, M. C., Percy, A., Hepper, P., Murphy, C., & Halliday, H. L. (2011). A RCT of peer-mentoring for first-time mothers in socially disadvantaged areas (The MOMENTS Study). *Archives of Disease in Childhood*, *96*(3), 252-258.

Friesen, B. J., & Koroloff, N. M. (1990). Family-centered services: Implications for mental health administra-

tion and research. *The Journal of Mental Health Administration*, *17*(1), 13-25.

Granat, T., Nordgren, I., Rein, G., & Sonnander, K. (2012). Group intervention for siblings of children with disabilities: a pilot study in a clinical setting. *Disability & Rehabilitation*, *34*(1), 69-75.

Koroloff, N. M., & Friesen, B. J. (1991). Support groups for parents of children with emotional disorders: a comparison of members and non-members. *Community Mental Health Journal*, *27*(4), 265-279.

Lobato, D. J., & Kao, B. T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, *27*(8), 711-716.

Lukens, E.P., Thorning, H. & Lohrer, S.P. (2004). Sibling perspectives on severe mental illness: Reflections on self and family. American Journal of Orthopsychiatry, 74, 489-501.

Ma, N., Roberts, R., Winefield, H., Furber, G. (2015). The prevalance of psychopathology in siblings of children with mental health problems: A 20-year systematic review. Child Psychiatry Hum Dev, 46(1), 130-149.

Maurin, Judith T. *et al*. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing,* 4(2), 99-107.

McCubbin, M., & S. T. Tina Huang. (1989). Family strengths in the care of handicapped children: targets for intervention. *Family Relations,* 38(4), 436-443.

Meyer, D. & Vadasy, P.F. (2007). *Sibshops: Workshops for Siblings of Children with Special Needs*. Baltimore, MD: Paul H Brookes Publishing Company.

NAMI: National Alliance on Mental Illness. (n.d.). Retrieved November 8, 2016, from http://www.nami.org/

PPAL: Children's Mental Health. (n.d.). Retrieved November 8, 2016, from http://ppal.net/

Sin, J., Moone, N. & Harris, P. (2008). Siblings of individuals with first-episode psychosis: Understanding their experiences and needs. Journal of Psychosocial Nursing, 46(6), 34-38.

Sin, J., Moone, N., Harris, P. *et al*. (2012). Understanding the experiences and service needs of siblings of individuals with first-episode psychosis: A phenomenological study. Early Intervention in Psychiatry, 6, 53-59.

Slowik, M., Willson, S. W., Loh, E. C.-C., & Noronha, S. (2004). Service innovations. *The Psychiatrist*, *28*(5), 177-179.