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Elizabeth M. Oakleaf  
MaineHealth

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## Family Caregivers Identify Their Needs from the Inpatient Team during a Loved One's Inpatient Psychiatric Hospitalization

### Authors

Elizabeth M. Oakleaf and Lillian J. Shields

## ORIGINAL RESEARCH

# Family Caregivers Identify Their Needs from the Inpatient Team during a Loved One's Inpatient Psychiatric Hospitalization

Elizabeth Oakleaf, LCSW,<sup>1</sup> Lillian Shields, LCSW<sup>1</sup>

<sup>1</sup>Spring Harbor Hospital, Westbrook, ME

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**Introduction:** According to existing literature, family-caregiver needs during a loved one's inpatient psychiatric hospitalization are not fully understood or addressed in practice. We aimed to identify specific, practical family caregiver needs from the inpatient team during a loved one's psychiatric hospitalization.

**Methods:** Semi-structured interviews were designed and tested through a phenomenological analytical approach. Interviews were conducted with family caregivers (n = 16, one caregiver per loved one) who participated in caring for a loved one (age 18-30 years) during an inpatient psychiatric hospitalization.

**Results:** Four main themes arose: the need to be listened to and collaborated with regarding treatment planning, the need for education and guidance about mental illness, the need for emotional support and validation by the inpatient team, and that family caregivers associate their experience with their perception of their loved one's experience.

**Discussion:** Interactions with the inpatient team are meaningful to family caregivers, who have needs that are or are not met. Study participants indicated that they feel better supported when they are fully included in their loved one's care, it matters how information and education are delivered and by whom, and they appreciate dedicated support for themselves. Furthermore, their feelings are influenced by their understanding of their loved one's experience.

**Conclusions:** Understanding what family caregivers value in their interactions with the inpatient team illuminates areas to design support for family caregivers with a loved one in a psychiatric hospital. Families want support from the whole team for different needs at different times throughout hospitalization and after discharge.

**Keywords:** psychiatric hospital, family, caregivers, caregiver burden, mental health

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Family caregivers are not fulfilled by their interactions with mental health providers.<sup>1,2,3,4</sup> A recent literature review found that family caregivers' expectations of support, communication, and participation from psychiatric professionals were not met before, during, or after hospitalization.<sup>5</sup> Behaviors valued by family caregivers include confirmation,<sup>2</sup> cooperation and education,<sup>4,6</sup> a sense of connection,<sup>7</sup> being given information and being listened to,<sup>8</sup> and confidentiality, prompt attention, and consistent care.<sup>9</sup> In this study, we

interviewed family caregivers with the goal of uncovering specific, practical information about their needs and with the intent of informing future practice. We focused on the young-adult population given the complexity of early-onset mental illness for family caregivers.

## METHODS

We used a phenomenological analytical approach, asking open-ended questions of family caregivers in interviews and giving them space to share their experiences openly.<sup>10</sup> This approach is designed to identify themes among a sample of people with similar lived experience and focuses on examining

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Correspondence: Elizabeth Mason Oakleaf, LCSW  
MaineHealth / Spring Harbor Hospital  
Westbrook, ME 04092  
Elizabeth.Oakleaf@mainehealth.org

how participants answer questions and what they said.

The study was conducted at a psychiatric hospital in a rural state in the Northeastern United States, with a catchment area encompassing a population of 1.33 million people in 2018.<sup>11</sup> We identified participants using purposive sampling and limited eligibility to primary family caregivers of young-adult inpatients (ages 18-30 years), who were hospitalized for any mental health reason, had signed a release of information for the primary family caregiver, and had been discharged before the interview. The family caregiver (one per patient) must have had 3 or more contacts with the family navigator, a licensed clinical social worker on the inpatient care team who is dedicated to support them. (The patient-family navigator concept was first described in 1989,<sup>12</sup> and this role was implemented in our hospital in 2015.) Recruitment, enrollment, and interviews were conducted between May 2018 and August 2018. Interviews were conducted by phone and audio-recorded.

Interviews used key questions and probing questions to elicit further information if needed (Table 1). Questions aimed to uncover family caregiver perceptions of interactions with the inpatient team and details about how their needs were or were not met. Questions were developed and ordered by both authors using the Interview Protocol Refinement Framework<sup>10,13</sup> to ensure efficacy and quality. We piloted the questions in a simulated interview with 3 colleagues. Interviews continued until subsequent participants offered no new information and saturation was achieved.

One of the authors analyzed the transcribed interviews using MAXQDA software following Creswell's<sup>14(p170)</sup> Template for Coding a Phenomenological Study. Each transcript was reviewed while highlighting notable sentences that provided an understanding of how the participants experienced the phenomena. Transcripts were reviewed multiple times to develop groups of these sentences into shared meaning clusters. Descriptions of each cluster were written to further define the clusters. In an iterative process, the descriptions were compared for a fit with the transcript to refine the clusters and test descriptions for accuracy, adjusting descriptions as needed.

The descriptions were finalized and summarized into themes of what the shared experiences were and how they were shared, offering insight into interpreting that experience. To validate our analysis, codes were triangulated with existing literature. Quantitative and demographic data were summarized as frequency (No., %) or median [range], as appropriate (Table 2).

The study was given expedited approval by the MaineHealth Institutional Review Board (reference number 1074287).

## RESULTS

We identified 97 eligible family caregivers and approached 47. Of these, 7 declined participation. We achieved saturation after 16 interviews. Table 2 provides information about these participants and their loved one's.

Four primary themes arose. Figure 1 shows these themes and the number of participants identifying them. These themes and their associated actionable needs are summarized in Table 3 and illustrated below using quotations from the family caregivers (individuals are identified by letter codes).

### 1. The value of being listened to and collaborated with regarding treatment planning

All participants identified the importance of feeling their input was solicited, respected, and incorporated into the care of their loved one. They specified not feeling rushed, having time to ask questions to clarify their understanding, and sharing their experiences with staff.

*I think to give the sense that they're not rushed. That they actually have some time to spend. That they're open and want to hear what you have to say, and validate what you say, and also provide information about what they're thinking and why and let you kind of question that and kind of a back-and-forth exchange (E).*

*People there would take the time to explain things to me. It might have been over and over, but I at least still got it...until I got it in my head, what was going on with her. They tried to kind of relieve my tension as far as what was going on with her, "This is why she's doing what she's doing. This is what*

**Table 1.** Key Questions with Probing Questions

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1. Please describe your experiences with providers while your [*patient's relationship to caregiver*] was at Spring Harbor Hospital?

Probing questions

- i. If your experiences were mostly positive, what made them feel that way?
- ii. If they were mostly negative, what made you feel that way?
- iii. What did you value about those interactions with the treatment team health care providers?
- iv. How could those interactions with the health care providers been *more* helpful to you?

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2. Based upon your experience, what do you think are the most important things for health care providers to do during their interactions with family members?

Probing questions

- i. How do you think the health care providers should behave when they work with family members?
- ii. What do you think the health care providers should tell family members about?
- iii. How do you think the health care providers should avoid behaving when they work with family members?
- iv. What do you think the health care providers should avoid saying to family members?
- v. Can you describe any interactions with providers that made you feel uncomfortable
- vi. Can you describe any interactions with providers that made you feel more comfortable?

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3. Please explain what the health care providers did to help you to understand, support, and manage your [*patient's relationship to caregiver*]'s mental health issues?

Probing questions

- i. What were the most helpful things that happened?
- ii. What were the most helpful things that were told to you?
- iii. What was the most confusing thing that happened?
- iv. What was the most confusing thing that was told to you?
- v. What were the least helpful things that happened?
- vi. What were the least helpful things that were told to you?

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4. What would you most want to change about your experience with the care providers that supported your [*patient's relationship to caregiver*] and your family to help you be able to manage your [*patient's relationship to caregiver*] with a mental illness?

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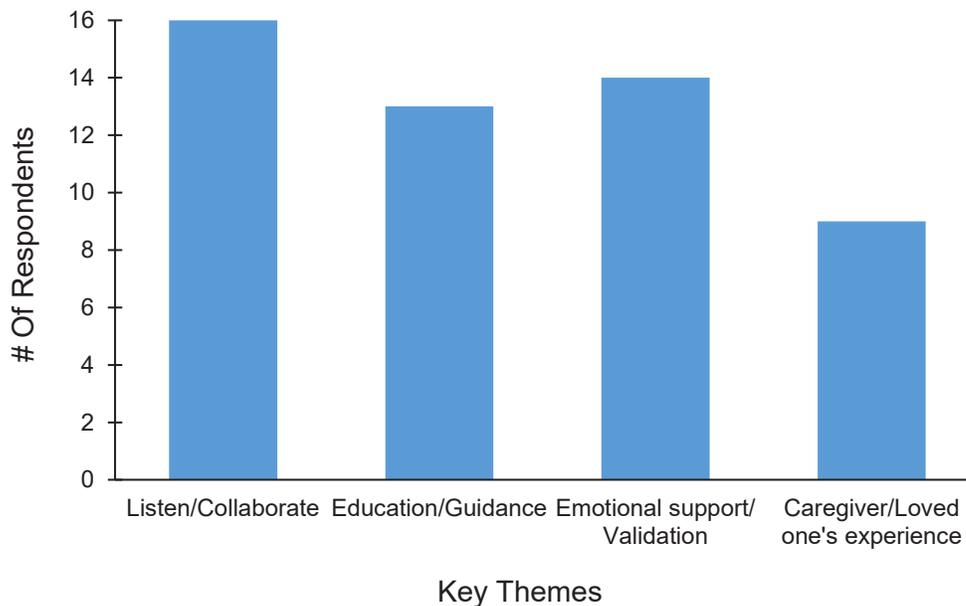
5. Can you think of anything that would have helped you cope better with your [*patient's relationship to caregiver*]'s illness after they left the hospital?

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**Table 2.** Participants and Their Associated Loved One\*

	Value
<b>Participants</b> (n = 16)	
Interview length, min, median [range]	29 [10-54]
Relationship to patient, No. (%) <sup>†</sup>	
Mother	14 (87.5)
Father	1 (6.2)
Grandmother	1 (6.2)
<b>Patients</b> (n = 16)	
Sex, No. (%)	
Female	8 (50.0)
Male	8 (50.0)
Age, y, median [range]	24.1 [18-30]
Primary diagnosis, No. (%)	
Schizophrenia spectrum	5 (31.2)
Depression	4 (25.0)
Bipolar disorder	3 (18.8)
Borderline personality disorder	3 (18.8)
Cognitive disorder	1 (6.2)
<b>Hospitalizations</b> , median [range]	
Number of psychiatric hospitalizations	3.5 [1-10]
Length of stay, days	25.8 [4-90]

\*All data are based on participant reports. <sup>†</sup>Percentages do not add up to 100% due to rounding.

**Figure 1.** Key Themes Among Respondents

**Table 3.** Key Themes and Actionable Items

Themes	Suggestions for interacting with family caregivers
The value of being <u>listened to and collaborated with</u> about treatment planning	<p>Inpatient Team</p> <ul style="list-style-type: none"> <li>• Take time</li> <li>• Do not assume they understand what you are explaining</li> <li>• Incorporate family-caregiver feedback in future meetings</li> <li>• Use active listening skills so they feel heard</li> <li>• Offer a back-and-forth exchange</li> <li>• Ask for their contribution to treatment discussions and family meetings</li> </ul>
The need for <u>education and guidance</u> about mental illness	<p>Physician</p> <ul style="list-style-type: none"> <li>• Relay diagnosis, medication, treatment options, and progress</li> <li>• Offer focused education</li> <li>• Repeat information</li> <li>• Offer access to the physician after discharge</li> </ul> <p>Inpatient team</p> <ul style="list-style-type: none"> <li>• Validate and normalize their experiences</li> <li>• Give realistic expectations</li> <li>• Inform them of community resources</li> <li>• Inform them of the do's and don't's for the diagnosis</li> <li>• Offer guidance on how to best support their loved one after discharge</li> <li>• Offer specific skills</li> </ul>
The importance of <u>emotional support and validation</u> by hospital staff	<p>Inpatient team</p> <ul style="list-style-type: none"> <li>• Offer dedicated support (eg, family navigator)</li> <li>• Offer human connection (someone to talk to about what they are going through)</li> <li>• Address and normalize that family caregivers struggle with self-blame, and help them understand what they can do</li> </ul>
<u>Caregivers'</u> and loved one's experiences are closely associated	<p>Inpatient team</p> <ul style="list-style-type: none"> <li>• Recognize that the family caregiver is not having a separate experience from their loved one</li> <li>• Integrate them into the patient's care with dedicated support (eg, family navigator)</li> </ul>

*problems she has." Everything was explained to me, which I totally love, because I wasn't getting that anywhere else (L).*

Every family caregiver identified collaboration with the inpatient team as a critical need, especially with those who are empowered to make decisions. Participants emphasized the importance of being

listened to and having their feedback incorporated into the team's approach to their loved one.

*I would like the health care providers to treat the family members that show great interest as part of the team. I have always looked at this as a team effort (F).*

*I guess the most important thing is to take some time and speak to family members, and try and understand what they're dealing with, who they're dealing with, and what may or may not help (P).*

*I think it would be nice...to emphasize the importance of asking questions about our loved one who is being hospitalized. "Is there anything in particular that your loved one is really inspired by? Or is there a special hobby?" You know, just something that they could engage in conversation about if given the opportunity (I).*

Family caregivers desired participation in physician-made decisions, rather than hearing about these decisions after the fact.

*...to be maybe part of that decision-making of her plan—where she's gonna go, how she's gonna go....Making it mandatory for the family to be able to intervene until there's, ...just have a safe plan for her and being part of that. That would be it (B).*

*It was pretty much told to us that this was what was decided and that was the way that it was going to be (J).*

Twelve participants, when asked about interfacing with members of the treatment team, spoke about the physician. These participants noted that they either appreciated or identified an unmet need in having time with the physician to be able to ask questions and participate in care decisions. Specifically, family caregivers identified wanting to hear directly from the physician about the course of treatment.

*...and with a doctor like a psychiatrist, there was almost no interaction (M).*

*I probably would have wanted more presence with the psychiatrist (I).*

*Like I said, I wasn't saying that the psychiatrist didn't provide a value, just that a little more conversation with us might have also been nice (P).*

## **2. The need for education and guidance about mental illness**

Thirteen participants emphasized the value of education and guidance about their loved one's

illnesses. They emphasized wanting concrete skills that would prepare them for discharge, such as what to do and not do, and where to access help in the community. They spoke most often about education around the diagnosis, and several also identified information about treatment options and prognosis as helpful.

*They were thorough with explaining the diagnosis and the treatment, and the why's and the why not's, and what you can do, what you can't do. Again, it goes back to just being informative. They informed me of things. They related back to me (B).*

*Well, I think on the part of the psychiatrist, just even kind of explaining about the diagnosis and what the treatment options were and what the progression might be to expect. And that was very helpful (E).*

A frequent area of unmet need was a lack of education about the diagnosis.

*Give the lowdown on what to expect. I mean, and maybe it's hard to do that, illnesses change so much, I guess. But a realistic expectation of the future, what to expect maybe (M).*

Half of the participants identified information about community resources as important.

*I think maybe just that concern and asking questions that help the family find other avenues. Like just helping us find different places to get some help. I guess I would have loved to have had sort of a, not a menu of solutions, but a list of places that offered different kinds of treatments for different parts of these illnesses that happen (G).*

*You know, sitting down and getting all those brochures and descriptions and being directed to NAMI [National Alliance for Mental Illness]. And then what to do, you know, directed to other agencies and so forth. The immediate health care providers in the immediate situation, I felt like they were just treating him, and I was visiting. But I, so, that in itself was help... (O).*

Many family caregivers wanted guidance on how to support their loved one after discharge.

*Because it is very scary to navigate when you've never dealt with anybody like that, and you don't know as a family member living in your house, what you have to hide. Like, what's safe? And can they be left alone (J)?*

*And I guess maybe it would be, maybe some further education on how do you as an adult, as a parent, how do you help, how can you be helpful for an adult child with that?...How do we manage her medications?...So, how do we do that? Do we automatically say, "Okay, it's all yours." Of course, we wanted to work with her. But was there potential guidance that we could have gotten that would be helpful (H).*

*The family navigator suggestion that he text me every day once he got out. Because one of my questions was how do we prevent this from happening again, hopefully? And that has worked really well (C).*

Some participants shared the difficulty of digesting complex information while in the crisis of a short inpatient hospitalization. They specifically emphasized the desire for access to guidance after hospitalization.

*The doctor at discharge was very informative, had articles and information to share about cannabis use to help my daughter understand that component in her mental health. None of this information got through at this time. As it turned out, we were going to need many more situations to get into before she could hear any of this, but it certainly helped start my understanding (N).*

### **3. The importance of emotional support and validation by hospital staff**

Fourteen participants identified the importance of family caregivers getting dedicated emotional support from the inpatient team to cope with their loved one's mental illness, and to validate their efforts and experiences. Among participants who identified specific staff as impacting their hospital experiences, 7 identified nurses and 7 identified social workers.

*And this one nurse took me aside and she just gave me a hug and said, "I know this is very stressful." That as a parent you don't, as a mother you don't expect to go through this at any given time. And I know this is very hard on you...having*

*somebody who makes the human connection to you and says, "I understand this process is extremely difficult" (A).*

*I guess just having the extra support. Having someone to talk to...that I could just share some of my frustration and some of my just, you know, my heartache. Strategies of what to do and what not to do. Kind of getting a second opinion. Well, should I do this, should I not do that? Just having somebody in the professional field be able to give me some advice on some of those things that I had struggled with (B).*

Three participants spoke about the importance of telling their stories and then receiving support in differentiating what is within and outside of their control.

*The biggest thing, I think, was knowing that it wasn't something I did or didn't do. That she had... it was an illness, and that it was important for me to take care of myself and get support for that. And that was kind of reassuring, that knowing that I can't make her do anything. I don't know if that was reassuring. But it was like there was only so much I could do (P).*

When asked about interactions with providers, all 8 participants who referred to the family navigator did so positively.

*I really valued the family navigator calling and following up and seeing if there was anything that we needed...like, I think that piece is very important. And I was actually surprised, like, knowing that my daughter is over 18, I was surprised that how much contact we were able to have, and I thought that that was a real positive (P).*

*And the family navigator phone calls...just felt great to have just another voice, another heart, another intelligent being who cares, in on the conversation and picking up with questions and concerns that the staff at the hospital doesn't necessarily...not that they don't have time. But it's just not their focus and their expertise, necessarily. So, those conversations I found to be really, really valuable, very comforting (I).*

*I think having the family navigator is a huge part of the well-being of the patients that go there because they can't live on their own. They need*

*support of whether it be family members or friends or significant others in their family to support them in getting well mentally (J).*

#### **4. Family caregivers' assessment of their experience of hospitalization was closely associated with their loved one's experience**

Nine family caregivers addressed their experiences with the team by citing both their own interactions and those of their loved one. For example, when asked if their experiences were mostly positive and what made them feel that way, responses were about their loved one's inpatient experience.

*We really feel like people are looking out for him. And we thought the team worked well together, and they did keep us informed well (E).*

*Well, one, she was very open and very willing to say things that were, you know, uh, were hard for my daughter to hear but that resonated with her. That she wasn't someone from the outside making judgments. She was somebody who was making connections (P).*

Family caregivers focused on how they perceived their loved one was treated by the team. Specifically, individualized interventions provided by the team were identified as positively impacting the course of treatment.

*They put him in a private room, which, I think, was very beneficial. They put him in an area that was a little quieter, which, I think, was very helpful to him. He gets very overstimulated quickly. So, that was good (E).*

*Yeah, I think some of the aides on the floor were, he would refer to them as, "so-and-so offered me this," and said that it's helped him. I mean, just in the kindest way. So, he felt that people were taking an interest in him and concerned about him (L).*

## **DISCUSSION**

Existing literature validated the themes of caregiver emotional support,<sup>1,5,7</sup> listen and collaborate,<sup>15,16,17,3,8</sup> education and guidance,<sup>16,17,3</sup> and family caregivers align their experience with their loved one's experience.<sup>1</sup> We identified similar themes, while also providing further specificity. Family caregivers confirmed that when the team actively listens to, collaborates with, and includes them in

treatment discussions, they feel better supported. Operationally, family caregivers want to be given time to digest information and ask questions, and to be able to add topics and questions during conversations.

Family caregivers value receiving education and believe that it, ultimately, impacts their loved one's health outcomes. However, it matters how the information is provided and by whom. Focused information makes family caregivers feel better supported and more prepared for discharge. They believe that opportunities to hear the same information repeatedly throughout hospitalization are essential. They also prefer receiving concrete, easy-to-understand tools to interact with their loved one. Education on diagnoses and medications are best explained by the physician, and access to the physician after discharge is valuable for clarifying information received during hospitalization. Yet, family caregivers' reported that emotional support, validation, and someone to listen to and normalize their experiences could be fulfilled by the team in a variety of roles. To family caregivers, the quality of the interaction was most important.

Family caregivers valued being able to discuss their questions and fears both during and after the hospitalization, and they appreciated having a dedicated person they could reach out to and who would periodically reach out to them. This dedicated family navigator provides family caregivers with a sense of support, validation, and ease of anxiety, as responses are given without judgment, and there is no real or perceived impact on the patient.

Although family caregivers were asked specifically about their experiences with the team, they often responded with views on both their experiences and their loved one's experiences. This response may suggest that family caregivers' assessment of their loved one's care influences the value they place on their own overall hospital experience. Or family caregivers may view their involvement in treatment as essential, in the sense that what is happening to their loved one is happening to them. Further, family caregivers connected favorable patient outcomes with their perception of good patient care and their positive interactions with the team.

## **CONCLUSION**

Our findings indicate that one role alone is insufficient to support the family caregiver, and

that family caregivers require support from a team to address their varied needs. Families appreciate a variety of support, including dedicated support from a family navigator. Future work is needed to develop a structured approach to supporting family caregivers across the inpatient team and determine its impact on both the patient and their family caregiver.

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