Living with a Mother with Chronic Depression: To Tell or Not To Tell?

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Abstract

Background: While there is mounting evidence that children of mothers with depression are at risk for increased psychopathology and disturbed family relationships, it is not yet known what the children's lives are like growing up with their mothers' depression. The purpose of the study was to understand children's experiences of living with mothers who have depression: specifically, how these children understand disclosing their experiences to others.

Method: Eight interviews were conducted with adult children of mothers with depression. Grounded theory methodology was used to collect and analyze the data.

Results: We identified three types of disclosing: self-disclosing, first disclosing, and selective disclosing. As the children grew up and began to understand their mothers' differentness as an illness, then as depression, their ways of disclosing changed, as did what they disclosed, where, when, and for what purposes. Most significantly, what is disclosed changed remarkably over time, depending on the offspring's perceptions of their mother's problem, the safety of disclosing, and the purpose and anticipated consequences of disclosing.

Conclusion: The results indicate that disclosing is not a single event but rather occurs in various forms, repeatedly, over time and in response to several factors.

INTRODUCTION

As many as 10 to 15 percent of new mothers have a serious episode of depression in the first year of their children's lives, and 50 percent of mothers of children younger than five years rate themselves as significantly depressed (1). Over the past 35 years, research on parents, especially mothers, with depression and their offspring has generated numerous reviews (2,3,4,5,6,7,8,9). This field of research is dominated by the notion that children of parents with depression are vulnerable for increased psychopathology as well as disturbed family relationships (8,10,11,12,13,14,15,16). The impact of mothers' depression on children is conceptualized via two mechanisms that are thought to be highly interrelated: A) "depressed mother" as a source of genetic transmission of depression to her children and B) "depressed mother" as a negative environment for children's development because she is not emotionally present or she is not able to parent. No study has yet documented a positive impact of a mother's depression on children. While there is

mounting evidence that children of mothers with depression are at risk, it is not yet known what the children's lives are like growing up with their mothers' depression.

Self-disclosure of an illness condition has been of great interest in the writings of clinical and counseling psychology as well as health services research. The researchers in these disciplines acknowledge that disclosing an illness condition regardless of its official clinical diagnosis is neither a simple nor single 'revealing' event (17). Many conditions influence one's decision whether to tell or not to tell, as well as what to tell and whom to tell (18). People who disclose experience the positive and negative consequences of disclosing, and their experiences influence their decisions about disclosing thereafter (1922). Self-disclosure in health services is conceptualized as a precondition to seeking care and services from health care providers in that one must tell why she or he sought care and services (22,23). Self-disclosure of illnesses such as cancer, HIV/AIDS, and mental illness have been studied and there is a role related to the perceived stigma

attached to the disclosed information ($_{24}$, $_{25}$). In these studies, they discuss mostly adults who disclose their own illness condition rather than another's condition such as a family member. Also, there is limited research regarding disclosure of a sibling's illness ($_{22}$). Also, to our knowledge, there does not appear be any research investigating mothers disclosing their depression to their children. Moreover, no research has explored children disclosing a parent's depression.

The initial purpose of our research was to understand the experiences of children whose mothers were depressed. The study used a qualitative, retrospective approach, asking participants to talk about how they remembered the experience as children and also their current understanding of this experience. From the analysis of this interview data, the focus of this study evolved to investigate how the children of mothers with depression disclose their mother's depression over time.

METHOD

Grounded theory (26,27) guided our data collection and analysis. Eight in-depth and in-person interviews were conducted with five adult children of mothers with depression. The authors received IRB approval for the study from the University of Wisconsin. Participants were recruited using the IRB-approved flyer that described the nature of the study, what was involved in participating in the study, and their right to choose or refuse to participate. The flyers were posted in local grocery stores in order to reach a broad population of people who grew up with mothers with depression. Participants indicated their interest by signing and returning the flyer. Each participant received \$10 for participating. Participants had lived with their mothers until they were between 15 and 20 years old. Their ages ranged from 26 to 50 and included three women and two men. Each of the participants' mothers had multiple hospitalizations for depression. Three participants were diagnosed with depression themselves. All interviews were audiotaped and transcribed for the analysis. The authors analyzed the data and presented the analysis periodically to a grounded theory research group to open the analysis to the group members' interpretations. Three of the five offspring were interviewed twice so that the authors could refine the ongoing analysis. The interviews were approximately 1.5 to 2.5 hours for the first-round interviews and the second-round interviews taking approximately 0.5 hours. The study was conducted using the grounded theory method, beginning with open coding to analyze initial interviews, followed by axial and selective coding in later interviews.

Consistent with the grounded theory methodology of grounding the phenomenon of inquiry in the perspective of the participants, early interview questions were broad and open for the participants so that they could relate whichever experiences they felt were relevant to living with a mother with depression. Additional unstructured questions were used throughout the study in order to test, clarify, and modify the developing conceptual matrix. Early interview questions included: "Tell me about your childhood," "Tell me about yourself," and "Tell me about what it was like to live with your mother." Several theoretical directions were identified from the first two interviews: A) older siblings taking on a parenting role in order to protect younger siblings, B) learning to deal with an emotionally versus physically absent parent, C) discovering differentness in a parent, D) revealing or disclosing their mother's differentness, and E) finding explanations for their mother's behavior in order to protect themselves. Although, each of these directions could be pursued as a separate line of research; we chose to pursue revealing or disclosing a mother's illness. Later interview questions were asked to open-up and refine the analysis of data relevant to disclosing. Some of these later interview questions included: "Tell me about the first time you talked to someone about your mother's depression as a kid," "How did you learn about your mother's depression?" "Tell me about the first time you talked about the depression or your life with a depressed mother when you were an adolescent." "What did you learn from talking to people at each of these earlier times?" "What happened when you talked about your mother's depression?" "When you were a child, what was your understanding of what was going on with your mother? Did someone explain it to you?" "How do you talk about your mother's depression now?" "How do you decide whom to tell?" "Is there a difference in how you talk to someone, for example, someone you are close to versus someone in a new relationship? Between a person you meet often and a person you meet less often? Between someone who knows about your family and someone who does not?" "What are safe and unsafe places and situations for talking about it?"

RESULTS

Three types of disclosing were identified: A) self-disclosing as discovery, B) first disclosing, and C) selective disclosing.

Figure 1

Table 1: Definitions of Three Types of Disclosing

Type of disclosing	Definitions
Self-disclosing as discovery	The children's realization to themselves that their mothers are somehow different from other mothers.
First disclosing	The first time the children revealed their experience with their mothers to other people.
Selective disclosing	The children's deliberate disclosure or non-disclosure of their experience with their mothers to other people.

Disclosing was not a single episode, but rather occurred as a multipoint process, with subsequent disclosures differing significantly from preceding ones. Offspring's understanding of their mothers' depression served as the context of disclosing; their way of disclosing changed from self-disclosing to first disclosing to selective disclosing. What they disclosed depended on their perception of the problem, their perception of safety, the purpose of disclosing, and the anticipated consequences of disclosing.

Self-disclosing as discovery: Self-disclosing as discovery is defined as the children's realization that their mothers are somehow different from other mothers. Self-disclosing happened when these participants were relatively young children, mostly in elementary school. Even though the children did not understand their mothers' depression, they discovered that their mothers were unusual or different from other mothers.

I knew she was unusual. I knew that when I was in grade school. She wasn't like the other mothers, she didn't act the same way, she didn't do the same things, she didn't know how to do things... It was in grade school that I realized that my mother didn't know how to do those things. I don't know why my mother didn't know, or she just couldn't... I never forget this, one of the most outstanding things in my life. She was going to make chicken sandwiches, and this day in particular, I don't know why it was, if she was particularly depressed or whatever, but she simply picked up a big piece of chicken and plopped it between two pieces of bread [laugh]. That's when I realized my mother is different.

Not understanding that their mothers had depression while discovering their mothers were different or unusual had several consequences that the children had to bear while they were growing up. The children were not able to separate the symptoms of depression from who their mother was. All adult children in this study perceived their mothers as remote and unresponsive to the emotional and physical needs of her children; someone who was "not there" for them.

She was a very remote person. She was there but not to any

extent at all. She had gone somewhere and never returned. I never sat on her lap at all. None of us [siblings] did.

She didn't want to be bothered. She didn't even want to be bothered to help us get dressed for school when we were little. It was too much bother. I remember, I was older than one of my sisters and we were half way to school, she would have been five years younger than me, and she had no underpants on, no nothing... We were allowed to JUST GO. She never made us take a bath, or wash up or do the routine child stuff. She just wasn't there.

One participant in this study described that her perception of her mother had a residual effect on her life as she was trying to gain her mother's love—which she believed to be lost when she was young—until she finally realized that her mother was unable (versus unwilling) to be there for her due to her depression. Two other participants attributed their feelings of insecurity in forming intimate relationships to the lack of emotional bonding with their mothers.

I think I definitely would feel more secure about myself and my relationships. People would have been a lot easier for me... in terms of trust or intimacy. I feel some things with my mom just made me skeptical of... relying on people.

Another consequence was that, because the children were sometimes blamed for making their moms sad or angry, the children were ashamed about themselves, thinking that something was wrong with them or that they were bad for making their mothers sad or angry.

I did not know when I was growing up my mother was depressed. Some days she would be in a good mood and be happy, and other days she would be real crabby and mean... As a child I didn't think that was her problem. I thought that was my fault that I made her sad and unhappy, and I felt like I'm a bad person because I was making her feel sad. She never told me that wasn't my fault and she did blame me for making her sad.

They also felt embarrassed about having a mother who did unusual things or who was different; therefore, they often tried to cover up the situation, construct reasonable explanations, talk about it only with siblings, or try to keep people away.

You tried to explain to your friends why your mother did odd things. I remember trying to cover up. That's the word, "cover up." All the time she did these odd things and you knew you had to... you had to survive out here. I did that all

the time, all of us [siblings] did. Those kind of things happened all the time, and you found yourself actually lying for your mother to cover up.

My mom was upstairs in her room crying and my friends came over and I wouldn't let them in. I didn't know how to explain, I felt embarrassed, I made up some excuses. I didn't want my friends to come in the house and hear my mom crying. It scared me.

First disclosing: First disclosing is defined as the first time the children revealed their experience with their mothers to other people. Some participants first disclosed when they were young and some others first disclosed as adults. Importantly, there was a difference in what was disclosed between the young disclosers and the adult disclosers. Young children first disclosed their mother's depression in terms of a general illness or something unusual rather than depression, while the adult disclosers disclosed it as depression.

I remember the first time saying to people when I was probably ten or something, saying to someone that my mom was sick. I didn't use the word depression, but I just used the word sickness.... When I had actually had an understanding of what it was, probably wasn't until I was fourteen or fifteen that I actually said to someone that my mom had been depressed.

Adult disclosers first disclosed their experience with their mothers in terms of their mothers having depression. The age range of the first disclosing by adult disclosers in this study was in the teens and early 20s. These adult disclosers had come to learn about their mothers' depression and disclosed it as they struggled to figure out their early lives with their mothers: what had been troubling the children and their family for such a long time. Because the children, when they were young, had no way of knowing that their mothers were depressed, most of them had a hard time identifying with what was going on in their family. As the children grew older and moved away from their parents' homes, they were increasingly able to compare their family to other families. Through this process, they came to identify or discover their mothers' depression. Sometimes these comparisons were offered by a therapist, and other times they learned about their mothers' depression by talking to knowledgeable friends. As their understanding of their mothers changed from believing their mothers were just sick or unusual to understanding that their mothers were depressed, what they disclosed about their mothers also changed.

I didn't know my mom has been depressed. Nobody talked to me. But I knew that my mom was different all of my life, but to us [siblings] it was a way of life. We were born in that environment and that was all we knew till I grew up and moved away from my parents' home.

The consequences of this first disclosing varied. Sometimes people were frightened, lost friendships, or angered family members by disclosing to outsiders. Sometimes offspring stopped talking about it or sought help. Who they disclosed to and the responses from that disclosing influenced future disclosing. Significantly, only one woman in this study who talked to a therapist while in her 20's had positive consequences from first disclosing: her experience with her mother's depression was validated. For all of the participants in this study, regardless of their understanding of depression and how old they were, talking about their mothers' illness was perceived as talking about themselves and their families. This was communicated clearly with instructions from family members, especially parents, not to talk about it to others. "My family was really ticked off at me because I talked about it to my friend. It was like an unwritten rule that we just don't talk about it."

Not understanding their mother's depression, being told not to talk about it, and not receiving any guidance in how to deal with the situation seem particularly difficult for the young disclosers. These young disclosers were confused about what to say and do when somebody asked about their mothers. They often felt compelled to make up excuses for their mother's unusual behaviors or illness. One man remembers that his mother went to the hospital after having a crying episode for several days:

My father denies this but I remember him saying that we shouldn't tell anyone about this, this is a family matter, and so when people would ask I would just say my mom was sick, and when people say what kind of illness, then, I don't know. I'd make something up, whatever... I was a kid. I don't think I dealt with it at all. I mean no one certainly helped me.

Selective disclosing: Selective disclosing is defined as the children's deliberate disclosure or non-disclosure of their experience with their mothers to other people. For all offspring of mothers with depression in this study, selective disclosing was the most sophisticated and important type of disclosing. It is sophisticated in that the offspring deliberately disclosed or did not disclose in order to avoid anticipated negative consequences and/or to gain positive consequences. It took consequences into account in deciding

whether, when, and to whom to disclose to. After experiencing consequences, mostly negative, from previous disclosing, they developed ways of protecting themselves and their families from negative consequences of disclosing. Offspring also learned to use selective disclosing to gain: understanding, support, and/or sympathy from others about their experiences.

Their perceptions of safety influenced their decisions about whether to disclose and to whom. Safety was determined by anticipating the listener's ability to be empathic or sympathetic, the children's beliefs about whether they were responsible for their mothers' depression, and their perceptions about societal acceptance of talking about depression and other personal matters. Participants felt safer when they talked about their mothers' depression with people who have lived through some tough life situations, with a close friend, or with a therapist. This is because the offspring could anticipate these listeners' responses more likely to be empathetic or sympathetic. When they were less certain about the type of response they would receive, participants felt less safe talking about their mothers' depression with people at work who they would have to face every day thereafter and with people whose lives they believed were relatively untroubled.

The average person doesn't understand what it was like because they haven't lived through it. They don't know what it's about and they think "oh, my God, you are a bad daughter; you are very untrustworthy, you are very bitter. There is something radically wrong with you. Why are you talking about your mother in such a negative tone?" It's something that they really don't understand because that hasn't been their life and they see mothers as warm, loving, and caring. They perceive "mother" in a different light than what I do.

I've found that people who've had sort of some tough experiences, any kind in their life, they are more likely to listen to my own tough experience in my family and they understand. Usually, the least understanding people who aren't worth telling this sort of thing are people who've had everything go well for them, their family is fine, and they are fine. They can't understand why other people aren't fine.

Over time, the offspring developed several strategies to assess the safety of disclosing. First, before they decided to disclose, they learned something about the listener's life and whether the listener had had any tough life experiences. Second, they "skimmed over" (quickly assessed) a potential

listener, attending to what the person focused on when recounting incidents and describing events. "When people start talking, whether they are talking about people and feelings and certain ideas or they are just talking about objective ordinary things." Participants assumed that when someone talked about people and feelings they would be more likely to understand their situation and be more sympathetic. Third, the offspring monitored the potential listener's responses as they disclose their mother's depression. "How they respond to the things that you say. You can tell by their voices, their looks on their face, and their responses to you in how they are going to react on what you are going to say."

The adult children in this study identified beliefs about their role in the depression as relevant to the safety of disclosing about their mothers. Regardless of the listener, when the children came to an understanding that they were not the cause of their mothers' depression, they were more likely to feel safe and to talk about it. Their beliefs that they were not responsible for their mothers' depression or sadness provided a sense of boundary.

I didn't know what depression was like until I started to see a therapist in college and started learning about... mental illnesses that I realized that she [mother] had been depressed. And I could see that I wasn't a bad person, that wasn't my fault that her feelings were sort of her responsibility and I did not need to be affected or ashamed.

All adult children in this study acknowledged that the societal trend to openly talk about personal problems and unusual experiences helped them to disclose their own experiences.

It seems like it is becoming easier as a society to talk about these things because there are books out on it, it is being talked about on television, on the talk shows, and it's more commonplace for people to come out and talk about their problems.

However, despite a general societal trend to openly talk about unusual experiences, all participants in this study acknowledged that the stigma attached to mental illness including depression often prevented them from talking about their mothers' depression. This is because their mothers' illness was relevant not just to their mothers but also to themselves in that their mothers' depression may have been genetically passed to them.

When you tell people that your mother is mentally ill... I've

noticed that feeling just that they are like, "oh, well one of your parents is mentally ill, maybe you are too, because you are her child."

DISCUSSION

Children of mothers with depression have long been subjects of research interest because they were considered to be vulnerable to or at risk for psychopathology in their development. No study has yet reported on those children's experiences of living with their mothers and how they talk about their mother's depression. The findings of this study begin to illuminate children's experiences of living with their mothers with depression and how they disclose their mother's depression over time. It is clear from this study that disclosing a mother's depression does not happen in a single episode but rather develops as the children deal with the information over time. As children of mothers with depression grow older and come to understand their mother's depression, their disclosing of it changes from a description of the mother being unusual or being sick to having depression. All children in this study felt they were responsible for their mother's depression, thinking they made her angry or sad; therefore, talking about their mothers' depression implicated themselves. Consequences of first disclosing changed the way the children disclosed their mothers' depression; most of them decided not to talk about it again until they reached a new understanding of their mothers' depression. Their sense of self and perceptions of safety influenced the children's decisions about how and with whom they share information about their mothers' depression. The children of mothers with depression could talk about the depression when they had come to understand that they were neither the cause of nor responsible for it. In addition, the stigma attached to depression and mental illness in general prevented them from talking about their mother's depression. This silence was due to fear that others knowing depression can be genetically inherited, may consider the children to be depressed as well. Therefore, the children learned to selectively disclose their experiences with their mothers; they disclosed only when they perceived the condition as safe in terms of anticipated consequences. They also learned to monitor for cues to how the listener would respond.

A number of researchers in the areas of cancer and HIV/AIDS have investigated how patients with these conditions talk about their illnesses (19,20,21, 24,25). These studies consistently find that people weigh the consequences of disclosing such information and therefore, carefully select

when and with whom they disclose information about their illness. However, these studies do not investigate how the children of these patients talk about their parents' illnesses, nor do they describe how the parents' illnesses influence their children's sense of self. While there is mounting evidence that a mother's depression may put her children at risk for negative psychosocial development (2,3,4,5,6,7,8,9,10,11,12,13,14,15,16), no study has so far investigated the lives and experiences of children of mothers with depression and how these children deal with such information. Likewise, no study has examined the question of how mothers with depression disclose the illness to their children.

Our study finds clear evidence that a mother's depression influences how her children think of themselves. Not being able to understand their mother's depression, all participants in this study, as children, believed themselves to be the cause of their mother's depression and felt responsible for it—this is definitely a burden that children should not bear. This finding is consistent with the perspective of researchers and clinicians in the field that "children readily assume responsibility for their parents' problems and are often fearful of talking about them because they think they will be blamed or separated from their families" (28).

This study raises several questions for health care services research and health care clinicians. First, who is the appropriate person to explain a mother's depression to her children? Should it be the mother herself, the father, the clinician who diagnoses the mother's depression, or someone else? Second, how should a mother's depression be explained to children of different ages? Is there any age that is appropriate for learning such information? One qualitative study (29) in an area of cancer research described 19 to 25 years as an appropriate age for comprehending a mother's cancer as a genetic vulnerability for the children themselves. Would that apply to the case of depression? Even if so, what can be done for children younger than that age? Third, when is the proper time and setting for intervening with women who are depressed? Pre- or post-partum? In a primary care or specialty care setting? And who should intervene—generalists or specialists? Should a clinician initiate the process, or should she/he wait until the patient brings up the issue? Fourth, how can the health system and clinicians help mothers with depression and their children?

Findings from this study raise solid conceptual questions that can guide future research. However, the findings are

limited by some major shortcomings. First, eight in-depth interviews with five offspring of mothers with depression comprise a very small sample for describing how children experience their mothers' depression in the context of disclosing it. A larger sample would provide an opportunity to confirm theoretical saturation. Second, even though retrospection made it possible to describe changes in disclosing over time, it limits accountability because the findings relied on participants' memories. A prospective study may be useful for capturing the children's experiences as they unfold. Third, although there were several conceptual directions related to experiences of living with mothers with depression, this study chose only one such direction due to time and fiscal constrains. Investigation of the other conceptual directions in future studies will help us to more fully describe children's experiences of living with mothers with depression.

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