NIH Public Access

Author Manuscript

Adm Policy Ment Health. Author manuscript; available in PMC 2013 January 22.

Published in final edited form as:

Adm Policy Ment Health. 2006 March ; 33(2): 133–145. doi:10.1007/s10488-006-0036-4.

What Teens Want: Barriers to Seeking Care for Depression

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Abstract

This study examined the experiences of teenagers seeking and receiving care for depression from primary care providers. We investigated teens' perceived barriers in obtaining care to determine how primary care can effectively address depressed teens' stated needs. In-depth individual (n = 15) and focus group (n = 7) interviews with adolescents were conducted and analyzed using grounded theory and prominent themes were identified. Teenagers reported faring best when providers actively considered and reflected upon the teenagers' developmentally appropriate desires to be normal, to feel connected, and to be autous. These goals are achieved by providers establishing rapport, exchanging information about depression etiology and treatment, and helping teens make decisions about their treatment. To the extent that providers improve efforts to help teens feel normal, autonomous, and connected, the teens report they are more likely to accept treatment for depression and report success in treatment.

Keywords

depression; adolescents; identity; primary care; patient-provider communication

INTRODUCTION

Major depression is a chronic, common disorder among adolescents, with lifetime recurrence rates estimated at about 70%, and most (40–60%) recurring within 2 years (Birmaher et al., 1996; Lewinsohn, Clarke, Seeley, & Rohde, 1994). Additionally, almost all who experience depression as adolescents experience another episode as an adult (Aseltine, Gore, & Colten, 1996). Depression is strongly associated with increased risk of suicide, the third leading cause of death among adolescents 15–24 years old (Centers for Disease Control, 2002).

Depressed individuals often present with difficulties in school, interpersonal relationships, and occupational adjustment; increased tobacco and substance abuse; and suicide attempts (Birmaher et al., 1996; Luber et al., 2000; Pincus & Pettit, 2001). Academic failure and school absences are particularly important consequences for adolescents: these events can result in the teenager being separated from his or her peer group, rejected from the peer group, and diverted from a normal developmental trajectory. Adolescent depression currently accounts for a substantial portion of the health care costs incurred by this age

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group (Birmaher et al., 1996), which are expected to increase as the prevalence of depression among children and adolescents rises and incidence occurs at younger ages (Gjerde, 1995). Despite these changes, rates of mental health service use are far below rates of mental health disorders (Dew, Dunn, Bromet, & Schulberg, 1988; Hirschfeld et al., 1997; Logan & King, 2001; Offer, Howard, Schonert, & Ostrov, 1991; Wu et al., 1999), especially among adolescents.

Mental health treatment is now often coordinated by primary care providers (Regier et al., 1993), whose roles have expanded to include assessment, diagnosis, determination of need for care, and care coordination (Rogers, May, & Oliver, 2001). Despite these changes, only half of adolescents experiencing a depressive episode contact someone in the health care sector (Ustun, 2000). In community samples, only 21–34% of adolescents meeting criteria for major depression have received medical attention (Flament, Cohen, Choquet, Jeammet, & Ledoux, 2001; Lewinsohn et al., 1994).

We address this underutilization of services from the conceptual framework of the Theory of Reasoned Action, in which individuals' analysis of anticipated risks and benefits of specific behaviors (such as seeking medical treatment for depression) influence behavioral intentions and treatment seeking (Azjen, 1996). Azjen describes internal and external influences on behavior. External influences are either unchangeable or not easily modified (such as race or prior experiences), but internal variables, such as behavioral beliefs, attitudes toward behavior, subjective norms, and normative beliefs, may be changed through education or experience. This study focuses on these internal variables.

Although there is evidence that primary care clinicians tend to be sensitive to manifestations of depression in adults and provide appropriate treatment and follow-up services for them (Shye, Freeborn, & Mullooly, 2000), limited research exists on how adolescents fare. While adolescents surely face barriers to mental health care similar to those adults face, adolescents may face obstacles to treatment beyond those faced by adults.

For example, teens may be concerned about discussing "personal" issues with their primary care provider (Pommier et al., 2001). Teens are sensitive to issues of confidentiality and often are reluctant to ask health providers even general health questions due to confidentiality concerns (Ackard & Newmark-Sztainer, 2001). The personal nature of emotional problems may also make teens reluctant to discuss these issues with their parents. When parents lack knowledge of teens' problems or have different views of their symptoms, obtaining services may be particularly difficult (Wu et al., 1999). Parents may also be more likely to overlook depression and other internalizing disorders because they often manifest in less disruptive ways than externalizing disorders such as Attention Deficit Hyperactivity Disorder (Wu et al., 1999). Consulting professionals for help on personal issues is also contradictory to adolescent goals of establishing autonomy and reducing dependence on adults (Logan & King, 2001). Although adolescents may have more avenues for obtaining help than children, they may resist adults' attempts to convince them to seek help for personal issues.

Depressed individuals are often apprehensive about approaching primary care providers, anticipating the possibility of negative and unwanted consequences of their disclosure and experiencing considerable anxiety about how to present their symptoms to primary care providers (Rogers et al., 2001). Participants in our study, for instance, stated that they disclosed information to providers carefully to minimize the risk of not being treated or not being legitimated as needing care, while attempting to ensure they were not assessed as more severely depressed than they were (Wisdom & Green, 2004).

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Another potential consequence of a mental illness diagnosis is stigmatization and rejection (Link & Phelan, 2001, Link et al., 1999). The public inaccurately views depressed people as more likely to be violent than troubled people (Link et al., 1999). Depressed adolescents, especially girls, are more likely to be viewed as less popular and less likeable by their peers than their non-depressed counterparts (Connolly, Geller, Marton, & Kutcher, 1992). Additionally, the experience of stigmatization can predict adverse mental health outcomes (Markowitz, 1998).

Individuals anticipating a diagnosis of depression may also be reluctant or unable to take responsibility for attending to the multiple tasks (e.g., interacting with health care providers, adhering to treatment, self-monitoring symptoms, managing illness effects, engaging in healthy activities) required in managing a chronic disease (Brown et al., 2001).

The experience of discussing depressive symptoms with one's health care provider is significant in individuals' cognitions of self and their conceptualization of depression and its causes (Rogers et al., 2001; Gammell & Stoppard, 1999; Wisdom & Green, 2004). Since the development of depression often includes sufferers' attempts to identify a cause for their symptoms (situational vs. organic), seeking treatment and directly addressing the issue may exacerbate the discomfort in both illness identity and the search for explanations (Estroff, Lachicotte, Illingsworth, & Johnston, 1991). Given the impossibility of disassociating one's self from the condition (Rogers et al., 2001), obtaining a diagnosis of depression may be particularly difficult for adolescents who are in the process of developing a mature identity and do not want a "mental illness identity" (Charmaz, 1997).

Many adults view treatment of depression through medical care systems with suspicion and favor alternative approaches, such as lifestyle interventions (Jorm et al., 2000). Adults often visit physicians for emotional problems only when lay resources are exhausted (Angermeyer, Ratschinger & Reidel-Heller, 1999). Although adolescents are aware of both medical and non-medical help agents (e.g., physicians and school counselors) and are aware of how to access them, they also prefer non-medical interventions (e.g., high school counselor) to entering treatment with a medical professional (Offer et al., 1991).

Teens may be concerned that talking to a medical professional about depression will result in being prescribed antidepressant medication. While the topic has not been studied extensively in adolescents, adults tend to be suspicious of psychopharmacological treatment (Offer et al., 1991; Jorm et al., 2000) and believe it is counter to their goals of personal empowerment (Gammell & Stoppard, 1999). College-age young adults also express ambivalence about taking medication (Venarde, 1999), stating concerns about being stereotyped as a "person who takes antidepressants" and a dislike of feeling reliant on medication to feel better. Recent controversy about possible suicide-precipitating effects of anti-depressant medication among adolescents may exacerbate youth and parent concerns about pharmacotherapy (Whittington et al., 2004).

There is some evidence that teens who visit primary care with depressive symptoms are likely to be prescribed antidepressants. Antidepressants are often a leading choice in primary care (Park & Goodyer, 2000), and a recent study found that 36% of incident child and adolescent mood disorder cases were dispensed a psychotropic medication within 30 days of diagnosis (DeBar, Clarke, O'Connor, & Nichols, 2001). Additionally, teens who first visited primary care providers were more likely to receive antidepressants than those who first visited specialty care professionals (DeBar et al., 2001).

Teens often view varying degrees of "storm and stress" as normative during adolescence and not cause for seeking medical attention (Flament et al., 2001). In addition, depressed adolescents often underestimate the severity of their symptoms and do not correctly perceive

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their degree of psychological risk (Culp, Clyman, & Culp, 1995). People often recognize somatic symptoms but do not recognize depression (Dew et al., 1988; Hirschfeld et al., 1997). Among those who recognize their depression, it is often attributed to situational rather than organic problems, and medical remedies are not seen as appropriate (Brown et al., 2001).

Despite identification of these issues, previous studies on adolescents' experiences of depression, help-seeking for depression, and utilization of professional mental health services have not addressed the entire process of recognizing depression, deciding to seek help, and obtaining assistance through primary care. Most have used paper-and-pencil surveys (e.g., Dew et al., 1988; Culp et al., 1995) or a combination of surveys and structured clinical interviews (e.g., Flament et al., 2001; Logan & King, 2002). Unaddressed in this previous work are adolescents' own words regarding their conceptualizations of depression etiology. This is important to investigate, as perceptions of the causes of depression are related to management strategies (Brown et al., 2001). Also unaddressed in previous work are adolescents' views of interventions and their perceptions of the helpfulness of those interventions. Since professional medical services may be the most appropriate option for many teens experiencing symptoms of depression, it is important to address teens' concerns about approaching a medical provider for evaluation and treatment of emotional problems.

This study investigates the experience of recognizing and seeking treatment for depression in a sample of adolescents. We used qualitative methods to explore how adolescents identify depression in themselves (or have it identified for them) and how they experience the process of seeking help. We identify factors related to the types of services sought and conceptualizations of professional medical and mental health services that affect treatment-seeking.

METHOD

To understand teens' experiences of obtaining medical care for depression, we used a modified grounded theory approach, based on the work of Strauss and Corbin (1998). Grounded theory allows participants to present their experience in their own words and facilitates the theory development based on the variety of participants' beliefs and behaviors. Grounded theory methodology includes the use of an emergent design, theoretical sampling, saturation, and concurrent data collection and analysis. Our methodology differed from this model to the extent that we used purposive rather than theoretical sampling. Purposive sampling involves the deliberate sampling for heterogeneity (Blankertz, 1998) on factors designated as important to the concepts being studied (e.g., gender, treatment status), whereas theoretical sampling seeks a sample that presents heterogeneity of concepts.

Setting

The research was conducted in the Northwest Division of Kaiser Permanente (KPNW). KPNW is a non-profit group model health maintenance organization that provides outpatient and inpatient care to approximately 450,000 members in northwest Oregon and southwest Washington. The demographic characteristics of the KPNW population are similar to those of the community it serves (Freeborn & Pope, 1994). The racial/ethnic makeup of the community is close to 90% white (non-Hispanic), with small percentages of persons with African, Hispanic, and Asian heritage. About 10% of KPNW membership is between 12 and 18 years old.

Much care for mood disorders, including depression, is provided by primary care clinicians (Shye et al., 2000), although HMO members may self-refer to the HMO's specialty mental health department or be referred by their primary care clinicians. KPNW's electronic

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medical record system contains information on patients' medical histories, procedures, diagnostic findings, and treatment. Members can opt out of having their medical records accessed for research purposes when they enroll in the health plan. Oregon and Washington state laws allow teenagers age 14 and over to obtain mental health treatment without parental consent. All procedures were reviewed and approved by KPNW's Institutional Review Board.

Sample Selection and Recruitment—In order to obtain the best possible representation of adolescents' views, we deliberately sampled for heterogeneity (Blankertz, 1998). We chose a sample of teenagers who varied in age, gender, presence of depression diagnosis, and prior treatment, and we used multiple methods (interviews and a focus group) to obtain information. Achieving a broad sample of participants is essential to obtaining variable viewpoints for qualitative analysis. For all parts of the study, both teen and parent consent was required. All participants received $10 gift certificates.

We recruited a sample of adolescents from a local high school for one 90-minute after-school focus group interview (n=7). Announcements posted in the school advertised participation in a focus group about "mental health and health care" and offered refreshments and a $10 gift certificate. HMO membership and diagnosis and treatment status of these individuals were not assessed.

To obtain variability regarding teen treatment experiences for individual interview participants, we recruited teens from KPNW using a variety of methods. All teens in the individual interview portion of the study met the following inclusion criteria: (a) current KPNW members; (b) aged 14–19; (c) diagnosis of major depression, dysthymia, or depression not otherwise specified from a primary care provider; (d) no history of psychotic disorders, mania (including bipolar disorder), or mental retardation; and (e) residence in the Portland, Oregon-Vancouver, Washington metropolitan area.

To identify teens who had received a diagnosis of depression from a primary care provider but who had not obtained treatment, we used health plan records to identify HMO members who met inclusion criteria and who had *not* had HMO treatment for depression. Depression treatment was defined as visiting a specialty mental health care provider at least once or receiving a prescription for antidepressant medication. Once these teens were identified (n=157), we sought their primary care providers' permission to contact them. Teens for whom primary care providers granted contact permission were sent letters, telephoned, and invited to participate in the study. We required both parent and teen consent to participate. Some teens from the non-treatment list subsequently obtained treatment (either began taking antidepressant medication or saw a specialty mental health therapist or psychiatrist) prior to contact or the interview; these teens were reclassified as "treated" participants. We continued recruiting until we had exhausted our list of teens who (a) met inclusion criteria; (b) had permission from their primary care provider to be contacted; (c) were willing to participate; and (d) whose parents consented to their teen's participation (n=5).

To recruit treated teenagers, we contacted participants in a prior study of a depression intervention (n=152) after obtaining permission from their primary care providers. Teenagers from the intervention group of the study received cognitive-behavioral therapy from master's level mental health therapists, while control group participants received treatment as usual from their primary care provider; all teens had started SSRI medication (Clarke et al., 2005). These teens met inclusion criteria indicated above. Teens were recruited during telephone follow-up interviews for the intervention study (n=10).

Treated and untreated interview participants from the health plan (total *n*=15) participated in a single 90-min individual interview.

Interview Guides—The interview guides for the in-depth individual and focus group interviews included questions about (a) participants' understanding of why they were depressed (e.g., Tell me about your depression; What caused your depression?); (b) concerns about approaching professionals for help (Tell me about how you got a diagnosis of depression; What kinds of things made you want to/not want to talk with a professional about depression?); (c) the process of obtaining professional treatment, including what office visits were like (Tell me about the first time you talked with a professional about depression); (d) relationship with primary care providers and how that affected views of depression and treatment (What was your relationship with your doctor like?); (e) willingness to engage in offered treatment (What kinds of treatment were discussed? Tell me about how you decided what to do); (f) perceived effectiveness of treatment (Do you think medications for depression/therapy work? Why/why not? Did they work for you?); and (g) how primary care providers, mental health specialty care providers, and other helping professionals can improve this process (What, if anything, do you wish happened differently?). We changed wording of the interview guides slightly to make them appropriate to group vs. individual format and treated vs. untreated status. Copies of the interview guide can be obtained by writing the first author.

Interviews and Analysis—Individual interviews were completed by the first author and a graduate research assistant at the Center for Health Research at KPNW in person (*n*=13) and over the telephone (*n*=2). The focus group interview at the high school was completed by the first author and a research assistant.

In using grounded theory methods (Strauss & Corbin, 1998) for the individual interviews, this portion of the study did not begin with explicit hypotheses to be tested. Instead, individuals were asked broad questions about their experiences, starting with the question, What is depression like for you? We also asked about what led to the participants receiving a diagnosis of depression and what the process of meeting with their primary care provider was like. Based on the results of earlier interviews and identification of issues that teens reported, we modified questions for later interviews and added questions that were more specific (e.g., How did the topic of depression initially arise with a primary care provider?). We continued modifying questions and interviewing teenagers until we determined we were not obtaining any new information on the topic.

Interviews were tape-recorded, and field notes documented additional information, such as emotional content and non-verbal communication. Field notes and tapes of interviews were transcribed verbatim, and both were included in analyses. We analyzed interview and field note text using the Atlas.ti 4.2 software system (Scientific Software Development, Berlin), which aids coding, organization, and retrieval of text for qualitative analysis.

We refined our themes through an iterative process. We examined the data and the generated open codes to form hypotheses about teens' views, which were then recompared to the data and codes. This analysis led to modification and focus of interview questions and further analysis. During each stage of the analysis, we recorded thoughts, ideas, and hypotheses about the process. This constant comparative analysis helped further refine the themes. Researchers conducting data analysis achieved 80–90% correspondence during coding.

We took several steps to increase methodological rigor: (a) multiple researchers participated in data collection and analysis to ensure multiple viewpoints and extensive discussion of perceptions of data, (b) we sought consensus on coder agreement to ensure consistent and

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reliable coding, (c) we considered rival explanations while analyzing data to facilitate trimming and validating the theoretical scheme, and (d) we compared researcher and theoretical findings to validate our findings (Blankertz, 1998).

RESULTS

Focus group interview participants were 5 female and 2 male 15-year-old high school sophomores. Although depression and treatment history were not directly assessed, three focus group participants disclosed that they had received psychotherapy or antidepressant medication at some time.

Individual interview participants (treated and untreated) were 8 female and 7 male teenagers aged 14 to 19 years (mean = 16.3, $SD = 1.5$). Thirteen teenagers were white (non-Hispanic), and two were Hispanic. Some participants were in treatment (anti-depressant medication and/or psychotherapy), but most reported no longer engaging in medical treatment. Two participants were morbidly obese, and three reported severe medical issues, such as fibromyalgia or a seizure disorder.

We found in our analyses that teens desire to be normal, to be connected, and to be autonomous. These desires often facilitated or limited teens' decisions regarding interacting with and accepting medical advice from providers, and teens reported increased satisfaction with and benefit from treatment services when these desires were addressed.

Theme 1: Being Normal

The most prevalent theme in teens' descriptions of their experiences was the pressing desire to be normal.

> I thought that I might need to [seek help] when I felt sad all the time. I knew that wasn't really normal. (14 year old untreated female)

A number of the teens had experienced significant life stressors, such as physical or sexual abuse that contributed to their feelings of not being normal. Some teens observed that it was not just the stress they experienced, but their cognitions about the events that led to depression and feeling abnormal.

> I think that [depression] relates to the stress that's involved in certain things. For me I'm pretty stressed about ways of improving myself and being smarter and always learning more so I can stay ahead … I'm sure it's my thinking that's stressful. I'm always working harder towards it. There are people … they screw up something they know they shouldn't have [and] they're beating themselves up on the inside. (17-year-old untreated male)

In order to appear "normal," teens tended to minimize symptoms to themselves and others. Others minimized symptoms by acting as if their stress was normal, and by initially rejecting the diagnosis of depression.

> They gave me the drugs, the Paxil and stuff like that, but 'I don't need that' is what I told them and I just took myself off [medication] and I basically refused treatment from a therapist too. I went and saw a therapist twice and then just decided, 'I'm a teenager, I'm supposed to have troubles,' so I just dealt with it on my own. (17-year-old treated male)

Teens were able to identify some "red flags" of behavior, thoughts, or feelings that departed from the teens' view of "normality" and thus indicated they needed assistance. For example, one teen reported that after months of symptoms of low energy, low self-esteem, and hypersomnia, only when he started feeling suicidal did he ask for help:

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> Moderator: How do you know when you should ask [for help]?
>
> Participant: When I started contemplating suicide. I look at scissors and think if I can slit my wrist with it or cut, do harm to myself. [pause] But it's so hard to talk to people. People start to notice different things about me too, that I'm not acting the same. That's when my parents got me involved with this [therapist]. (15-year-old treated male)

Teens were reluctant to approach primary care for help with depressive symptoms for many reasons. Teens often had high expectations of themselves and viewed visiting a primary care provider as a weakness.

> I thought about [talking to a doctor] a little bit but I pretty much had told myself that really I was just stupid and it wasn't something that needed be looked at like that, that I was just over-reacting to things … I didn't want somebody to look at me and say 'what are you thinking?' I was highly afraid of somebody telling me that what I was feeling wasn't right, that I shouldn't be feeling this way. (19-year-old untreated female)

Teens' reluctance to consult medical providers about their concerns was also strongly related to issues about identity. Most teens tended to reject the possibility of an identity as an ill person and presented depression as something they *have*, not something they *are* (Estroff, 1989). In general, these teenagers did not want to be seen as "depressed people."

> A lot of people, when they think of mental health they think you're *mental*. So I guess it's the name. When people say mental, you're *mental*, you have *problems*, and I know I don't have problems like that. (17-year-old untreated female)

Many assumed that talking with their primary care provider about depression would lead to receiving antidepressant medication. Although their information about medication varied considerably, most rejected the notion of "being medicated," in large part because they viewed it as counter to their image of themselves as "normal."

> I really wanted to try on my own, find my own way to overcome my depression because I thought I was a strong enough person. I used to be a strong enough person. I could overcome it, and I wanted to try to be that strong person again, and I was able to, so I decided not to take my medication. (19-year old untreated female)
>
> I didn't like the thought of a pill. I felt I shouldn't need a pill to be, to make me *feel*. [pause] There was a reason [I was depressed]. It's better to confront the reason than cover things I feel. It just felt artificial and I didn't like that. (17-year-old treated male)

Concern about confidentiality was an important factor in teens' willingness to approach a professional. Many viewed expression of their distress and feelings of inadequacy as privileged information that, if exposed, could have dire consequences.

> My parents forced me to go to a doctor and it's a lot harder to talk to him because I feel that anything I say I don't have any patient–doctor confidentiality … I've only had one doctor that I know would never tell my parents anything that I asked him not to say, but every other doctor it felt like anything I said they could use against me. (15-year old treated male)

Finally, teenagers also cited concerns that if they told providers how they felt, they would be judged as being "weird," as having insignificant problems, as stupid, or as crazy:

> I was always afraid that [the primary care provider was] going to say it's stupid or it's dumb that you feel that way, about being depressed, [like] 'That's not a reason

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> to get depressed' and I didn't want them to say stuff about things I felt because I didn't want to feel stupid. (15-year old male, focus group)

> There's just some stuff I would not tell doctors or nurses that I've done because they might associate to them that I seem crazy in some way … or that I need to be put away because sometimes I have acted crazy and it's not good, but it's happened. (15-year old treated male)

Theme 2: Being Connected

When teens visited a health care provider, they wanted connection with that provider-to know that the provider is listening to them, is concerned about their well-being, and is not merely "processing" their complaints.

> I think it's the biggest thing is that it was able for me to know that it was okay, it's okay for me to tell her these things I was feeling. (18-year-old treated female)

Teens appeared to be skilled at picking up providers' verbal and non-verbal cues to assess whether the provider is listening and reflecting, or whether he or she "really hears" the teen. Teens expressed that if they are not "picking up the right cues," they will choose to withhold information from the provider and withdraw from the interactions. They acknowledged that this reaction sometimes led to less-than-ideal services, but defended their choices by viewing the provider's asking about their personal life and then not appearing to care as an assault on their integrity.

> Yeah, I'd like [providers] to discuss more with me about why they think [depression] is happening to me, or what they learn in talking to me, because in speaking to them, I don't know if they're learning anything so I don't know if it's really a waste of time to speak to them because they don't give me any feedback. (18-year-old treated male)

Teens want to know that the provider is human too, and that he or she has experienced sadness, anxiety, suspicion, and other feelings teens are experiencing. They get this information based on the provider's skill at expressing empathy and communicating with them.

> [I'd like to know that] at one point in [the provider's] life they had something kind of similar so they're not just coming from [the point of view of] someone who's never really had serious depression, who doesn't even know what it felt like, trying to diagnose it or trying to help you when they have no idea. (15-year old male, focus group)

Teens want providers to serve several purposes. In their view, providers should investigate the problem from multiple sources whenever possible, while maintaining confidentiality. Teens reported frustration when providers listened only to a parent and hardly or not at all to the teen's point of view. Teens also wanted privacy when speaking to their provider and often chose not to disclose in front of parents when parents were not asked to leave. They said that asking a parent for privacy with their provider was often difficult, and requested that physicians ask parents to leave rather than leaving the impetus on the teen.

> A lot of the time it feels like doctors aren't really listening to me. It feels like they listen to my parents, but they're not paying attention to me … That's why I don't want to see [my doctor]. (15-year-old treated male)

> When you interview, I think you should do kid first, parent, and then them together and you'll be able to find the truth somewhere in there … There's just different ways that people see things, so the kid could be right and the mother could be right, but who are you to say which is *right*? (18-year-old treated female)

Second, teens wanted to hear feedback and information about depression from providers. Most reported feeling frustrated when physicians refused to leave the technical realm of description to comment on the personal history the teens reluctantly provided.

> I wouldn't always say jump straight to the medication, I would say definitely talk to them, tell them what's going on, that changes they're going through, especially when they're younger, talk to them about their changes physically and emotionally and definitely talk to them about depression and go in depth. (19-year-old untreated female)

Despite this stated desire for information, most teens in this study reported dissatisfaction with the amount and type of information they were provided. Additionally, teens tended to have inaccurate understandings of biological mechanisms of depression and little or no information on alternative theories (e.g., cognitive, behavioral, social):

> When the body comes under stress you can become depressed and the body stops producing endorphins and that's what depression medications [do:] help your body continue producing endorphins so you have a balance. (17-year old treated male)

In addition, biologically focused information provided by physicians to teens was counter to the teens' own characterization of depression as caused by external stressors and resolvable by personal actions.

> I think that maybe some of the doctors shouldn't be so dependent on the medicines like Paxil and Zoloft, Prozac, that maybe there should just be some types of programs where people can think. A lot of depression may stem from loneliness or being singled out, so instead of pushing them towards drugs maybe you should push them toward a YMCA or a summer camp or something … somewhere they can have people their own age who can relate to them. (17-year-old treated male)

Particularly lacking for the interviewed teens was information on treatment. Most teens reported their provider recommended only medication and did not discuss other options. This reinforced teens' views of themselves as abnormal and "messed up," and was often rejected in favor of continued distress.

Teens who had received some form of treatment knew more about treatment options than teens who had not been in treatment, and untreated teens tended to be more skeptical about it.

> Can it be treated? I don't know. I don't know that much about it. I don't think there's a certain way. There's not medical help. There's anti-depressant pills or whatever, but how well do those actually work? (14-year-old untreated female)

Finally, teens wanted their providers to work with them to find solutions. Many reported their provider passively accepted information, made a diagnosis, then prescribed medication without asking questions such as "What have you tried to make yourself feel better?" or "What do you think would help you feel better?" Given that many teens were experiencing severe life stressors, such as parental separation, this oversight seemed particularly deleterious. Conversely, providers who developed a relationship with teens were more likely to engage them in treatment than those who did not.

> At first I refused to [take medication]. I was like, 'I'm fine.' … The doctor was very persistent on it because she knew that I needed it, and so I think that she just said things that made me think maybe I do need it. I look back now and I know I did. I think it's for the better that I started it. (17 year old treated female)

Teens indicated that feeling understood by their provider made them more likely to accept her or his recommendations, and made them feel more positive about their prognosis.

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Connection with a provider who offers thoughtful, considerate advice and suggestions can contribute to healing:

> She's been my doctor for a long time, so talking to her actually helped a lot. She was sitting there and she was like, 'There's a lot of ways you can get help.' I think she actually helped in a way, there was just little steps of people pushing me up, pushing me up further and further. (14-year-old untreated female)

Theme 3: Being Autonomous

Teens were concerned about maintaining their autonomy. At the same time, they were acutely aware of being in a developmental place between being a child and being an adult, with neither the full benefits nor the full responsibilities of either. This depressed teen had recently moved out of her parents' home:

> I am in an adult situation, but I'm still, I'm transitioning from the mentality of a kid to an adult, so it's harder to make that transition when that cloud always seems to be over you. (19-year-old untreated female)

The interviewed teens reported that the desire for autonomy was an issue for them when they sought treatment. Not having a voice in their treatment or getting little information about what was happening was particularly distressing.

> The doc must think there was something seriously wrong with me because I ended up with this drug test and I had no idea why. I never felt this was coming. It's just really hard because you're hit with it. It's the worst feeling. (15-year old male, treatment group)

Most teens reported struggling to make sense of the situations they found themselves in. They reported wanting the involvement and guidance of parents and providers, but the freedom and autonomy to make decisions for themselves. Those who did receive this kind of connection and information from providers were able to make informed choices that helped them feel empowered.

> Basically mostly it's about getting through your ideas in your own head and talking to someone else and they don't even have to comment that much for you to straighten out a lot of things in your head. (15-year-old female, focus group)

While most teens sought to balance autonomy with guidance, some teens flexed their autonomy by actively rebelling against adults.

> I guess I do my own thing. I don't want other people to tell me what to do and stuff, tell me that I have to take this or be on medication and all this other stuff. I just like to do what I want. (14-year-old treated male)

Other teens were too depressed or lethargic to be active in *any* area, including their autonomy.

> Moderator: What was it like when you went in to see your primary care physician?
>
> Participant: I don't remember because I think I fell asleep while waiting for him and my mom went in to talk to him and I woke up a little bit. (17-year-old treated male)

Regardless of the presence of parents, teens were interested in maintaining some autonomy in the patient-provider relationship. This teen reported that she appreciated her provider's willingness to work with her ambivalence about medication.

> [My doctor] wanted me to try Prozac because she thought I could be suffering from depression. What she did was put it on my medication list and said that it was up to

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> me if I decided that I really needed it, if things got bad enough that I could take it, and under my own personal decision. (19-year old untreated female)

DISCUSSION

Findings from this study indicate that teenagers' depression causes them to question their normalcy, connection, and autonomy. They often view their despair as a weakness of character, and find disclosing their "real self" to health care providers a frightening, difficult experience. When disclosure is met with compassion, connection, information, and choices from providers, teens are more likely to view the visit as positive. When teens feel their provider did not give feedback or information, judged them as abnormal or "mental," or provided medication without discussion of alternatives, they were not satisfied with the interaction and reported a lower likelihood of complying with treatment recommendations.

This study's results confirm that in some respects, teenagers are similar to adults in their attitudes and behaviors about seeking assistance for depression. Like adults, this study's teens' experiences of depression involved a struggle to maintain an identity and initial rejection of an illness identity (Charmaz, 1997; Estroff, 1989). Also similar to adults, these teens visited a medical professional only as a last resort, after other self-help interventions failed (Rogers et al., 2001). Teens in this study were suspicious of mental health treatment in general and of psychopharmaceutic interventions in particular, as reported in studies of adults (Jorm et al., 2000; Angermeyer et al., 1999; Venarde, 1999).

Teens also present with some developmentally appropriate and unique issues that pertain to their help-seeking behavior for depression (Logan & King, 2001). Teens experience a number of cognitive, somatic, and social changes as they go through puberty, consider career options, consolidate values, and develop new and changing relationships. Contrasted with adults, the threat of an illness identity is likely to be much more salient to adolescents already struggling with defining their identity. Because of this threat, they may be more likely to refuse a diagnostic label or treatment or to be unclear with providers about their experiences.

Teens also experience difficulties accessing medical services for depression because they are still under the care of parents. Teens are typically the legal responsibility of a parent or guardian and seek medical care under an adult's health care policy; thus, they are dependent on the people from whom they are struggling to individuate. This conflict may be exacerbated for teens with family difficulties, such as parental marital separation or illness. While state laws where the study was conducted allow teens age 14 and older to initiate medical care independently from their parents, no teen in this study indicated awareness of this legal right. It is possible that more teens would seek services if this were more widely known.

Teens tended to view taking anti-depressant medication as inconsistent with their views of themselves as autonomous, independent, healthy, and normal adolescents. Even when they realized their depressive experience was not normal, taking medication was still a difficult decision, and providers did not adequately address concerns. In particular, teens whose health care providers recommended medication as the only appropriate intervention were less likely to accept treatment. Additionally, many teens reported that they resisted even seeking treatment because they expected their provider to just "medicate" them.

These results imply that clinician behavior affects teens' responses to recommended treatment. Based on the findings from this study, teen-recommended considerations for primary care providers who offer mental health care to adolescents are presented in Table 1. These suggestions are based on teenagers' reports of what they found helpful or what they

wanted from providers, and are not presented as empirically supported clinical practice guidelines. Providers could help teens feel normal by choosing a collaborative model of communication: establishing rapport, inquiring about teens' experiences, and normalizing their experiences. When providers express empathy and exchange information, teens feel more connected. Providers also can increase teens' autonomy by providing information regarding the etiology and treatment of depression. Primary care providers are a valuable link for many depressed teens who seek relief from their symptoms. Awareness of teens' developmentally appropriate desires to be normal, connected, and autonomous can improve the care of teens who seek services in primary care. Results from several studies of physician residents and medical students suggest increasing these types of empathic responses to patient concerns (Burack, Irby, Carline, Root, & Larson, 1999; Seaberg, Godwin, & Perry, 2000).

The findings from this study also suggest that the process of obtaining professional treatment for depression may be improved if teens have information about depression and treatment options for it. Mental health literacy regarding recognition of depression among adults is low (Lauber, Nordt, Falcato, & Rossler, 2003), but programs to increase teens' knowledge of mental illness and attitudes about seeking professional help have demonstrated effectiveness in increasing behavioral intentions (e.g., Esters, Cooker, & Ittenbach, 1998).

The conclusions drawn from this study are limited in a number of ways. First, while a small qualitative sample is appropriate at this stage of research (i.e., for developing ideas), further qualitative and quantitative work is needed with larger and more diverse samples in different geographic areas to better generalize findings. In addition, teens in this study provided retrospective accounts of their experiences, which could have been affected by current depressive symptoms or by intervening factors occurring since their initial visit. On the other hand, our variety of recruitment methods enabled us to obtain a sample of teens that had considerably different experiences with care for depression, which strengthens the validity of our study (Strauss & Corbin, 1998). Finally, while teens in this study reported what they want from providers and what their likely reactions will be to modified provider practices, modified provider behavior may or may not affect adolescent behavior; these concepts require testing.

The conclusions from this study are not entirely unique; others have suggested collaborative models of service delivery for treatment of depressed adolescents in primary care (Asarnow, Jaycox, & Anderson, 2002). Empirical research has supported patient-provider communication and participatory decision-making as related to positive health outcomes in other chronic diseases (e.g., diabetes; Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). The research presented here provides additional evidence that provider communication and decision-making strategies are important to teens seeking help in primary care for depressive symptoms. The challenge is to find effective brief strategies that can be employed within the constraints of primary care visits. According to these teens, *some* providers are providing services in this way. Future studies should examine teen-provider communication *in vivo* during visits and compare applications of these recommendations to outcomes.

Acknowledgments

This research was supported by a National Research Service Award from the Agency for Health Care Policy and Research and a Greenlick Grant from the Department of Public Health and Preventive Medicine at the Oregon Health & Science University, both to the first author. This work was completed during the first author's appointment at the Center for Health Research, Kaiser Permanente Northwest. The authors would like to thank the teenagers who participated in the study and Chrystal Agnor, Christopher Kelleher, and Cheryl Ritenbaugh for their invaluable assistance.

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Table 1

Teen-recommended Considerations for Primary Care Clinicians Working with Adolescents who are Experiencing Symptoms of Depression

Being Normal

- Teens may arrive at a medical office feeling extremely distressed and abnormal.
- Teens want the office to be a safe place to talk and indicate they want providers to:
  - **a.** Establish that it's okay to feel distressed occasionally
  - **b.** Explain confidentiality
  - **c.** Request time alone without parent
  - **d.** Explain that symptoms may be a normal response to abnormal events
- Teens often want to describe their circumstances. It may be helpful to inquire about specific life stressors, teens' cognitions about events, and their "red flags" (why they came to the provider).
- Teens appreciate normalizing comments:
  - **a.** "Depression doesn't mean you're weak–it takes strength to ask for help"
  - **b.** "While some temporary distress is normal, sometimes it gets out of control and is then important to discuss"

Being Connected

- Teens desire establishment of rapport by:
  - **a.** Expressing empathy
  - **b.** Providing feedback
  - **c.** Exchanging information
  - **d.** Utilizing active listening and reflecting statements
  - **e.** Monitoring non-verbal cues and tone
- Teens may have difficulty asking a parent to leave the office and may need the physician's help in establishing privacy. Separate parent and teen interviews may help providers gain a better perspective on the problem.
- Teens often have attempted to make themselves feel better but may not recognize that these attempts may be beneficial to their recovery. Asking about these attempts and providing information about depression and its treatment may be helpful.
- Teens want information; providing multiple perspectives such as a handout or Internet links to information could be helpful.
- Teens often have specific ideas about antidepressants that could be built upon to encourage recovery; inquiring about their perceptions can provide information that can assist providers.

Being Autonomous

- Teens state that they want information about treatment options to facilitate decision-making and the autonomy to choose between treatments whenever possible.
- Warning signs (e.g., suicidal thoughts) could be described to teens to let them know what constitutes a need for immediate intervention.
- Teens state that collaborative approaches to intervention are more likely to result in treatment adherence.