WHAT TEENS NEED:

BARRIERS TO SEEKING CARE FOR DEPRESSION

by

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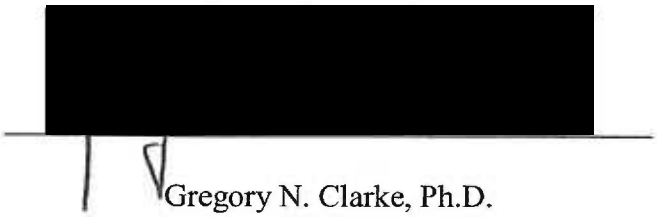

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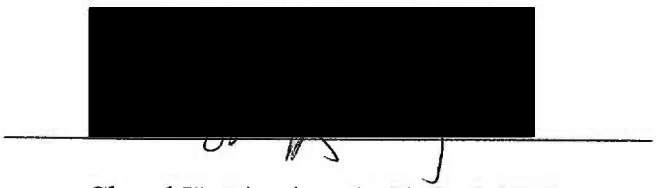

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Abstract

While current research indicates adolescents underutilize professional medical services for depressive disorder and symptomatology, these studies do not fully address adolescents' experiences of obtaining care. This study used in-depth and focus group interviews to examine adolescents' experiences of being depressed and obtaining treatment. Results indicate teenagers fare best when providers actively considered and reflected upon the teenagers' developmentally-appropriate desires to be normal, to feel connected, and to be autonomous. Health care providers can help to establish rapport, normalize teens' experiences, and counteract stigma to help teens feel they are normal. Providing empathy and exchanging information about depression etiology and treatment helps teens connect with their providers. Working with teens to use that information to make decisions about their treatment helps teens participate in their own recovery and be more autonomous. Addressing teens' concerns in these ways may enhance teens' willingness to accept treatment for depression.

KEY WORDS: depression, adolescents, identity, primary care, patient-provider communication

Background

Major depression is a chronic, common disorder among adolescents, with recurrence rates estimated at about 70%, and most (40-60%) relapsing 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, 1994; Cicchetti & Toth, 1995). 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 adolescents: these events can result in the teenager being separated from his or her peer group, rejection from the peer group, and diversion from a normal developmental trajectory. Adolescent depression currently accounts for a substantial portion of the health care costs incurred by this age group (Birmaher et al., 1996; Wagner et al., 2000), 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.

Underutilization of mental health services and barriers to treatment

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, Ustun (2000) reported that only half of adolescents experiencing a depressive episode contact someone in the health care sector. In community samples, only 21 to 34% of adolescents meeting criteria for major depression have received medical attention (Flament, Cohen, Choquet, Jeammet & Ledoux, 2001· Lewinsohn et al., 1994).

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

Consider Issues Too Personal. Teens may be concerned about discussing "personal" issues with their primary care provider (Pommier et al., 2001). Teens also are sensitive to issues of confidentiality and often are reluctant to ask health providers even general health questions due to confidentiality concerns (Ackard & Neumark-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 (Logan & King, 2001).

Concern About Consequences. Rogers, May, and Oliver (2001) described depressed individuals as 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. Participants disclosed information 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.

Another potential consequence of a mental illness diagnosis is stigmatization and rejection (Link & Phelan, 2001; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 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). Peer rejection isolates teens, keeping them from developing a strong network of social support during adolescence (Coie, 1990).

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).

Meaning to Self. 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 (Gammell & Stoppard, 1999; Rogers, May & Oliver, 2001). 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 the self from the condition" (Rogers, May & Oliver, 2001, p. 319) 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 an "illness identity" as mentally ill (Charmaz, 1997, Karp, 1994).

Preference for Non-Medical Interventions and Opposition to Antidepressant Medication. 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, Matschinger & Riedel-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 (Angermeyer, Matschinger, & Riedel-Heller, 1999; Jorm et al., 2000) and feel 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.

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 (e.g., 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, Clarke, O'Connor & Nichols, 2001).

Underestimation of Severity. 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 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., Culp, Clyman & Culp, 1995; Dew et al., 1988) or a combination of surveys and structured clinical interviews (e.g., Logan & King, 2002; Flament et al, 2001). 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

Setting

The research was conducted in the Northwest Division of Kaiser Permanente (KPNW). KPNW is a nonprofit 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). Much care for mood disorders, including depression, is provided by primary care clinicians (Shye, Freeborn, & Mullooly, 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 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. State laws allows teenagers age 13 (Washington) or 14 (Oregon) and over to obtain mental health treatment without parental consent. All procedures were reviewed and approved by the research center's Institutional Review Board.

Study Procedures and Materials

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. For all parts of the study, both the teen and

parent consent was required. All participants received $10 gift certificates.

Using health plan records, we identified HMO members aged 14-19 with diagnoses of depression or dysthymia who had *not* had HMO treatment for depression (n = 157). Treatment was defined as having at least one visit to a specialty mental health care provider or obtaining antidepressant medication. After obtaining primary care providers' permission, teens were contacted by letter and phone and invited to participate in the study (n = 8). Some teens had obtained treatment prior to contact or the interview; these teens were reclassified as "treated."

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 while control group participants received treatment as usual from their primary care provider; all teens had started SSRI medication (Clarke et al., 2002). Teens were recruited during telephone follow-up interviews for the intervention study (n = 7). Treated and untreated teens from the health plan (total n = 15) participated in a single 90-minute individual interview.

Finally, we recruited a sample of adolescents from a local high school for a 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.

Participant characteristics. Individual interview participants 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.

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

Interview guides. We used in-depth individual and focus group interviews to learn about participants' experiences with depression and with obtaining treatment for depression. Interview guides included questions about (a) participants' understanding of why they were depressed; (b) concerns about approaching professionals for help; (c) the process of obtaining professional treatment, including what office visits were like; (d) relationship with primary care providers and how that affected views of depression and treatment; (e) willingness to engage in offered treatment; (f) perceived effectiveness of treatment; and (g) how primary care providers, mental health specialty care providers, and other helping professionals can improve this process. 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 from the author.

Interviews and Analysis. Individual interviews were completed by the first author (JPW) and a graduate research assistant at the Kaiser Permanente Center for Health Research in person ($n = 13$) or over the telephone ($n = 2$). The focus group interview was

completed by the author and a research assistant at a local high school. Interviews were tape-recorded and fieldnotes documented additional information. Tapes of interviews and fieldnotes were transcribed verbatim, and both were included in the analyses.

We began the qualitative analysis process by developing a coding scheme to capture the content and themes within each topic area. Interview and fieldnote text were coded using the Atlas.ti 4.2 software system (Scientific Software Development, 2002), which aids coding, organization, and retrieval of text for qualitative analysis. We controlled for observational bias by having multiple research team members conduct interviews, code transcripts, and analyze data. We also monitored intercoder agreement during transcript coding, tested rival explanations while analyzing data, and compared researcher and theoretical findings to enhance our interpretive confidence (Boyatzis, 1998).

Results

We found evidence for the following themes in our analyses: desire to be normal, a desire to be connected, and a desire to be autonomous.

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 it'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:

> 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).

Some teens indicated that if anti-depressant medication worked for them, it would confirm they were "mentally ill"; the possibility of this back-attribution dissuaded some teens from trying medication. Additionally, two teens who were in substance abuse recovery indicated they rejected medication because they wanted to be completely "drug free," but this concern was not mentioned by other teens.

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 nonsignificant 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 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. 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.

> [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 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 is often a miserable condition during which they struggle with feelings of 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; Karp, 1994). Also similar to adults, these teens visited a medical professional only as a last resort, after other self-help interventions have failed (Rogers, May & Oliver, 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 (Angermeyer, Matschinger & Riedel-Heller, 1999; Jorm et al., 2000; 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 of their unique position as near-adults who 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; they are therefore dependent on the people from whom they are struggling to individuate. This conflict may be exacerbated for teens with family difficulties, such as parental 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 seeking treatment because they *expected* their provider to just "medicate" them. Teens who were in substance abuse treatment rejected medication, consistent with the attitudes in some traditional self-help groups to be completely "drug-free." Teens in substance abuse treatment may require careful discussion by providers about medication issues.

These results imply that clinician behavior affects teens' responses to recommended treatment. A complete list of recommendations based on teens' experiences is provided in Table 1. 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 are seeking 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.

The conclusions drawn from this study are limited in a number of ways. First, our sample was small; to better generalize findings, further work is needed with larger and more diverse samples in different geographic areas. 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.

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), and 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, at least *some* providers are providing services in this way. Future studies should examine teen-provider communication in vivo during visits.

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Table 1. 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.
	Make the office a safe place for teens to talk (a) establishing that it's okay to feel distressed occasionally (b) confidentiality will be maintained (c) request time alone without parent
	It would be helpful to inquire about specific life stressors, teens' cognitions about events, and their "red flags" (why they came to the doctor); explain that symptoms may be a normal response to abnormal events.
	Normalizing comments, such as "Depression doesn't mean you're weak – it takes strength to ask for help" or "While some temporary distress is normal, sometimes it gets out of control and is then important to discuss" help teens.
Being Connected	Empathy, feedback, and information exchange help establish rapport with teens.
	Active listening and reflecting statements ensure the teen knows you're listening. Nonverbal cues, a judging stance, or patronizing tone discourage teens from disclosing distress.

	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 help providers gain a better perspective on the problem.
	Teens often have attempted to make themselves feel better. Asking about these attempts and providing information about depression and its treatment are helpful. Provide multiple perspectives when possible (a handout or web site link could be helpful).
	A diagnosis can be explained as a name for a specific collection of behaviors, not as a permanent label. When behavior changes, the label changes.
	Teens often have specific ideas about antidepressants that could be built upon to encourage recovery ("Sometimes people who are depressed are helped by medication. What do you know about medicine for depression?").
Being Autonomous	Teens need information about treatment options to facilitate decision-making.
	Allow teen the autonomy to choose between treatments whenever possible.
	Warning signs (e.g., suicidal thoughts) could be conveyed to teens to let them know what constitutes a need for immediate intervention.

	Collaborative approaches to intervention are more likely to result in treatment adherence.