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Amy Sylwestrzak
The Children's Advocacy Center of Northwest Cook County

Chelsea E. Overholt
The Chicago School of Professional Psychology

Kelly I. Ristau
The Chicago School of Professional Psychology

Kendell L. Coker
University of New Haven, kcoker@newhaven.edu

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Self-Reported Barriers to Treatment Engagement: Adolescent Perspectives from the National Comorbidity Survey-Adolescent Supplement (NCS-A)

Amy Sylwestrzak, M.A.[a]

Chelsea E. Overholt, M.A.[b]*

Kelly I. Ristau, B.A.[c]

Kendell L. Coker, Ph.D., J.D.[d]

a The Department of Forensic Psychology, The Chicago School of Professional Psychology, 325 N. Wells Chicago, Illinois, 60654, USA. E-mail: asylwestrzak@thechicagoschool.edu

b The Department of Forensic Psychology, The Chicago School of Professional Psychology, 325 N. Wells Chicago, Illinois, 60654, USA. E-mail: coverholt@thechicagoschool.edu, Phone: 312-467-2581, Fax: 312-488-6327

c The Department of Forensic Psychology, The Chicago School of Professional Psychology, 325 N. Wells Chicago, Illinois, 60654, USA. E-mail: kir0442@ego.thechicagoschool.edu

d The Department of Forensic Psychology, The Chicago School of Professional Psychology, Chicago, Illinois, 60654, USA; Department of Psychology & Department Criminal Justice, University of New Haven, West Haven, Connecticut, 06516, USA. E-mail: kcoker@thechicagoschool.edu

ABSTRACT

Introduction

The objective of this study was to assess youth self-reported treatment barriers in the past 12 months to obtain youth's perspective on reasons they seek treatment, do not engage in treatment, or terminate treatment.

Method

The present study uses data from the National Comorbidity Survey-Adolescent Supplement (NCS-A), a nationally representative survey administered to youth ages 13-18 that was conducted between February 1, 2001 and January 30, 2004. A total of 10,123 youth participated in the NCS-A study and provided the information on which the current paper draws its data.

Results

Within the past 12 months over 63% of youth reported seeking treatment to manage and cope with emotions. The greatest percentage of youth reported that they did not seek treatment because they wanted to handle the problem on their own (59.3%). The greatest percentage of youth reported that treatment was terminated because they wanted to handle the problem on their own (57.5%).

Discussion

Findings suggest professionals need to educate youth about the importance of professional treatment to increase engagement. If providers can motivate youth to see the value of treatment and help them understand that there can be positive outcomes, they may be less likely to terminate prematurely.

Keywords: Adolescents, Mental health treatment, Treatment engagement, Treatment barriers

Introduction

There are multiple barriers which can prevent youth from obtaining and completing treatment. Researchers have found that approximately 20 percent of youth suffer from mental health problems[1]. However, only about one third of youth who are in need of treatment ever receive services[2], and approximately half of youth that have significant mental illness do not attend treatment. Furthermore, approximately 40 percent of youth who attend treatment will discontinue services prematurely[3, 4]. Youth are often not interested in seeking treatment or staying in treatment. Research suggests this may be due to the treatment options available to youth, the stigma associated with mental health treatment, and youth not understanding the impact treatment can have on their symptoms and quality of life[5, 6].

With growing awareness and increased understanding of mental health problems in schools and the juvenile justice system, more youth are exposed to the idea of professional treatment[7, 8]. When detection of mental health problems occurs early, and intervention takes place, youth have increased success in modifying problem behaviors[9, 10]. Oftentimes, youth are encouraged by their parents, teachers, school administrators, and court mandates to participate in treatment. Although youth may report not wanting to be involved in treatment, research suggests receiving services can have long-term benefits[9, 10, 11]. Researchers have found that up to 60% of adult substance dependence may be prevented by early detection and treatment of substance use disorders in youth[12, 13]. Furthermore, early intervention and successful treatment of mental illness in childhood and adolescence can reduce the impact that mental illness has on a person's life[10, 11, 14].

Research suggests that professionals who are aware of the barriers that youth face and the reasons that youth are reluctant to engage in treatment are better able to address these issues and

prevent early dropout and premature termination[15]. This study highlights some of the self-reported environmental, structural, and societal issues that discourage youth from seeking help. Environmental barriers, such as a lack of family support and cooperation, the location of services, transportation difficulties, and time constraints prevent some youth from accessing and successfully completing treatment[16]. Individuals can encounter a variety of logistical and concrete structural barriers to treatment such as cost, insufficient coverage and lack of insurance, wait lists, and a lack of available providers[17]. Societal barriers, specifically the stigma associated with mental health treatment and care, have been found to be a common concern for individuals who are referred for services[18]. In fact, many individuals in need of services will not seek treatment to avoid the stigma associated with mental illness[18]. Furthermore, a lack of awareness about treatment benefits keeps youth from engaging in mental health services[6]. In addition, research has found that a poor therapeutic relationship between the clinician and the youth was a significant factor in early termination from treatment[16].

When these barriers are removed or remedied, youth will demonstrate greater success with treatment involvement. Youth who successfully complete professional treatment are found to have lower rates of substance use, fewer behavioral problems, and lower recidivism rates[10, 19, 20, 21]. Ignorance about these environmental, structural, and societal barriers may cause treatment providers to erroneously think that youth are not engaging in treatment due to lack of motivation[17, 22].

Previous studies that have collected youth self-reports on treatment barriers are limited in the sense that their data was not generalizable[17, 23]. These studies drew upon samples from specific communities or institutions, therefore limiting the application of their results to the youth in those specific geographical areas. Other studies that have reviewed treatment barriers

for youth have drawn upon reports from professionals or family members to gather data regarding barriers to treatment[16, 24, 25]. Research on the accuracy of youth self-report has been inconsistent. While some studies have found youth are not always accurate in their self-report, others have shown youth self-report to have high reliability[26, 27, 28].

The present study uses data from the National Comorbidity Survey-Adolescent Supplement (NCS-A), a nationally representative survey administered to youth ages 13-18. In order to yield information regarding the most salient barriers that youth reportedly experienced when referred for professional services, we analyzed data describing why youth did not receive treatment, why treatment was delayed, and why treatment was terminated early. Using a large, nationally representative dataset allows the researchers to explore reported barriers to treatment that are not specific to region, location, or a particular demographic. By examining the collective issues that youth reportedly experience when considering treatment and understanding the reasons youth are resistant to seeking treatment, professionals can develop innovative ways to address these concerns and help youth successfully enter and continue in treatment. The goals of this study are to identify the reported referral sources and reasons for treatment referral for youth; and examine the reported reasons why youth do not seek treatment and terminate treatment.

Methods

The current study used data collected from the NCS-A, a nationally representative survey that was conducted between February 1, 2001 and January 30, 2004. The Human Subjects Committee of both Harvard Medical School and the University of Michigan approved survey protocols and procedures. The NCS-A was administered by 18 professional interviewers from

the Institute for Social Research at the University of Michigan, Ann Arbor. A total of 10,123 youth between the ages of 13 and 18 participated in the NCS-A study and provided the information on which the current paper draws its data. The mode of data collection for the NCS-A consisted of interviews over the telephone, computer-assisted personal interviews, and computer-assisted telephone interviews. Interviewers obtained written consent from parents of the youth who participated in the survey prior to its administration.

The NCS-A survey was initially designed to sample adolescents living in households included in the National Comorbidity Survey- Replication (NCS-R). However, due to a limited number of adolescent participants, additional participants were drawn from a representative school-based sample, resulting in a dual frame design. Overall, after combining the 2 subsamples, the NCS-A response rate was 82.9%, with the household sample response rate at 85.9% and the school-based sample response rate at 74.7%. Cases were weighted for variation in within-household likelihood of selection (in the household sample) and for residual variations between the sample and the U.S. population on the basis of sociodemographic and geographic variables. Additional information on weighting procedures can be located in the NCS-A user guide.

During the interviews, youth were asked a series of questions to determine mental health symptoms and involvement in professional treatment. The items that were used for this study focused on who referred or encouraged youth to seek treatment, why youth wanted to seek treatment, why youth decided not to seek treatment, and why youth terminated treatment. In order to identify self-reported reasons for treatment referral in the past 12 months, the NCS-A asked youth from a list of 8 options what they were "hoping to get from treatment." Table 1 lists the options youth were told to choose from and they were allowed to make multiple selections.

Next, youth were asked follow up questions based on the initial answers they provided. For example, youth who indicated they had terminated treatment services were asked follow up questions regarding the reasons for said termination. The question read, “I'm going to read a list of reasons for quitting and ask you to say 'yes' or 'no' for whether each one was a reason you quit.” Follow-up items asked youth to respond “yes” or “no” to indicate whether various statements applied to them. Follow up items included statements such as: “I wanted to handle the problem on my own; I had bad experiences with previous treatment providers; treatment was too expensive; and I was concerned about what people would think if they found out I was in treatment.” Discrepancy in response rate to various questions can be attributed to the fact that some sub-item questions may not have applied to all youth or some youth answered affirmatively to multiple sub-items. In other words, not all questions were applicable to every youth and as a result there is a discrepancy in total numbers of youth who responded to each item.

Results

Sociodemographic information was collected on each youth during the NCS-A survey administration. Results indicate that approximately half of the total sample (n = 10,123) was male (51.3%), with slightly fewer females (48.7%), and the mean age was 15.2 years old. More than one-third of the sample consisted of youth between ages 13 and 14 years old (36.2%). The remaining age distribution of the sample was relatively equal between youth aged 15 to 16 and 17 to 18 years old. The sample consisted of 65.6% non-Hispanic whites, 15.1% non-Hispanic blacks, and 14.4% Hispanics.

Youth were asked to indicate who first encouraged or referred them to seek treatment. Out of 936 youth who reported they were referred or encouraged to attend treatment, the highest rates of referral or encouragement came from parents (69.2%), followed by other family

members or friends (8.4%), the judicial system (8.2%), school professionals (7.8%), mental health professionals (2.5%), and others (3.8%).

Youth were asked to indicate the reasons they were referred to treatment (Table 1). Over 63% of youth reported seeking treatment to manage and cope with emotions. Other top reported reasons for seeking treatment include controlling problem behaviors (11.6%) and coping with stress (6.9%). The lowest reported reasons for seeking treatment include youth seeking treatment to come to term with their past (1.8%), to help make life decisions (2.9%), and to deal with body complaints (3.4%).

Youth also provided their reasons for not seeking treatment (Table 2). The greatest percentage of youth reported that they did not seek treatment because they wanted to handle the problem on their own (59.3%), followed by those who thought the problem would get better (52.7%), and those who indicated the problem went away (48.6%). The lowest reported reasons that youth did not seek treatment include youth not being able to get an appointment (4.8%), health insurance not covering the costs of treatment (8.5%), and youth not being satisfied with the available service providers (9.3%). Just fewer than 15% of youth reported treatment cost as a reason for not seeking services.

Youth also reported their reasons for terminating treatment (Table 3). The greatest percentage of youth reported that treatment was terminated because they wanted to handle the problem on their own (57.5%), followed by youth who terminated because they did not need help anymore (55.4%), and those who terminated because they did not believe they were getting better (54.5%). Furthermore, a significant number of youth (31.3%) reported that they terminated services due to fear of what others would think. An additional 30.2% of youth reported they

terminated services because they believed treatment would fail. More than 16% of youth reported treatment cost as a reason for terminating services. The lowest reported reasons that youth terminated services were not being able to get an appointment (3.1%), health insurance not covering the costs of treatment (4.0%), and youth not being satisfied with the available service providers (7.5%).

Discussion

This study supplements existing literature on youth barriers to mental health treatment by offering opinions from the youth's point of view using a nationally representative sample which improves the findings generalizability. Previous studies have focused on reports from staff and parents but not youth. Those who have focused on youth self-report have sampled youth from specific geographic regions and this may have results that are location specific. The current study enhances knowledge about youth treatment barriers as it focuses specifically on youth's interpretation of barriers and reasons for not engaging in treatment.

This study found that a significant number of youth reported being referred for treatment to help with emotions. During this time of development, adolescents may need support with regulating and expressing emotions as well as coping with changes in physical appearance and cognition[29]. Additionally, controlling problem behaviors was the second highest reported reason for referral. These problem behaviors included drinking problems and fighting. This is consistent with current literature that shows adolescents often struggle with increases in internalizing and externalizing problems[27]. Through treatment, youth may learn to identify and manage problem behaviors thus reducing their engagement in these behaviors. This is consistent with past research that found youth who successfully engage in treatment show a reduction in symptoms and problem behaviors[9, 10]. Lastly, coping with ongoing stress was the third highest reported

reason for treatment referral. The development of positive coping skills through treatment and guidance may help youth better manage stress, problem behaviors, and emotions. Identifying reasons youth seek treatment can help service providers better understand youth's perception of their problems and better engage youth in their own treatment and recovery process.

A substantial portion of youth reported that the top reason for not wanting to seek treatment was their desire to handle the problem on their own. During adolescence, youth begin to establish autonomy and independence, often distancing themselves from outside help and attempting to solve problems without assistance[30]. In the current study, youth reported not wanting to receive help for their problem as they thought they would be able to manage it independently of treatment. Previous research has found that adolescents with serious mental health problems, including suicidal ideation, depression and substance abuse, often choose to handle the problems without professional treatment[31]. Furthermore, results from the current study show that adolescents did not seek treatment because they thought the problem would improve on its own. These youth reported that they believed their problems would improve over time and did not think that treatment would be beneficial or help alleviate their symptoms. This finding is consistent with research that shows youth are consistently more self-reliant during adolescence and this self-reliant behavior extends to mental health treatment[30]. The third highest reported reason for not seeking treatment was that youth were not bothered or affected by their problem or symptoms at first. Youth who were recommended to receive treatment for a problem that was not impairing them directly (e.g., social functioning, educational attainment), did not view their problem as severe enough to warrant treatment. Future research should focus on helping youth develop a balance for their need autonomy and independence with the need for treatment with serious mental health concerns. Failure to seek treatment can have significant

consequences if youth are not able to recognize the severity of problems and manage the problems on their own.

When reviewing reasons why youth terminated treatment early, providers should focus on why youth believe they can handle problems on their own, what helped the problems get better, and what caused the problems to go away. Researchers found that adolescent clients who were motivated to continue treatment and who held positive expectations of the process were more likely to adhere to treatment[32]. If providers can motivate youth to see the value of treatment and help them understand that there can be positive outcomes, they may be less likely to terminate prematurely. Results of the current study show that youth are often reluctant to continue in treatment if observable positive results are not seen. It is important for clinicians to consider this information when planning and choosing treatment options with youth. Furthermore, research has shown that inadequate coping skills are a major risk factor for young adult criminal behavior[33]. If these topics can be addressed in a treatment setting, treatment providers can help youth learn to develop coping skills that will allow them to be successful outside of the treatment environment if they choose to terminate services.

Results showed that a sizeable portion of youth did not seek treatment or terminated treatment because of fear of what others would think. This is consistent with current literature that shows a common barrier to treatment is social stigma. Researchers found that social stigma had negative consequences for clients who feared being labeled with a disorder and who were hesitant with continuing treatment[34]. This finding may be related to the stigma associated with mental health treatment and should be researched further in relation to youth's engagement in treatment.

The limitations of this study include the use of a previously collected data sample, the

NCS-A. Data was drawn from previously conducted interviews and researchers for the current study did not have contact with participants. As a result, follow-up and clarifying questions could not be gathered for the current study. Furthermore, the organization of the item questionnaire allowed participants to indicate multiple reasons for seeking treatment, delaying treatment, terminating treatment, and not seeking treatment. As a result, it is impossible to differentiate a main cause for each youth's reasons for treatment engagement. The reasons that youth indicated could be a combination of multiple factors. The strength of each factor cannot be assessed based on the given data. It is possible that a combination of factors, rather than any one factor alone may have the greatest impact on youth's decision to engage, delay, terminate, or not seek treatment altogether.

Another limitation of this study includes the use of a self-report measure with adolescents. Research on the reliability of youth self report has been inconsistent. Some studies have suggested that youth over- or under- report criminal activities, mental health symptoms, and drug use[35, 36]. However, there have been multiple studies which contradict this argument thereby showing that youth can be quite accurate and truthful when providing information to researchers. In their review of over 70 studies, a research team[37] found that youth self-report is influenced by cognitive and situational factors, but these factors do not threaten the validity of their self-report in all areas. Research has revealed that youth self-report is often accurate and reliable in areas such as reported alcohol and drug use, tobacco use, medication access, suicidal ideation, and sexual activity[28, 36, 38,39,40]. Furthermore, youth were found to be reliable in their reporting of barriers pertaining to treatment[26, 41].

Implications and Contribution

This study found a significant amount of youth referred for treatment. The most self-reported reasons for not engaging in or terminating treatment included the desire to self-manage problems and believing alleviation would occur without treatment. Findings suggest professionals should educate youth about the importance of professional treatment to increase engagement.

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Table 1: Youth self-reported reasons for treatment referral

Reason for referral	N (%)*
Help with emotions (e.g., sadness, anger)	527 (63.6)
Control problem behaviors (e.g., drinking problems, fighting)	96 (11.6)
Cope with ongoing stress (e.g., stress at home)	57 (6.9)
Other reasons	46 (5.5)
Cope with recent stressful events (e.g., divorce of parents, death of loved one)	36 (4.3)
Deal with a general body complaints (e.g., tiredness, headaches)	28 (3.4)
Help make a life decision (e.g., to quit school or leave home)	24 (2.9)
Come to terms with your past (e.g., your feelings about childhood)	15 (1.8)

*The reflected percentages in this column represents the total number of youth (N=849) who responded to this particular item divided by the number of youth who endorsed this item

Table 2: Youth self-reported reasons for not seeking treatment

Reason for not seeking treatment.	Endorsed "yes"/Total (%)*
Wanted to handle problem on my own	255/357 (71.4)
Thought problem would improve on its own	247/356 (69.4)
Problem did not bother me much at first	189/357 (52.9)
Did not think treatment would work	171/356 (48.0)
Feared what people would think	101/356 (28.4)
Inconvenient/time-consuming	99/356 (27.8)
Did not know who to see	85/356 (23.9)
Prior treatment did not work	73/356 (20.5)
Feared involuntary hospitalization	69/356 (19.4)
Transportation/schedule difficulties	63/356 (17.7)
Concerned about cost	51/356 (14.3)
Not satisfied with available services	33/356 (9.3)
Health insurance would not cover treatment	30/355 (8.5)
Could not get an appointment	17/355 (4.8)

*The reflected percentages in this column represents the total number of youth who responded to this particular item divided by the number of youth who endorsed this item

Table 3: Youth self-reported reasons for terminating treatment.

Reason for treatment termination	Endorsed "yes"/Total (%)*
Wanted to handle problem on my own	134/226 (59.3)
Thought problem would get better	119/226 (52.7)
Problem went away	211/434 (48.6)
Did not know who to see	79/226 (35.0)
Feared what others would think	71/227 (31.3)
Thought treatment would fail	68/225 (30.2)
Treatment would take too much time	67/227 (26.9)
Problem did not bother me much	41/227 (18.1)
Feared involuntary hospitalization	39/227 (17.2)
Too expensive	37/224 (16.5)
Schedule/time/transportation issues	36/227 (15.9)
Past treatment did not help	36/227 (15.9)
Not covered by insurance	32/426 (7.5)
Not satisfied with available services	9/227 (4.0)
Could not get an appointment	7/227 (3.1)

*The reflected percentages in this column represents the total number of youth who responded to this particular item divided by the number of youth who endorsed this item