Quality of Life and Psychosocial Profile Among Young Women With Fetal Alcohol Spectrum Disorders

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Prenatal alcohol exposure can result in a range of neurodevelopmental disorders termed fetal alcohol spectrum disorders (FASD). Clinical reports indicate a poor quality of life (QOL) among individuals with FASD; however, QOL has not been formally assessed and reported in this population. We describe psychosocial and QOL assessment scores among 11 women with FASD. These women had poor QOL scores and high levels of mental health disorders and behavioral problems relative to standardization samples and other at-risk populations. We suggest that psychiatric distress may play a substantial role in the reduced quality of life reported among adults with FASD.
Keywords: developmental, developmental disability, FAS, fetal alcohol spectrum disorders, fetal alcohol syndrome, intellectual disability, mental retardation, psychiatric disorder, psychosocial assessment, quality of life, substance abuse

Fetal alcohol syndrome (FAS) and alcohol-related neurodevelopmental disorders (ARND) are permanent birth defects caused by maternal alcohol use during pregnancy; FAS is a leading preventable cause of intellectual disability.[1] Depending on dose, timing, frequency, and genetic susceptibility, prenatal alcohol exposure can result in a range of neurodevelopmental disorders including FAS and ARND that have been termed fetal alcohol spectrum disorders (FASD).[21,27]

The neuropsychological deficits associated with prenatal alcohol exposure affect multiple areas of functioning.[17] Even if an affected individual has intellectual abilities in the normal range, other problems in adaptive behavior, attention, memory, abstract thinking, and executive functioning (i.e., cognitive abilities that include sequencing of information and behavior, cognitive flexibility, response inhibition, planning, and organizing behavior) may seriously impede his or her ability to work, to live independently, and to maintain social relationships.[26]

Clinical reports indicate that a poor quality of life is a grim reality for most adults with FASD because their broad spectrum neurobehavioral deficits continue to impair functioning across the lifespan, and because access to services that might ameliorate their circumstances is either inconsistent or uncoordinated. An individual's self-report of quality of life is important in order for clinicians to understand the impact of a medical or psychiatric condition.[16,22,24,32] However, to our knowledge, quality of life has not been formally assessed and reported in this population.

In 1999, the Parent-Child Assistance Program (PCAP) at the University of Washington expanded its evidence-based and widely replicated intervention model in order to enroll a sample of women diagnosed with FAS or another fetal alcohol-related diagnosis. The PCAP 3-year home visitation model was designed originally in 1991 to work with high-risk alcohol and drug-abusing pregnant women, with the primary goal of preventing future births of children prenatally exposed to alcohol and drugs.[7,10,11] As part of a research unit that has conducted FASD research since the 1970's, we hypothesized that our combined expertise on FASD and on interventions with high-risk women could be applied to the FASD population for whom interventions had not been developed, by enrolling some young women with FASD into the existing PCAP. In 2001 we began the 12-month pilot study reported here with the aim of assessing and better understanding quality of life and psychosocial problems among these women. Elsewhere we have reported specific strategies developed to increase connection to community services and improve quality of services delivered.[12]

The purpose of this report is to:

• Describe demographic and psychosocial characteristics of the FASD group enrolled in this pilot study;

• Compare participants' psychosocial and quality of life assessment scores to standardized norms or scores from populations with other chronic conditions.

METHODS

STUDY PARTICIPANTS

Participants were initially enrolled in the standard 3-year PCAP intervention between August 1999 and August 2001, and at entry were assigned to a PCAP advocate case manager who delivered home visitation and intervention services according to protocols described elsewhere.[9] Participants were recruited through community referral, from sources including hospital and welfare social workers, the judicial system, and from our research unit's fetal alcohol follow-up study. Women were considered eligible for this nested 12-month pilot study who: 1) had a documented medical diagnosis of FAS or fetal alcohol effects (FAE) (a term that has now been replaced by alcohol-related neurodevelopmental disorder); and 2) had at least one year remaining in the 3-year PCAP program. The pilot study was conducted from June 2001 through May 2002.

MEASUREMENTS

The Addiction Severity Index 5th Edition (ASI) was administered to all participants at intake into PCAP by a clinical supervisor (a master's level mental health specialist). The ASI is a face-to-face, semi-structured one-hour interview assessment of problem severity in seven domains: medical, employment, legal, family/social, psychiatric/emotional, alcohol, and other drug use. It has been widely used in clinical and research settings with a variety of populations.[18,19,34] In addition, we administered an ASI addendum, developed by PCAP in 1997 for use with high-risk women, which included supplemental questions about childhood history characteristics, contraceptive methods, and community service utilization and needs.

Three standardized self-report measures (described below) were administered to the group with FASD during the first three months of the pilot study by the program social worker or a clinical supervisor. Each of these instruments was designed at a 4th to 6th grade comprehension level.

1. The Brief Symptom Inventory (BSI),[6] a short form of the Symptom Checklist-90, is a 53-item psychiatric symptom checklist widely used in adult populations to yield a quantitative, continuous measure of psychiatric distress. The BSI yields nine primary symptom dimensions (Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, Psychoticism) and a Global Severity Index (GSI). The test-retest reliability coefficients for BSI symptom dimensions range from a low of 0.68 (Somatization) to a high of 0.91 (Phobic Anxiety). The GSI has a reliability coefficient of 0.90.

2. The Young Adult Self-Report (YASR) questionnaire[2] assesses social, emotional, and behavior problems in young adulthood as well as socially desirable behaviors. The YASR yields eight syndrome scales (Anxious/Depressed, Withdrawn, Somatic Complaints, Thought Problems, Attention Problems, Intrusive, Aggressive Behavior, and Delinquent Behavior) and a Total Problems Scale. The test-retest coefficients for the YASR syndrome scales range from a low of 0.72 (Thought Problems) to a high of 0.89 (Anxious/Depressed). The Total Problems Scale has a reliability coefficient of 0.89.

3. The World Health Organization Quality of Life (WHOQOL-BREF)[33] is a 26-item assessment derived from the more extensive WHOQOL-100. The WHOQOL-BREF incorporates items from each of the 24 quality of life facets in the longer form, and measures four broad domains relevant in cultures worldwide (Physical Health, Psychological, Social Relationships, and Environment). Test-retest reliability coefficients for the four domains are as follows: 0.66 (Physical Health); 0.72 (Psychological); 0.76 (Social Relationships); and 0.87 (Environment). The short form correlates highly with the WHOQOL-100 domain scores, has good discriminant and content validity, internal consistency, and is broadly applicable across diseases and medical conditions.

IQ scores for the group with FASD were obtained from clinical or diagnostic records. IQ was assessed using either the Wechsler Adult Intelligence Scale-Revised,[30] the Wechsler Intelligence Scale for Children-Revised (WISC-R),

or the WISC-Third Edition,[29,31] depending on the age at testing.

We calculated descriptive statistics for demographic and social characteristics, and means, standard deviations (SD), and 95% confidence intervals (CI) for YASR and WHOQOL-BREF scores.

The University of Washington Institutional Review Board approved the research study, and informed, signed consent was obtained from all participants. We obtained a certificate of confidentiality from the federal Department of Health and Human Services to further protect participants' privacy.

RESULTS

A total of 11 PCAP clients with FASD were enrolled in this pilot study. Diagnostic evaluations were made by experienced dysmorphologists at a teaching hospital; mean age at diagnosis was 13.4 years (SD = 6.6; range 1 to 25). At enrollment the average age of participants was 19.8 years (range 14 to 29), most were white (82%), unmarried (82%), and poorly educated (55% had a 9th grade education or less). Among the 7 (64%) who were mothers, the mean number of children was 1.3 (range 1-2); approximately three-quarters of the children were living with their biologic mothers.

As children, all of the clients had mothers who abused alcohol, and 46% reported that their mothers also abused illegal drugs. Most of the clients had been physically and/or sexually abused (64% and 91% respectively). Only 27% lived with their biologic family throughout childhood; 64% were raised for 2 or more years outside their biologic family; 3 were adopted between the ages of 5 and 10 years.

As adults, slightly more than half of the clients lived in an unstable housing situation, relied on government assistance as the main source of income, or had been incarcerated (jailed) in the past. Four percent (36%) reported having a serious, chronic medical condition such as a seizure disorder or kidney failure. Eight (73%) of the women had used alcohol or illegal drugs in the 10 months prior to intake: 6 drank alcohol; 7 reported use of marijuana, cocaine, heroin, or amphetamines.

On the ASI, 7 of 9 clients (78%) reported having had a psychiatric evaluation (2 had missing data), and 6 of these knew their diagnosis: bipolar disorder (n=4), depression (n=1), and schizophrenia (n=1). Eighty-eight percent (7/8) reported a family history of mental illness (3 had missing data). Mean IQ was 82 (SD=14.0; range 56 to 98); two women had IQ scores below 70, indicating intellectual functioning in the mentally retarded range.

PSYCHOSOCIAL ASSESSMENT RESULTS

On the Brief Symptom Inventory (BSI),[6] mean scores of the group with FASD were greater than 1.0 SD above standardized means on 6 of 9 primary symptom dimensions (Obsessive-Compulsive, Interpersonal Sensitivity, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism). Global Severity Index (GSI) was 65.4 (SD=8.3). Six participants had a GSI greater than or equal to 63, a threshold score that presumes a psychiatric diagnosis and indicates the need for more in-depth psychiatric assessment.

Scores from the FASD group were similar to standardized scores of psychiatric inpatients and outpatients (within one SD on all BSI dimensions and the GSI). Compared to a standardized non-patient sample, scores from the FASD group indicated more psychiatric distress: they were one to two SD's higher on the GSI and on all symptom dimensions except Somatization.

On the Young Adult Self-Report (YASR),[2] the mean score of the group with FASD was approximately 1.0 SD above the standardized mean on 5 of 9 problem scales, with a high score of 64.1 on the Attention Problems Scale (Table 1). The Total Problems Scale mean score was 62.0; two participants scored in the borderline clinical range (between 60-63); six scored between 65 and 82, a range considered to be clearly clinically deviant from normal and to warrant further evaluation.

We compared these FASD scores with those from two published YASR reference samples: a normative female sample; and a clinically referred sample of young females who either were recently incarcerated or received mental health or substance abuse services.[2] Compared to the normative reference sample, FASD scores were higher (more problematic) on all scales; in addition, for the Attention, Delinquent Behavior, and Total Problems Scales, the normative sample mean was below the lower limit of the 95% CI for the FASD group (Table 1). Compared to the clinically referred sample, the group with FASD had higher scores on 6 of 8 individual problem scales and on the Total Problem Scale; however,

TABLE 1. YOUNG ADULT SELF-REPORT (YASR) SCORES FOR THE FASD SAMPLE COMPARED TO SELECTED YASR FEMALE REFERENCE SAMPLES				
YASR Scales[a]	**FASD** **(N=11)**		**YASR Normative[b]** **(N=575)**	**YASR Clinically Referred[c]** **(N=242)**
	Mean (SD)	**(95% CI)**	**Mean (SD)**	**Mean (SD)**
Syndrome Scales				
Anxious/Depressed	58.3 (9.9)	(51.6, 64.9)	54.1 (6.4)	59.6 (10.2)
Withdrawn	56.6 (6.8)	(52.0, 61.1)	54.0 (6.0)	57.5 (7.7)
Somatic	58.9 (8.0)	(53.5, 64.3)	54.0 (5.8)	56.9 (7.8)
Thought Problems	58.9 (9.9)	(52.3, 65.6)	52.6 (5.7)	56.9 (9.6)
Attention Problems	64.1 (10.6)	(57.0, 71.2)	53.8 (5.9)	58.1 (8.4)
Intrusive	59.6 (9.5)	(53.1, 65.9)	54.0 (5.8)	55.7 (6.9)
Aggressive Behavior	60.5 (10.1)	(53.6, 67.3)	54.0 (6.0)	58.5 (9.2)
Delinquent Behavior	59.7 (7.3)	(54.9, 64.6)	53.9 (5.6)	57.2 (8.4)
Total Problems Scale	62.0 (12.3)	(53.8, 70.2)	50.1 (10.1)	57.8 (11.1)
[a] Raw scores on the YASR are converted to normalized T-scores (Mean = 50; SD = 10). Higher scores indicate higher levels of problem behaviors.				
[b] The YASR Normative female sample (N = 575) is drawn from a national representative sample (N = 1242) age 18-27 years who completed the YASR in 1995-1996, who were not incarcerated and had not received mental health or substance abuse treatment in the previous year.[2]				
[c] The YASR Clinically Referred female sample (N = 242) is drawn from a national representative sample age 18-27 years who received mental health treatment, alcohol or drug abuse services, or were incarcerated in the year prior to completing the YASR.[2]				

on all scales the clinically referred sample mean fell within the 95% CI for the FASD group.

For the group with FASD, WHOQOL-BREF quality of life mean scores ranged from 56.5 on the environment domain to 64.4 on the social domain (higher scores indicate better quality) (Table 2). We compared scores with those from three WHOQOL-100 standardization samples: 1) a healthy sample (n = 128) free from a chronic medical condition; 2) a pregnant sample (n = 64) free of a concurrent medical condition (e.g., gestational diabetes), expecting an uncomplicated pregnancy, and completing the instrument one month prior to delivery; and 3) a chronically ill sample (n = 251) with one or more conditions (e.g., hypertension, cancer, chronic pain) for at least a year and receiving some form of regular outpatient medical care.[4] The group with FASD reported lower (poorer) quality of life scores on all four domains compared to the healthy standardization sample; in the psychological domain the healthy sample mean was higher than the upper limit of the 95% CI for the FASD group. In the environment domain the FASD group scored lower than the three standardization samples.

TABLE 2. WHOQOL-BREF SCORES FOR THE FASD SAMPLE COMPARED TO WHOQOL-100 SCORES FOR THREE STANDARDIZATION SAMPLES					
	FASD		Three Standardization Samples[b]		
			Healthy	Pregnant	Chronically Ill
	(N=11)		(N=128)	(N=64)	(N=251)
	Mean (SD)	95% CI	Mean (SD)	Mean (SD)	Mean (SD)
Domains[a]					
Physical	63.6 (19.6)	(49.5, 77.6)	77.1 (11.6)	61.2 (14.0)	54.2 (19.7)
Psychological	62.9 (17.0)	(51.4, 74.3)	75.1 (10.7)	71.8 (14.7)	61.4 (16.6)
Social	64.4 (19.0)	(51.6, 77.2)	71.7 (14.4)	73.0 (13.6)	57.0 (20.2)
Environment	56.5 (26.3)	(38.8, 74.2)	71.7 (11.5)	71.9 (13.2)	63.3 (16.3)
[a] The 4 domains are common to both the WHOQOL-BREF and WHOQOL-100. Scores range from 0 to 100, with higher scores indicating higher quality of life.					
[b] The three standardization samples are validation samples for the WHOQOL-100.[33] "Healthy" sample race was white (84%), median age = 41.5 years, mean education = 15.3 years. "Pregnant" sample race was white (84%), median age = 29.8 years, mean education = 15.4 years. "Chronically Ill" sample was 57% female, white race (85%), median age = 49.0 years, mean education = 14.8 years.					

DISCUSSION

This study presents data from a small but well-characterized sample suggesting that women who have FASD have a poor quality of life and higher levels of psychiatric distress and behavioral problems relative to other at-risk populations. Over half of the FASD study group had levels of mental health symptoms that presume psychiatric diagnoses, a finding consistent with other research reports.[8,20] As we might expect, compared to standardized reference samples, the group with FASD experienced more problem behaviors than do typical young women, and they evidenced a level of problem behaviors similar to women who had been incarcerated or in treatment. Their quality of life scores were most similar to individuals who have a chronic illness. To our knowledge this is the first formal assessment of quality of life reported among individuals with FASD using a standardized, widely-used instrument. Our findings should be interpreted in light of study limitations. The small sample size of this pilot study precluded statistical comparison with standardization samples on the multiple subscale outcomes. The data are based on self-report; however, our findings are consistent with clinical reports on this population.[25]

The intellectual and developmental disabilities that are primary characteristics of FASD may confer social disadvantages (e.g., unstable housing and incarceration) that contribute to both psychiatric distress and poor life quality. Psychiatric distress is reported by others to be a predictor of lower perceived quality of life.[3,15] While this cross sectional study could not determine whether participants' psychiatric conditions co-morbid with their FASD preceded or were the consequence of their disadvantaged adult life circumstances, we suggest that psychiatric distress plays a substantial role in the reduced quality of life they reported. By way of comparison, among individuals with Down's syndrome who also have permanent intellectual limitations, identification and treatment of psychiatric disorders have resulted in improvements in quality of life.[23]

A case vignette illustrates the interplay of these factors for a young woman with fetal alcohol syndrome. Ms. A came to live with a family member when she was six years old, and was diagnosed with FAS at the age of 12. She received ongoing special education services for her learning difficulties along with outpatient mental health treatment. Providers were sometimes unfamiliar with FAS, and even if they were familiar, they typically had unrealistic expectations for what could be accomplished. At age 18 Ms. A was still playing with dolls and at the same time was engaged in high-risk sexual activity. Between a stable home environment and the psychiatric care available, she maintained reasonable grades and was on track to graduate. Unfortunately, circumstances changed. Ms. A's caregiver became overwhelmed with other family issues. Ms. A took matters into her own hands and left to live with another family member who was herself unstable, and did not provide the structure Ms. A needed. Because no one made her do it, Ms. A quit seeing her mental health therapist. Her age-inappropriate social skills meant that she had few genuine friends and was vulnerable to victimization. She began to experience a cascade of difficult life circumstances—she dropped out of school, started using alcohol and drugs (possibly to self-medicate psychiatric distress), became transient, was raped, committed a crime, and was incarcerated. By any measure, these grim circumstances constituted a poor quality of life for Ms. A.

Ideally, a diagnosis of FAS or another fetal alcohol-related diagnosis can provide the individual, and those with whom s/he interacts, an explanation and clearer understanding of past behavior and functioning, more realistic expectations for the future, and hope for acquiring compensation strategies. More pragmatically, a formal diagnosis can be the first step in receiving appropriate treatment and services that might ameliorate the adverse life outcomes common to individuals with FASD and improve their quality of life. The diagnosis should have practical value in determining eligibility for disability insurance, mental health treatment, family respite care, subsidized housing, and specialized vocational programs. Yet in our experience people with FASD typically do not receive the coordinated, multi-systemic management recommended for such individuals.[5,13,14,25] Providers often know very little about FASD, the complex co-morbidities, and the resulting implications for clinical practice. Even if services are available, stringent institutional eligibility criteria can prevent a diagnosed individual from receiving or being able to pay for them.

Fetal alcohol spectrum disorders are complex and further research is needed with larger sample sizes. Findings from this small selected female sample are not generalizable to the larger population of individuals with FASD, but they do generate important research questions. How is quality of life related to the primary feature of FASD itself (i.e., the organic brain damage that give rise to learning and cognitive disabilities), the secondary consequences of FASD (e.g., the social disadvantages of having impaired cognitive functioning, regardless of etiology), and psychiatric distress? Can enhanced treatment and services ameliorate social disadvantages and improve quality of life among these individuals? Given that early FAS/FAE diagnosis has been shown to be associated with reduced risk for adverse life outcomes,[28] how is age at diagnosis associated with adult quality of life?

Our intention in this pilot study was to draw attention to the quality of life and the complex problems faced by people with FASD. We cannot alter their permanent brain damage, but with a greater understanding of FASD we have the potential to better serve fetal alcohol affected individuals, and ultimately improve their quality of life.

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