Level of Burden: Women with More Than One Co-Occurring Disorder†

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Abstract—Utilizing an expanded concept of level of burden, the impact of multiple problems experienced by women in a residential drug abuse treatment program on treatment retention and outcomes is investigated. Level of burden is defined in this study as the number and severity of problems, including psychological problems, cognitive impairment, chronic health problems, HIV/AIDS status, as well as substance abuse. In the first study of 260 women, the ability to retain women in treatment as a function of their level of burden is examined using the technique of survival analysis. Results indicate that early in the course of treatment, high-burden clients tend to be the highest risks for early termination. In addition, there is a significant interaction between time in the program and level of burden. In the second study of 68 women, partial correlations between level of burden and ratings of outcomes by program staff at time of discharge are examined. Results show that many of the treatment outcomes are significantly negatively correlated with the initial levels of burden. Implications for treatment providers and directives for future studies are discussed.

Keywords—co-occurring disorders, level of burden, substance abuse, treatment, women

Increasing attention has been paid to dual diagnosis or co-occurring disorders in the substance abusing population (Walker et al. 1994; Ziedonis et al. 1994; Regier et al. 1990; Ross, Glaser & Germanson 1988). Generally, individuals with comorbid substance abuse or dependence and psychiatric disorders have a poor prognosis (Drake et al. 1993). This has been attributed to the fact that individuals with dual diagnoses may come to treatment depleted of resources (e.g., unemployed, in financial difficulty, homeless). Another reason postulated for the poor outcomes experienced by dually diagnosed individuals is that they may receive insufficient doses of treatment given their level of dysfunction (Lidz & Platt 1995; Alterman, McLellan & Shifman 1993). Not surprisingly, clients with triple diagnoses (including substance abuse, mental illness, and cognitive impairment) were found to have higher rates of homelessness, legal problems, and histories of noncompliance with treatment compared with singly or dually diagnosed individuals (Strain et al. 1993). It is possible that such clients have such severe symptoms of mental illness,

substance abuse, or cognitive impairment that they cannot participate completely in treatments.

It has been suggested recently that multiply diagnosed individuals may not be able to withstand the burden of integrating the different clinical approaches utilized to treat their substance abuse and psychiatric conditions (Lidz & Platt 1995). This concept of client burden will be further explored in this article, in which an expanded concept of level of burden is used to investigate the impact of multiple problems and disorders experienced by women in a drug abuse treatment program. Level of burden is defined in the present study as the number and severity of problems experienced by the women themselves, as well as by staff and the community.

Over the past four decades, a number of studies have focused on the concept of caregiver burden. Persons with mental illness and individuals with senile dementia/Alzheimer's disease have been portrayed as stressful or burdensome to families, often depleting financial, social, and emotional resources. Much of this research on family burden grew out of an interest in understanding the social costs of deinstitutionalization (Greenberg, Greenley & Benedict 1994; Bulger, Wandersman & Goldman 1993; Marsh 1992; Lawton et al. 1989; Zarit, Reever, Bach-Peterson 1989; Cook & Pickett 1987-88; Potasznik & Nelson 1984; Goldman 1982; Bergmann et al. 1978). As a

result of deinstitutionalization, more families have been faced with the task of caring for their ill family members. Most studies on caregiving burden distinguish between subjective burden and objective burden. Subjective burden has been conceptualized as emotional reactions to caregiving, such as worry, sadness, and resentment. Objective burden has been defined in terms of behavioral phenomena, such as worrisome patient behavior (e.g., hostility) and disruption of family life (e.g., loss of opportunities to socialize).

Researchers have studied the burden of caregiving with a view of developing interventions to help these families. Thus far, their contributions have been limited to establishing that burden exists and that mutual-support groups might help families feel less burdened. Because the research to date has focused on the role of the patient as the recipient of care, there is a major gap in the knowledge about the burden on the client.

Exploring the level of burden from the client's perspective is important for several reasons. First, individuals with three of four disorders, such as alcohol and/or other drug abuse, mental illness, cognitive impairment, HIV/AIDS, and other health problems, experience continuous challenges to their self-esteem from the negative images and the social stigma associated with the illnesses. Second, understanding the impact of the level of burden on the client may help caregiving staff understand how to intervene when the client exhibits "noncompliance" with treatment or a poor connection with treatment providers. Third, this understanding can also contribute to the development of interventions to help staff, family members, and the larger community.

STUDY 1:
RETENTION IN TREATMENT

A major issue in substance abuse treatment is the ability to retain women in treatment for the full course of their program (Huba, Melchior & Brown 1995; De Leon & Schwartz 1984). Because the needs of all women substance abusers—and especially those with higher levels of burden—are great and multifaceted, a comprehensive and long-term program of treatment is needed. To meet the needs of women addicts and their children, the PROTOTYPES Women's Center has developed specialized services to provide a supportive therapeutic environment for a woman and her dependent children as she assumes a drug-free life, learns to cope with stress without alcohol and other drugs, develops daily-living skills and the ability to hold a job, and learns to understand and improve her role as a parent. Because women addicted to alcohol and other drugs and their children must cope with many different issues, PROTOTYPES has developed a complex program that seeks to provide needed services to a woman *when she is most ready to learn new skills, attitudes, and coping strategies*. Concurrently, a woman is immersed in an intensive recovery program

embodying state-of-the-art social-model principles where women in different stages of their own recovery help other women. While there is a core program, women's individual trajectories through the program may vary, just as the environments they must face after the program will vary. The program is organized as a therapeutic community (TC) with progression through four phases, each of which builds on skills learned in a previous stage(s) of treatment.

In each phase, the women assume increasingly more responsibility, beginning with household tasks and maintaining adequate childcare. As women successfully progress, they take on additional responsibilities, such as supervising other residents in household tasks. When a woman begins to look for outside employment, she has a "buddy-mother" who goes with her and supports her increasing independence. She is given passes outside the facility, increasing in duration from 4 to 8 to 12 hours to overnight. Eventually, she plans her own weekend passes and work schedule. At this point, she may hire another woman in the program to watch her child while she is at work. Women gradually take on responsibilities similar to those they will need when they reenter the community.

In this first study, the ability to retain women in treatment is examined as a function of level of burden using the technique of survival analysis. Prior analyses of these data (Huba, Melchior & Brown 1995; Melchior, Huba & Brown 1994) have shown that the race/ethnic identity of the individual does not impact on the ability to retain her in the program, but that the presence of active criminal justice supervision does (in a positive manner). Additionally, the drug of preference and the overall personality profile of the client relates to her retention in the program. These analyses address the question as to whether the overall level of "burden" (i.e., the total number of "diagnoses" or "significant problems") impacts on the number of days that the client can be retained in the program. The technique of survival analysis (Cox regression) is used. (For a fuller description of this method and its use in assessing program retention, see Huba, Melchior and Brown 1995).

METHOD

A sample of 260 women admitted with their children to a comprehensive residential drug abuse treatment program—PROTOTYPES Women's Center in Los Angeles—from October 1, 1990 to June 30, 1994 were given a battery of instruments. The major variables on which data were collected included demographic characteristics, substance abuse history and current use (prior to admission), psychological problems, cognitive impairment, general health status, and HIV/AIDS status. For the purposes of the current analyses, a subsample of 203 women for whom there were complete data on all measures is used.

TABLE I
CORRELATIONS AMONG BURDEN ELEMENTS (N=203)

	1	2	3	4	5	6	7	8	9
Heroin Use	—								
Amphetamine Use	-.15	—							
Cocaine Use	-.11	-.60	—						
Alcohol Use	-.20	-.20	.13	—					
HIV-Positive	.09	-.09	.12	.02	—				
Psychological Problems	.10	.08	-.04	-.04	.03	—			
Homeless	.08	.00	.07	.03	-.01	.10	—		
Cognitive Impairment	.07	-.18	.02	.07	.07	.21	-.01	—	
Health Problems	.26	-.03	-.08	-.17	-.04	.00	.11	.01	—

This group of women had an average age of 30.9 years. In this sample, 38.4% were African-Americans, 26.6% were Latinas, 30.5% were Caucasians, 3.4% were Asian-Americans, and 1.0% were Native Americans. The women were retained an average of 209.3 days in treatment.

Measures

Demographic Characteristics and Substance Abuse. Background data, including women's racial/ethnic identity, drugs of choice prior to entering treatment, and homeless status, are collected at program intake using a standard form that is used to contribute data to the federal minimum dataset (Client Data System). In addition, the client's HIV status at intake is noted, if known.

Basic Personality Inventory (BPI). The BPI is a 240-item instrument designed to measure "abnormal" forms of personality functioning (Jackson 1989). The inventory has excellent psychometric properties. The BPI is administered when the woman has been in treatment for six weeks.

Luria-Nebraska Neuropsychological Screening Test (LNNB-ST). The LNNB-ST is a short screening test that indicates whether a full neuropsychological evaluation is needed (Golden 1988). The standard instructions for this test indicate that administration should stop when the respondent reaches a score of 8. It is administered when the woman has been in treatment for six weeks.

Medical Problems. A health questionnaire completed by the program medical staff is used to indicate the health history of each client. This information is collected within 30 days of a woman entering the residential treatment program.

Program Retention. For the present analyses, program retention is indicated as the number of days women had been retained in the residential treatment program as of August 30, 1994. Time in treatment is measured as the number of days in the program current through that date.

Coding Level of Burden

One "point" is given to an overall index of burden for the client for each of a number of conditions that are present. To represent psychological problems or diagnosis, one point is given if there are three or more elevated scores (T-scores of 70 or above, a common cutoff point) on the BPI scales of hypochondriasis, depression, persecutory ideas, anxiety, thought disorder, social introversion, or self-deprecation. Two validity scales and three content scales (alienation, impulse expression, and interpersonal problems) were omitted from the composite because they are commonly associated with substance-abusing populations and do not represent additional "psychological" burden. The percentage of women who received a positive score on this indicator was 23.2%.

Health problems were coded by the presence of one or more of the following problems: gallbladder disease, cancer, diabetes, epilepsy, hepatitis, or tuberculosis. Current levels of sexually transmitted diseases are high in this population and hence were not included in the composite. The percentage of the women who received a positive score on this indicator was 27.6%.

A point for cognitive impairment was given if the client was at or above the LNNB-ST score of 8, which is the commonly used index for this test. The percentage of

FIGURE 1
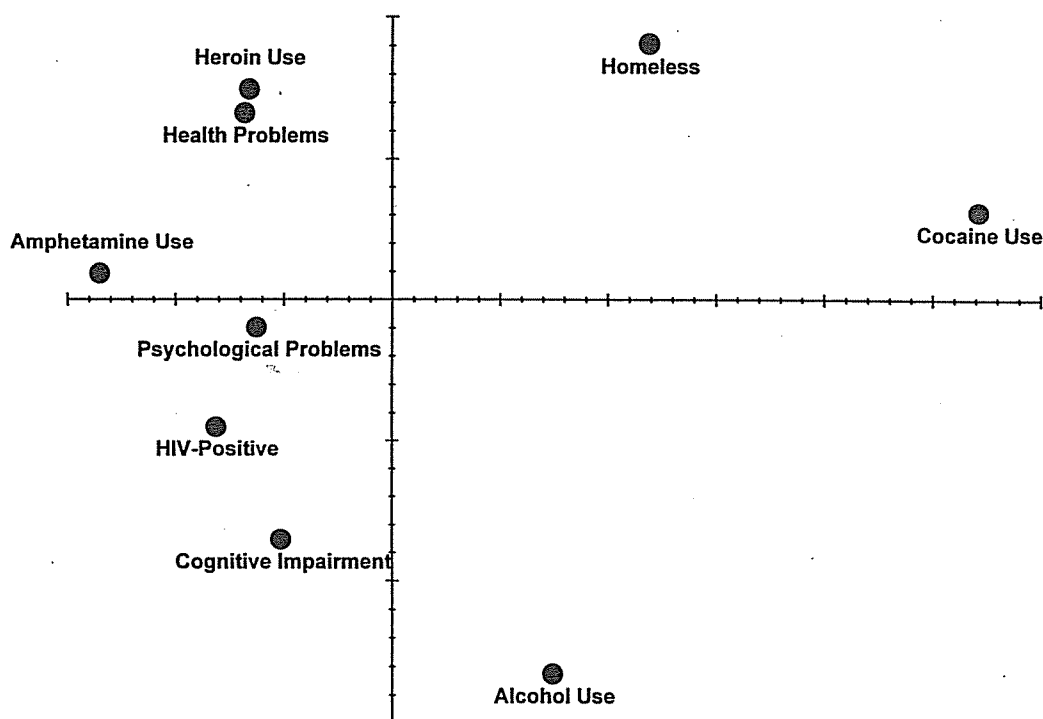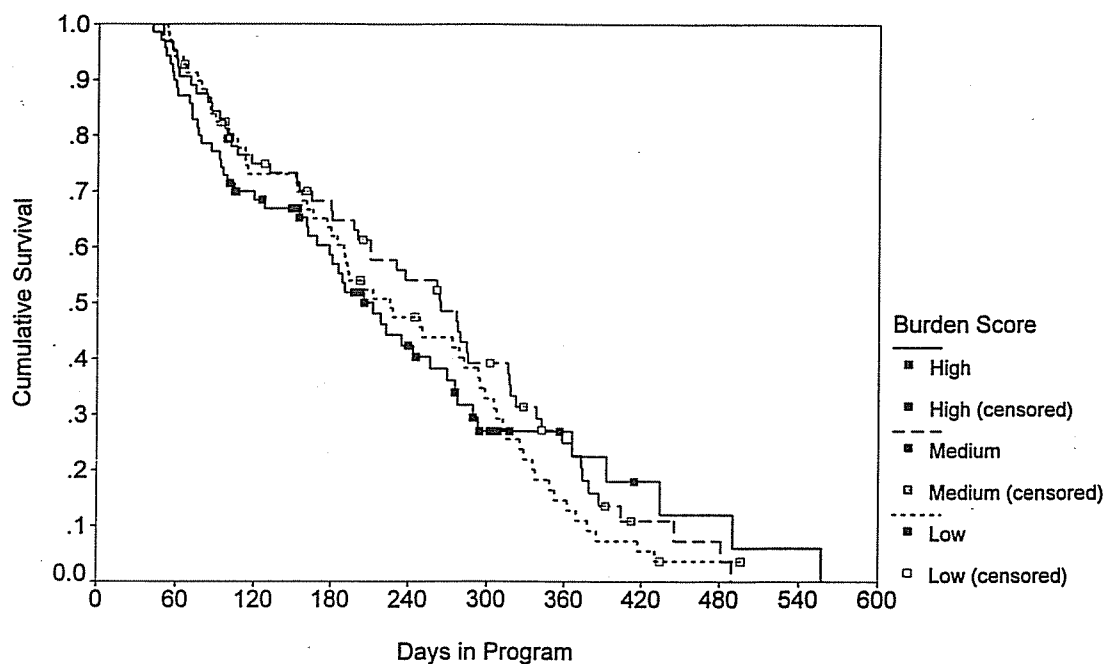## MULTIDIMENSIONAL SCALING OF BURDEN ELEMENTS (N=203)

FIGURE 2
SURVIVAL CURVE OF WOMEN IN RESIDENTIAL TREATMENT,
GROUPED BY LEVEL OF BURDEN (N=203)

the women who received a point on this index was 31.5%.

A point was given for HIV status if the client was verified to be positive by an HIV antibody test conducted at the program or received from another medical provider. The percentage of the women who were HIV-positive was 6.9%.

A point was coded for homelessness if the client noted that she considered herself to be homeless at the time of admission to the program. The percentage of the women who indicated that they considered themselves to be homeless was 52.2%.

In addition to the factors listed above, one point each was coded to the "burden" index if the client indicated that each of heroin (34.0% of the women), cocaine (73.4%), amphetamines (19.7%), or alcohol (39.9%) was among her three most common drugs of abuse.

It should be noted that in the context of the analyses presented here, overall burden is coded as a simple sum of the factors listed above. Each receives the same weight in the sum, so there are many different ways that an individual client could get a particular score, such as 4.

RESULTS

Distribution of Burden

The average level-of-burden score was 3.1, with a standard deviation of 1.3. The distribution was as follows: 0.5% had a score of 0; 8.9% had a score of 1; 24.6% had a score of 2; 31.5% had a score of 3; 22.2% had a score of 4; 7.9% had a score of 5; 3.4% had a score of 6; and 1.0% had a score of 7.

Correlation of Burden Elements

Phi-coefficients (product-moment correlations calculated on dichotomous variables) for the burden elements are presented in Table I. Note that the small, and largely nonsignificant coefficients indicate that the specific elements in the burden construct are not completely concomitant with one another, but rather should be considered to be a set of relatively uncorrelated risk factors.

To further explore the relationship among the burden elements, Figure 1 presents a nonmetric multidimensional scaling analysis of these elements. In this nonmetric multidimensional scaling, conditions of burden that tend to co-occur in the same individual are close to one another. Note that health and psychological problems tend to be more related to heroin and amphetamine users and that homelessness tends to be more associated with cocaine abuse.

Survival Analysis

As discussed above, the longer a woman stays in treatment, the more likely her recovery will be successful. Although it is inevitable that some individuals leave treatment prematurely, those women who remain in the PROTOTYPES program take on progressively more responsibilities and learn adaptive strategies that help them live drug-free outside of the residential treatment program. Does level of burden differentiate those women who remain in treatment from those who depart early? This question is addressed by using survival analysis (Singer & Willet 1991; Kaplan & Meier 1958) and the related technique of Cox regression (Singer & Willet 1991; Cox & Oakes 1984; Cox 1972) to study the retention characteristics of the program expanding on earlier studies of program retention with this group (Huba, Melchior & Brown 1995; Melchior, Huba & Brown 1994). The general issue that survival analysis is designed to address is how long subjects "survive" in the treatment program (Singer & Willet 1991). For instance, the PROTOTYPES residential program can take as long as 18 months. Yet, individual women may choose to leave the program earlier, and, as with all long-term drug abuse treatment programs, this does happen with some frequency.

In survival analysis, data are presented as survival curves. A survival curve is the percentage of clients who are still in the program after a given number of days have elapsed. Figure 2 presents the survival curve for women admitted to the residential program at PROTOTYPES from October 1, 1990 to June 30, 1994 as of August 30, 1994 from whom there is information on the elements of the burden construct. Some of the women admitted during the period that the grant was active still remain in the program. In survival analysis, such cases are called "censored," in that insufficient time has elapsed for all cases to have experienced the event being studied; in this instance discharge from the program. The analytical procedures take into account the censored cases. The data in Figure 2 are based on 203 women, 44 of whom are still in the program on August 30, 1994, and 159 observations on women who have left the program by August 30, 1994.

As a first analysis, the survival curves in Figure 2 have been presented separately for three groups of women. The low-burden group (n=69) had 0, 1, or 2 of the burden factors, the medium-burden group (n=64) had 3 burden factors, and the high-burden group (n=70) had 4 to 7 burden factors.

Figure 2 should be read as follows. The days in the program are the actual number of days the woman is in the residential program; the day an admission form is completed is counted as a full day. The cumulative probability of survival is the percentage of all women in that group who stay in the residential program for the given number of days. Note that the curves for the three burden groups are different. Early in the course of treatment, high-burden clients tend to be the highest risks for early termination. This is represented in Figure 2 by the solid black line, which is the lowest line on the chart in the first half of the figure.

TABLE II
PARTIAL CORRELATIONS BETWEEN TREATMENT OUTCOME RATINGS
AND BURDEN, CONTROLLING FOR OVERALL TIME IN PROGRAM

Rating Item	Partial Correlation	n*
Client's progress toward getting a job or going to school or getting training when she leaves PROTOTYPES	-.25**	64
Client's progress toward getting a job she would like when she leaves PROTOTYPES	-.36***	64
Client's progress toward getting a safe place to live when she leaves PROTOTYPES	-.37***	64
Client's progress toward getting things she needs, such as food and clothes for herself and her child(ren), when she leaves PROTOTYPES	-.35**	64
Client's progress toward getting/staying out of trouble with the law when she leaves PROTOTYPES	-.18	64
Client's progress toward getting/keeping herself healthy when she leaves PROTOTYPES	-.24**	64
Client's progress toward keeping her child(ren) healthy when she leaves PROTOTYPES	-.35***	47
Client's progress toward dealing with everyday problems and hassles when she leaves PROTOTYPES	-.29**	64
Client's progress toward keeping from using alcohol and other drugs when she leaves PROTOTYPES	-.26**	64
Client's progress toward better relations with her partner when she leaves PROTOTYPES	-.14	41
Client's progress toward better relations with her family when she leaves PROTOTYPES	-.33***	64
Client's progress toward doing fun activities with her child(ren) when she leaves PROTOTYPES	-.33***	53
Client's progress toward going to support groups (e.g., AA, CA, or NA) when she leaves PROTOTYPES	-.27**	64
Client's progress toward using her free time in a positive way when she leaves PROTOTYPES	-.27**	63
Client's overall progress to date	-.24**	64

*Reduced sample size on some items is due to nonapplicability of those items to some women.
**$p<.05$
***$p<.01$

At approximately one year of program duration, however, the lines intersect, and the high-burden clients tend to stay in the treatment program longer than lower-burden clients after this point. Likewise, the light-dashed line representing the low-burden clients indicates that after approximately one year they tend to leave treatment earlier than higher-need clients. It is likely that if low-need women reach the later phases of treatment, the program meets their needs in less time and they tend to complete sooner.

The Relationship of Program Retention to Burden
In addition to analyzing survival curves (i.e., the percentage of cases remaining in residential treatment or "surviving" after a given number of days), methods of survival analysis can be used to determine whether the survival curves are the same for different groups. Technically, the method of survival analysis employed in this report consists of using Cox regression with a time-dependent predictor to predict the pattern of retention in the program. Using burden as a continuous variable (ranging from 0 to 7 in this sample), it was found that there is a significant interaction between the time in the program and level of burden ($\chi^2=6.32$, d.f.=1, $p<.02$), as well as a main effect of burden ($\chi^2=4.61$, d.f.=1, $p<.05$) on the dependent variable of program retention. Higher levels of burden are related to generally lower levels of retention in the program, but

this is moderated by the time in the program. As can be seen in Figure 2, for those very few people still in the program at the end of a year, most had initially high levels of burden. In effect, there is a statistically significant tendency for the highest-burden clients to drop out of the program at early stages in the treatment regimen. If such clients make it through the initial stages of the program, they will tend to be retained longer because their treatment needs are highest.

STUDY 2:
TREATMENT OUTCOMES

A second major issue related to burden is whether a client who has a higher initial level of burden will have a poorer overall outcome from the residential program. In order to study this issue, the partial correlations between overall burden level and ratings made by program staff at the time discharge were examined. Because these ratings were "phased into the program" during the course when data reported here were collected, such ratings are only available for a subset of 68 women for whom the burden ratings are available. Discharge ratings are made by a consensus of treatment staff for 15 domains using a standardized four-point scale. Client progress is rated in terms of skills they have gained related to potential employment or education, relationships, sobriety, criminal justice involvement, coping strategies, and overall progress. Specific rating items are presented in Table II, as well as the partial correlations between the initial burden index and each of the items on the treatment scale. Each correlation was calculated controlling the overall amount of time in the treatment program.

As can be seen in Table II, many of the treatment outcomes are significantly negatively correlated with the initial burden levels in the program. This means that those clients who initially present with many of the elements of burden benefit relatively less from the program.

DISCUSSION

The present study investigated the impact of multiple problems experienced by women in a drug abuse treatment program (client burden) on their treatment retention and outcomes. Higher levels of burden are related to lower levels of retention in the program, but this is moderated by time in the program. It has been a finding for many decades that the highest dropout rates in TCs is in the early months. It takes some time to see reductions in the anxiety and fear that clients bring with them into treatment. It also takes some

time to feel positive connection to and establish therapeutic alliances with providers. This connection is an important component in the TC, since staff and other more experienced residents in the community are the role models and teachers for behavior change. As can be seen, the highest-burden clients tend to drop out of treatment at early stages. It is possible that high-burden clients are easily overwhelmed by the transition required in entering a residential drug abuse treatment program. Although the treatment program offers a safe and supportive environment, women with severe mental or physical illnesses may be overwhelmed by the need to participate with others, to behave in a structured community way, and to comply with program rules and procedures.

It is even more important to focus attention on these early phases for the multiply diagnosed, high-need client. It may be necessary to design "treatment preparedness" strategies for these clients to ensure their staying in treatment. One possible strategy would be to begin case management from day one to assist the client in dealing with practical problems and to prevent disrupting treatment. Results also show that if the high-burden women stay in treatment past the early stages, they can benefit. For these clients, long-term continuous care appears to be the most beneficial. It is also important to note that, in the face of managed care, lower-need clients may be able to leave residential treatment in a shorter period and be picked up in an outpatient aftercare program.

The other major finding of this study is that clients with the highest levels of burden may benefit less from the program. Program staff rated the clients with multiple needs as having made less progress at termination in getting jobs, finding a safe place to live, getting food and clothes for themselves and their children, keeping their children healthy, dealing with family, and doing fun things with their children than clients with fewer problems. It is likely that the highest-burdened clients need ongoing case-management services to assist them in many of their tasks of daily living. This area will be explored in future studies.

However, it is also possible that when confronted with the highest-need clients, staff feel more concerned about the ability of these clients to function when they leave the program. They may see the progress of these clients differently than other clients. It is also possible that staff may then invest less time in the high-burden clients; therefore, the clients will show poorer outcomes because they receive less treatment. Thus, staff burden is another area that needs to be explored in further studies.

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