

**Preliminary Report on Consumer Experiences of Psychiatric  
Emergency Services in Boston**

**A Report of The Boston Community Academic Mental Health Partnership  
(B-CAMHP)**

**April, 2009**

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Boston**

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## **Acknowledgements**

We wish to thank our study participants, who gave generously of their time, shared their stories, and helped us to begin to better meet the needs of people using psychiatric emergency services. This project could not have been completed without the time and efforts given by the many individuals and agencies involved in this work. The Boston Community Academic Mental Health Partnership (B-CAMHP) was supported by a grant from the National Institute of Mental Health (#MH076740:PI Lincoln).

## **Background**

In April, 2006 the Boston Community Academic Partnership (B-CAMHP) began a highly innovative project to increase our understanding of consumer perspectives of psychiatric emergency care. The B-CAMHP is a partnership of four community-based consumer/family run agencies, a university partner, and the Metro-Boston Region of the Massachusetts Department of Mental Health. Each of these agencies play significant and varied roles in state and local mental health policy and research. The partners currently include:

**Northeastern University** is a private research university located in the heart of Boston, and a leader in interdisciplinary research, urban engagement, and the integration of classroom learning with real-world experience. A core mission is *“To create and translate knowledge to meet global and societal needs.”*

**Consumer Quality Initiatives, Inc. (CQI)** is a mental health, consumer-directed and staffed, quality improvement and research organization based in Massachusetts. CQI’s mission is to develop opportunities for the meaningful involvement of consumers and family members in all aspects of mental health research and program evaluation.

**Metro-Boston Region, Massachusetts Department of Mental Health (DMH)** is the State Mental Health Authority whose objectives are to assure and provide access to services and supports to meet the mental health needs of individuals of all ages, enabling them to live, work, and participate in their communities; to establish standards to ensure effective and culturally competent care to promote recovery; and to set policy, promote self-determination, protect human rights, and support mental health training and research. It is the Boston area office that works on this grant.

**The Massachusetts Chapter of the National Alliance for the Mentally Ill (NAMI-MASS)** is a non-profit consumer and family member run organization dedicated to improving the quality of life of people affected by mental illness or biological brain disorders. **Parent/Professional Advocacy League (PAL)**, is directed by parents of youth who have (or previously had) serious emotional disturbance. Provided are support, education, and advocacy around issues related to children's mental health.

This is accomplished by working in partnerships with both families and professionals,

with the goal of enabling families to live in their communities in an environment of stability and respect.

**The Transformation Center (TC)** is a consumer run organization that provides statewide technical assistance and training to: people with mental health conditions, providers and other stakeholders on recovery, empowerment and cultural change.

The B-CAMHP partners have committed to a shared mission:

*The Boston Community Academic Mental Health Partnership (B-CAMHP) was established to create a mechanism for persons with mental health and/or addiction recovery needs to fully participate in the design and conduct of mental health research.*

The B-CAMHP is committed to conducting community- based participatory mental health research in the Boston area. As a first project, and as part of the initial NIMH funded grant, the partnership chose to focus attention on consumer perspectives on psychiatric emergency care. In preliminary meetings this group identified psychiatric emergency care as the critical first area of focus following discussions on how frequent use of psychiatric emergency services was detrimental to the consumer and costly to the state. Many members could reference either their own negative experience or those of family members. Consumer and family member perspectives have been all but ignored by research on psychiatric emergency care.

In this report, we present the preliminary findings of this first B-CAMHP pilot study. It is the intent of the B-CAMHP that these findings be used to shape the provision of psychiatric emergency care in ways that better serve the people using these services and their families as well as the people who work in psychiatric emergency settings.

### **Background on Psychiatric Emergency Care**

In recent years there has been a dramatic increase in the number of people who use psychiatric emergency services (Allen, 1996). Many factors contributed to this change: deinstitutionalization, increasing numbers of people with no permanent home, increasing psychiatric and substance abuse comorbidity, and dwindling social service safety nets. These factors have increased the demand for PES care at the same time that legal and mental health care system changes, including managed care, have restricted the

availability of inpatient care. While Psychiatric Emergency Rooms are important services, they are often “crowded, underfunded, and facing increasing staff shortages and a dwindling availability of hospital beds” (Stefan, 2006). These factors contribute to unpleasant experiences for both service users and staff. Many service users view EDs with “bitterness and distrust”, and ED staff often feels they lack the time or the skills to provide appropriate care to those in psychiatric crisis (Stefan, 2006).

This shift in the locus of mental health care and the social context within which mental health services are provided has led to some people frequently using psychiatric emergency room services. The frequent use of PES services has been studied primarily from one perspective, which assumes frequent use of these services to be an inappropriate or inefficient use of mental health services. Patients who frequently use PES services are labeled as “recidivists” and often described as treatment resisters, frequent flyers, revolving door patients, or "unmotivated or at least ambivalent" (Goldfinger, Hopkin, & Surber, 1984, p.15). Frequent users have been estimated to constitute 7 to 18% of PER patients (Bassuk & Gerson, 1980; Buaer & Balter, 1971; Slaby & Perry, 1981).

Research efforts have focused on identifying the clinical and socio-demographic characteristics of these patients and determining how they differ from "non-frequent" users of services. In most studies, age has not proven to be a significant distinguishing variable. Bassuk and Gerson (1980), however, found a statistically significant overrepresentation of repeaters in the 31-to-50 age group. Women were not overrepresented among repeaters in three controlled studies (Bassuk & Gerson, 1980; Buaer & Balter, 1971; Slaby & Perry, 1981). Other variables that have failed to discriminate between repeaters and non-repeaters include, race, education and unemployment. Repeaters were more likely to lack social supports (Bassuk & Gerson, 1980; Miller, 1968; Munves, Trimboli & North, 1983), to have a prior psychiatric hospitalization (Bassuk & Gerson, 1980; Buaer & Balter, 1971; Munves, et al., 1983), to be concurrently in psychiatric treatment, and to have a chronic psychiatric illness (Slaby & Perry, 1981). The data also suggests that repeaters are more often self-referred and more likely to be hospitalized (Buaer & Balter, 1971). Assumptions are then often made that these characteristics, i.e., social isolation, are causal in their frequent use of PER services. Many assumptions have been made by researchers studying frequent users of PER

services including that frequent use of PER services is inappropriate, costly, and leads to negative treatment outcomes. "One serious difficulty inherent in any discussion of effective treatment for the acute care recidivists is the remarkable paucity of our knowledge about them." (Goldfinger, et al., 1984, p.20). The current socio-historical context of mental illness necessitates a re-examination of these assumptions. The PER has always served as an open door for mental health care. Emergency rooms can be described as barometers for society. People who are pushed to the margins by pressures operating in society will be disproportionately represented among those seeking care at the PER. The manifest function of the PER is to provide emergency psychiatric care for people in acute crisis, parallel to the general emergency rooms. However, PERs also serve a latent function of safety, food, shelter and social interaction (Malone, 1998).

Appropriate use of PER services by patients struggling with chronic mental illness has been inadequately defined. However, "recidivism" has been defined in many ways. There is little agreement about how many visits are needed for a patient to be labeled recidivist. Definitions tend to be determined by the length of the study, and criteria include a minimum of two or more visits in the time period. Definitions of repeaters vary liberally from one visit per year (Bassuk & Gerson, 1980; Munves, et al., 1983; Slaby & Perry, 1981), to more than one visit in six months (Buaern & Balter, 1971; Miller, 1968; Ungerleider, 1960), to more than one visit per four months (Schwartz, Weiss, & Miner, 1972). This variability in the criteria used to define recidivism has of course led to even greater disagreement as to the characteristics of recidivist patients. The most frequent method used for studying "recidivist" patients however defined, has been quantitative analyses. A variety of clinical and social variables are examined to determine which characteristics differentiate 'recidivist' and 'non-recidivist' patients. Finally, researchers often assume that these differentiating characteristics are causally linked to the patient's presentation at the emergency services). For instance, if patients described as "recidivists" are less likely than other patients to have social support, researchers conclude that this is an important factor in the reason for their visit.

The current literature on psychiatric emergency service utilization provides us with inadequate knowledge to design psychiatric emergency interventions and care that meet the standards outlined in the President's New Freedom Commission Report. A

tremendous gap is the absence of the inclusion of consumer and family members' experiences. We have identified **no** study in which repeat users of psychiatric emergency services were asked about the service utilization patterns. In addition, we have been unable to find any research on psychiatric emergency care which has drawn upon the principles of CBPR. In this critical area of study this is a particularly important limitation. The inclusion of the community in the development and conduct of research on psychiatric emergency services is a key contribution of this proposal. The need for new methods of service delivery and programs that better meet the needs of consumers, family members and providers is clear. The B-CAMHP is a first step in the ultimate development of interventions informed by the experiences and knowledge of the multiple stakeholders involved with these services.

### **Psychiatric Emergency Services Pilot**

In an effort to be able to best address the issue of psychiatric emergency care, the B-CAMHP invited the Boston Emergency Services Team (BEST) to join as a partner on this project. BEST is the psychiatric emergency services provider for the Metro-Boston area. They provide services to more than 40,000 people and their families each year. As part of its Department of Mental Health mandate, BEST has a very elaborate data management system. In addition to gathering demographic data on all people who use the continuum of emergency services provided, the system currently generates service utilization reports on all services provided.

The Boston Emergency Services Team, under the leadership of Boston Medical Center and in partnership with Massachusetts General Hospital, Baycove Human Services Inc., North Suffolk Mental Health Association, along with the support of the Massachusetts Behavioral Health Partnership and the Massachusetts Department of Mental Health, provides 24 hour emergency service for adults and children in need of immediate psychiatric intervention. Individuals who need emergency care are assessed and briefly treated by experienced, master's level clinicians and physicians who specialize in rapid response to those in psychiatric crisis. BEST provides a comprehensive, highly integrated system of crisis evaluation and treatment services to the greater Boston area; this includes, children, adolescents, adults, the elderly, homeless,

mentally ill and the multi-cultural populations within the Metro Boston area. BEST became a critical part of the Project Team responsible for this work by facilitating access to service users through assistance in recruiting study participants, gathering and analyzing data, and the creation of this report.

## **Study Methods**

### Community-Based Participatory Research Principles and Mental Health

While there has been “a dramatic increase in the attention and resources devoted to partnership or collaborative approaches to public health goals in the US,” (Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2001, p.495) few of these efforts have focused on establishing significant roles for mental health consumers (Delman, 2005). Mental health consumers have historically been a marginalized and stigmatized group who have little power compared to individuals who make treatment and mental health policy decisions (Ochocka, Janzen, & Nelson 2002). The decision-making process around the allocation of funds and services for mental health consumers has left out consumer input, resulting in service gaps and barriers to service utilization (G. Caplan & R. Caplan, 2000; Rosenheck, 2000). Using methods to empower consumers to make treatment decisions and including the experiences and views of consumers in program/policy planning has been shown to create a closer match between consumer needs and system resources, while improving consumer quality of life and service satisfaction and beginning to address system wide social justice issues such as stigma and discrimination (Ochocka et al., 2002; Schalock, Bonham, & Marchand, 2000).

The recent President’s New Freedom Commission report (*Achieving the Promise: Transforming Mental Health Care in America*) is critical of the nation’s mental health system (Department of Health and Human Services (DHHS), 2003). Among other critiques, the report concluded that the mental health service system has not been responsive to the needs of consumers and families, and that the findings of rigorous research have not been effectively translated into practice (DHHS, 2003, p.67; Institute of Medicine, 2001). Thus, a significant recommendation of the President’s report is to involve consumers and families in the planning and evaluation of services, with a specific reference to consumer led research and evaluation (DHHS, 2003, p.37).

Community-based participatory research (CBPR) methodologies equitably involve all stakeholders in the research process and recognize the unique strengths that each brings. Essential to community-based research is the active re-allotment of power between all involved members and constituents in the research process (Strand, Marullo, Cutforth, Stoeker, & Donohue, 2003). CBPR emphasizes reciprocal transfer of knowledge, skills and capacity throughout the process, imparting community members with tangible and practical benefits as a result of their engagement and participation (Minkler, Blackwell, Thompson, & Tamir, 2003). Thus, CBPR strengthens co-learning and capacity building among all partners.

Involvement of community members establishes the critical link between research and action or practice because community members buy in to a process that involves them from the beginning placing them in a better position to apply findings to actual practice and disseminate those findings (Israel, et al., 2003). CBPR is more easily translated into practice since community-defined research is relevant to the local conditions, with consumers taking an equal role (Israel, et al., 2003). Consumers not only buy in to it, but can explain it to their peers. In essence, the purpose of CBPR is not simply to develop knowledge within a discipline, but to create knowledge that "contributes to making a concrete and constructive difference in the world" (Sclove, 1997, p.542).

#### Recruitment and Training of the Research Associates

Six part-time Research Associates (RAs) were hired to allow for greater flexibility and more diversity of perspectives. RAs were chosen to represent the diversity of people who use PES, in terms of racial, ethnic, gender, and age diversity. In preparation for designing and conducting the research study, all RAs participated in an interactive, structured training. A primary purpose of the training was to ensure all RAs would begin the project with a shared language and level of knowledge, allowing them to communicate and collaborate at a high level. The 16 hour training was presented in a workshop format, with a major emphasis on participatory methods, including role plays. Topics covered included developing research questions, interviewing techniques for qualitative research, research ethics, collaborative research models, current research in psychiatric emergency services, recovery and peer support, and the role of family

members. Upon completion of the training each RA successfully passed both an oral and written exam in order to be certified as a Community RA.

#### Development of Specific Study Question(s) and Study Methodology

The PES Project Team began meeting weekly in December, 2006. Following a series of facilitated discussions the group focused the research questions and developed appropriate study methods. The goal of the pilot study was determined to be: To increase our understanding of the repeat use of PES through the inclusion of service users perspectives and experiences. The group chose to take a mixed methods approach to this exploratory work and chose to include both quantitative and qualitative data.

#### Human Subjects Protection

This study was fully approved by multiple IRBs including the Boston University Medical Center IRB, the Department of Mental Health Central Office Research Review Committee (CORRC), and the Northeastern University IRB.

#### Study Sample

The initial study design was based on recruiting repeat users (defined as having used PES twice in 60 days) from the Boston Medical Center Psychiatric Emergency Service. Psychiatric emergency services (PES) was defined as having used any BEST service (including BMC PED , the Crisis Stabilization Unit at the Fuller, the Crisis Intervention Mobile Team, and the Urgent Care Centers at the Fuller and the Lindeman) and thus potential participants were to be identified through the use of the BEST database. Despite great effort we were unable to recruit participants through the BMC emergency room. Thus, following additional IRB approvals, recruitment efforts were moved to the Crisis Stabilization Unit (CSU) in the Fuller Mental Health Center. In addition, our inclusion criteria were broadened to include:

- having used BEST services twice in 90 days
- not currently under guardianship
- not deemed to be a danger to self or others at time of referral

Eligible participants were asked at discharge, following all dispositional decisions, whether they would be willing to speak with someone about a study of people's experiences of PES. They were given a referral card with the Project Director's

contact information and asked if they would be willing to provide contact information and to be contacted by study personnel.

Eligible participants were contacted by a study RA, who explained the study and stressed the unique nature of our study design with interviewers who had themselves used PES, and asked if they would like to participate in the study. People who chose to participate were interviewed by RAs in safe and private settings agreed upon by the participant and the RA.

Eighteen people participated in the study. Demographic data is thus available on each of the 18 participants however qualitative data were only fully gathered on 16 participants. Missing qualitative data was due to a lost tape and one incomplete interview.

#### Data Collection

The interview guide was developed by the PES Project Team through an interactive process. Questions were suggested by Project Team members and then reduced to minimize repetition and participant burden. The interview was pilot tested and then further revisions were made. The final guide included the gathering of social and demographic data as well as nine open-ended questions. The guide gathered information on the participants' most recent use of PES as well as their experiences of PES in the past.

Participants were asked for permission to audio tape the interview and all but one of the interviews were audio taped. Notes were taken by the interviewer when audio-taping was not possible. All tapes were transcribed and data were entered into HyperResearch a program especially useful for data sorting and supporting analyses.

#### Coding Procedures

A rigorous data coding and analyses procedures were developed specifically keeping with CBPR principles. The team, RAs, Lindeman (CQI), Lincoln (PI) and Wallace (Project Director) met weekly to develop a process that was both methodologically sound and feasible for group coding and analyses process.

The development of the coding scheme involved many steps. First, three transcripts were selected to be used for the development of the procedures. These transcripts were reviewed by the group as a whole. Each researcher then underlined segments of relevant text in relation to the study questions, and the segments were then

compared to determine consistency across reviewers. Next, preliminary summary tags were created to describe these segments of data. Tags were then reviewed by the group and organized into clusters or groups of like tags. Groups of tags were then reviewed for singular ideas and groups of tags were given descriptive titles. These were then used to develop codes and definitions of codes. Codes and definitions were reviewed by the group and codes were then applied to the original three transcripts by multiple coders. Coding was then compared for inter-rater reliability and differences were discussed until agreement of appropriate coding was reached. Once consensus was reached that the coding schema was appropriate, one coder (KL) coded the remaining transcripts. Coded transcripts were reviewed by the team and difficult segments of text were discussed.

### Analysis Procedures

The analysis process evolved during the course of the project due to challenges of funding, RA time availability, and varying levels of interest in the process. Each person involved in the research was given a binder of data, including basic demographic info for the sample, the final codebook for reference (see Appendix A), a printed copy of each coded transcript, and copies of a Preliminary Analysis Form and an Analysis Memo.

Weekly meetings continued and each researcher read each fully coded transcripts. Discussion of qualitative methods continued, particularly the ways (both appropriate and inappropriate) that lived experience interacted with the qualitative analysis process.

Ultimately the analysis plan included the following components:

1. All analysts read every transcript.
2. Code reports were run and at least two analysts were assigned to the code.  
The PI had to read every code report.
3. Each analyst recorded notes/findings on the Analysis Memo.
4. Analyst pairs were given the opportunity to meet and discuss together the similarities and differences in their findings.
5. Analyst pairs presented their findings from the code report to the team, bringing any unresolved issues to the team for a larger group discussion.  
Group members had the opportunity to ask clarifying questions and bring up issues that they were surprised by or found to be missing.
6. The analyst pairs wrote the Analysis Memo summary for that code report.

## **Results**

### Demographic Characteristics of the Study Participants

Eighteen participants enrolled in the study. Data on the demographic and service utilization of these 18 are presented here in Tables 1 and 2. As noted above, qualitative data were available from 16 of the 18 participants. Eighteen individuals participated in this pilot study. As evidenced in the demographic tables, the participants in this pilot study reflected the diversity of people who use Psychiatric Emergency Services (PES). However, our sample differed from the overall BEST population of repeat users of PES in several notable ways. The study sample was 72% male while a similar BEST population is 56% male, and 22% self-identified as Hispanic ethnicity. Half of the participants were white, 28% African American and two people self-identified as multi-racial. Among those who use BEST services 17% identify as Hispanic/Latino. The study sample was also disproportionately White as compared to the overall BEST data in which 37% of clients are noted as White. The mean age was 40 years old, and 56% reported their highest level of education as being some high school. The majority of the sample (61%) reported being single and never having been married. Twenty-eight percent were divorced or separated.

In regard to service use (Table 2), fifty percent of the study sample used PES 1-2 times in the 180 days prior to their interview, with a slight majority of this group (28%) using the PES twice. Similarly, 50% of the study sample used the PES three or more times in the 180 days prior to their interview, however the majority of this group (28%) visited the PES 4-6 times. When broken down by the number of visits 90 days prior to and 90 days after their interview, more participants used the PES prior to being interviewed than afterwards. For example, while most participants (78%) used the PES 1-2 times before participating in the study, almost half of the sample (44%) did not use PES at all 90 days after being interviewed, with only 39% using PES 1-2 times. Furthermore, if high use is defined as having more than 3 PES visits in 180 days based on an average of 3 visits in our sample, high users are more likely to be female, under thirty years of age, to rate their health as being fair, to be unemployed, and to have less education than those participants with 3 visits or less.

**Table 1: PES Study Demographics Table of Repeat Users**

|                            | N                                   | (%)  |    |
|----------------------------|-------------------------------------|------|----|
| <b>Gender</b>              | Male                                | 13   | 72 |
|                            | Female                              | 5    | 27 |
| <b>Ethnicity</b>           | Non-Hispanic                        | 14   | 78 |
|                            | Hispanic                            | 4    | 22 |
| <b>Race</b>                | White                               | 9    | 50 |
|                            | African American                    | 5    | 28 |
|                            | Multiracial                         | 2    | 11 |
|                            | Hispanic                            | 1    | 6  |
|                            | Native American                     | 1    | 6  |
|                            | Other                               |      |    |
| <b>Age</b>                 | ≤20                                 | 3    | 17 |
|                            | 21-30                               | 1    | 6  |
|                            | 31-40                               | 3    | 17 |
|                            | 41-50                               | 8    | 44 |
|                            | ≥51                                 | 3    | 17 |
|                            | Mean                                | 39.8 |    |
| <b>Primary Language</b>    |                                     |      |    |
|                            | English                             | 15   | 83 |
|                            | English/Spanish                     | 1    | 6  |
|                            | Portuguese                          | 1    | 6  |
|                            | Spanish                             | 1    | 6  |
| <b>Physical Health</b>     |                                     |      |    |
|                            | Fair                                | 10   | 56 |
|                            | Good                                | 8    | 44 |
| <b>Relationship Status</b> |                                     |      |    |
|                            | Single Never Married                | 1    | 61 |
|                            | Divorced/Separated                  | 5    | 28 |
|                            | Married/Living with Partner         | 1    | 6  |
|                            | Widowed                             | 1    | 6  |
| <b>Housing Status</b>      |                                     |      |    |
|                            | No Stable Address                   | 7    | 39 |
|                            | Live Alone                          | 4    | 22 |
|                            | Live with Family                    | 3    | 17 |
|                            | Live with Roommates                 | 2    | 11 |
|                            | Live in Group Home/Nursing Home     | 1    | 6  |
|                            | Live w/Spouse/Significant Other     | 1    | 6  |
| <b>Work Status</b>         |                                     |      |    |
|                            | Unemployed                          | 16   | 89 |
|                            | Other                               | 1    | 6  |
|                            | Working for Pay                     | 1    | 6  |
| <b>Education</b>           | Some High School (did not graduate) | 10   | 56 |
|                            | Graduated From High School          | 5    | 28 |
|                            | Some College (did not graduate)     | 2    | 11 |
|                            | Masters Degree                      | 1    | 6  |
| <b>Insurance</b>           | MassHealth                          | 15   | 83 |
|                            | BMC HealthNet                       | 2    | 11 |
|                            | Commonwealth Care                   | 1    | 6  |
| <b>Substance Use</b>       |                                     |      |    |
|                            | Yes                                 | 11   | 61 |
|                            | No                                  | 2    | 11 |
|                            | Unknown                             | 5    | 28 |

**Table 2: Psychiatric Emergency Service Use of the Study Sample**

| # of visits past 180 days                       | <u>N</u> | <u>%</u> |
|---|----------|----------|
| 1   | 4        | 22       |
| 2   | 5        | 28       |
| 3   | 2        | 11       |
| 4-6   | 5        | 28       |
| >6  | 2        | 11       |
| Average # visits =3                             |          |          |
| # of visits within 90 days before the interview |          |          |
| <b>0</b>  | 0        | 0        |
| <b>1</b>  | 7        | 39       |
| <b>2</b>  | 7        | 39       |
| <b>3</b>  | 2        | 11       |
| <b>4-6</b>                                      | 2        | 11       |
| # of visits within 90 days after the interview  |          |          |
| 0   | 8        | 44       |
| 1   | 5        | 28       |
| 2   | 2        | 11       |
| 3   | 2        | 11       |
| 4-6   | 1        | 6        |

Qualitative findings

We present the results here in five areas based on what we have learned from our study participants about their repeat use of PES. First, we have increased our understanding of **why people say they use these services and what they are hoping to receive**. Importantly, we can begin to understand whether people who repeatedly use PES see this as something they would like to continue to do or, whether they would prefer to use the PES less. Secondly, we’ve found that despite the diversity within our sample, **instability** was a common theme in our participants’ lives. We explored instability in housing, employment, financial status, social relationships, formal/treatment services, and psychiatric medication. Third, the participants had **mixed experiences with formal, semi-formal, and informal supports**. Finally, **substance use and abuse** were major issues in the lives of participants and this was identified as a key aspect of their repeat use of PES.

**1. Why do people say they use psychiatric emergency services? What do people using PES want?**

Several important areas were examined in the data to better understand why people use psychiatric emergency services. Here we discuss people's explanation for why they used services and what people wanted from their use of PES. While people used the PES for a wide variety reasons, there were some clear patterns of service use. Nine of the participants reported that they had stopped using their psychiatric medication prior to the PES visit. Among those who discussed having stopped their medication, more than ½ reported that this was due to not having access to their meds either because they couldn't pay for them or didn't have insurance. A couple people described that their medication had recently been stolen.

In addition, 8 people, or half of the sample, described feeling depressed or suicidal prior to the PES visit. Four people attributed their PES visit to substance use and violence (both perpetration of and victimization) was involved in four PES visits. As one participant stated, "Deep depression, I was crying a lot...I was drinking a lot and I wasn't taking my medication because I didn't have any" (009). Another stated, "I had plenty of beer and rum and I had to self medicate myself... (I went back to ER because) I couldn't take it anymore" (003).

People also want different things from their use of PES. People sought inpatient treatment, outpatient care, day programs, medications, talk therapy and other non-formal care such as "A place where I can be safe" (022), a time-out, or "a pottery class (017). People often described "looking to feel better." As one person noted, "I wanted to feel normal again" (009). Another stated, "To make sure I wasn't crazy" (010). Two people discussed wanting a miracle medication or a cure for their depression, "Miracle medication that would stop making me feel the way I felt" (003). Another said they used PES, "To get back on my medication, to find out how to cure my depression" (014). Finally, several people who were brought to PES by others, did not articulate specific services or care that they wanted at the PES.

### **Experiences of PES and Using PES More/Less**

The majority of people had positive experiences of their PES use. They describe receiving many services and types of care as part of the PES visit. Several people describe detoxing at the CSU. Eight people received meds as part of their PES visit.

Three people talked about their service use being a chance to rest, sleep and have some respite. PES visits also facilitated service access outside of the PES, as people were referred to programs and appointments with treaters as part of their discharge plans. Basic needs were sometimes addressed as well. For example: “And they got me a contract bed at a shelter. I got to be there at like 4:00. So, you know, everything I need they came through with” (019). Finally, people described the importance of the staff of the PES listening to them as very helpful. The staff, “put me in the right direction” (002), “staff listened” (020), “they treated me right” (009).

However, not all participants had a positive experience. As one participant said “This is where I’m at – this is why I feel that the hospital should have more consideration to other people’s feelings and needs... other than just saying there is no bed, there is no room.” They can place me anywhere-- I don’t give a damn as long as I can get some help” (001). Another participant seemed to feel judged for her frequent use: “I believe that – I know their response, it was ‘Wow, you’ve had a lot of hospital inpatient stays, and then you just keep coming back and back and back,’ and the woman explaining that was like, you can’t do that...” (017).

### **Using PES More/Less**

Participants differed in their perspectives as to whether they would prefer to use PES more frequently, less frequently or the same amount. As one noted, [I would like to use services]”about the same... because I'm getting better, it's helping out” (014). Others reported that they would like to use PES more frequently; for example one explained:

[ I would like to use PES] more frequently... ‘cause I think that, um, more frequently because I um I would do better. You know, I would do better. ‘Cause, you know, there have been times that... I was in a program – a kind of hospital. It was called the partial program, and, um... I just go there like nine in the morning to like four in the afternoon and... we talked to doctors, nurses, and like church people. You know, \*things\* like every day. And one-on-one, group counseling. And I stayed on my medication. And I did good (019).

Finally, some participants did report wanting to reduce their use of PES and discussed what would be helpful for them to achieve this goal. “Less frequent. I tell you what, I come to the realization, which I came to it for a while, I could benefit from an

anger management group or course or classes” (016). Participants identified having a psychiatrist or a therapist as an important factor in using PES less often. In addition, attending AA or NA and taking medication were seen as helpful in reducing frequency of PES visits. As one participant noted, “First of all take the meds like he's prescribed, have a support system, have your therapist, psychiatrist, your sponsor if you are in sobriety like me um utilize all of them and live in a safe environment” (011).

## 2. Instability

The most consistent finding among our study participants was the high level of instability across multiple domains of people’s lives. Many of the repeat users of PES reported being **homeless** or having no stable address. Of those who had no stable home, 6 of 8, identified the stress of housing instability as being a major factor in their PES use and their mental health status. One participant stated, “It just makes me like cry a lot because a lot of times I don’t have the things I need you know, like a regular apartment.” (009). Others, while housed, reported feeling unsafe in their living situation. For example, one participant expressed: “Part of my major depression, my home life, where I’m staying. Um, just, I’m just getting pushed up on, and I really don’t like it.” (017). The lack of housing stability and safety were repeatedly referred to as reasons for depression, hopelessness and subsequent hospitalizations. One participant discussing housing said:

The things I want is hard to get because you know like the things like housing or something I go to these little depressions here and there and you know I cry a little bit but I'm trying at least I am trying to do you know what I mean I'm trying the best I can (005).

Only one participant was employed and one was in a VA work program. Half of the participants reported significant stress and unhappiness about their **lack of employment** and the subsequent financial stress.

I was feeling very depressed and suicidal due to my life situation... because I'm homeless and unemployed and I have no money and I have nowhere to go during the day... i just feel I have nothing left to live for (013).

One participant described unemployment as proof he/she was not the “ideal prim perfect young adult” (016).

There is also a high level of instability around maintenance of **psychiatric medication**. People described having stopped taking their medication, often due to

financial problems. One explained, "I have to get my prescriptions filled. I couldn't today, no money, but I could do it tomorrow" [with the study incentive money] (014). Another lamented about access to medication, "So I went home and I was just so bloody nervous and I actually stayed at home – no medication after being on so much. Nowhere to fill prescriptions and no insurance." (005).

Participants spoke of wanting to get back on medication but also were aware of the limitations of medication, two participants commented on this: "I just wanted to feel normal again. I wanted to feel level – my mood to be better. You know, when I take my medication you know I feel better" (009) and "Medication seems to help but it is not a cure – it just makes you feel a bit better" (013).

Most participants have been on many different medication regimens and often are taking multiple medications at once. As one participant noted, "When I came in I had two medications... I ended up with five more I have seven all together now."(008). These multiple experiences with medication have left participants aware of the necessity of trying new meds, waiting to see if they work, and weary of the side effects. One person said, "Because some medications work for me and some don't" (011), "I have never been this size before – I'm just blowing up I just can't stop eating" (011). Several described the desperation they felt in hoping the meds would work. "I hope and pray that my medication works again because they changed it a little bit" (013).

Participants also report that they have few stable social relationships in their lives. They often describe having "burnt their bridges" with their family and friends. As one person stated,

Because I am lonely – I don't have anybody to call I do have a family the but they don't want to talk to me any more and I lost some phone numbers – they changed phone numbers on me because I kept bugging them for help, for some place to stay and to call somebody and I burnt those bridges (013).

### **3. Substance Use/Mental Illness**

Substance use was discussed in all but one of the interviews. Participants described many ways that substance use impacted their lives, health, and mental health. We will discuss three important aspects of substance use and abuse in the lives of our

participants: substance use/mental health trajectories, the role of peer support groups, and the formal systems issues identified by participants

People described different etiological patterns of the relationship between substance use and symptoms of mental illness which ultimately leave them struggling with both substance use and mental health problems. Many described stopping their prescribed psychiatric medication and then drinking or using other substances, and then this leading to worse mental health. Some people describe drinking or drug use leading to depression, such as this participant who said, “I was on drugs and it caught up with me” (008). Others described depressions as leading to drinking, “I was coming off alcohol detox. I ended up in an emergency room, being depressed” (010), and: “The depression started first then came the alcohol” (003). Or, “Sure some people say you’re using that as an excuse but you know they are not in my shoes they are not walking in my shoes. I know myself better than they know me; I think the depression takes me to drink” (003).

Finally, others acknowledged that ultimately for them which came first was no longer relevant.

Yeah, like when they say about dual diagnosis is depression can cause alcoholism and alcoholism can cause depression and I seem to fall under both categories. I just get depressed and then I bump into some old friends and they say you look bad, have a drink and then I get more depressed and then I need detox and I need psychological help because alcohol is a depressant and when I am depressed drinking more alcohol makes me worse (013).

As noted below (p.22), participants describe AA and NA as playing important roles in their lives. However, many also address the challenges of living with both mental illness and substance use and participating in these groups. “Yeah, they (AA/NA) don’t want you to talk about meds – they don’t even want to hear it and I don’t even say it because they just tell you to shut up – it has been done” (011). Most clearly feel that these organizations are helpful, but some find their full participation limited by group policies that either formally or informally discourages the use of psychiatric medication.

Finally, the participants often describe seeking services in psychiatric emergency settings and finding that treatment staff were focused more on their substance use than on their mental illness. People often reported that they didn’t want “more detox” but wanted

help for their symptoms of mental illness. Some felt that when they presented in a psychiatric emergency setting they were over-identified with their substance use.

They are so used to me doing drugs and not taking my medications they will always want to throw me in detox. I'm not here for detoxing, I need help...I don't want nobody to get focused, get tunnel vision, crack, crack, crack when it's not just crack, crack, crack (001).

Participants frequently responded that they would like more programs for “dual diagnosis” and those who didn't use this specific language described wanting treatment options that better addressed their needs related to their substance use and their psychiatric symptoms.

#### **4. Supports: Mixed Experiences**

People's mixed experiences with supports were a key part of their stories. These included: informal supports - such as family and friends; semi-formal supports – such as peer run groups; and formal supports, such as treatment providers.

##### **Informal Supports**

Most respondents discussed family and partner issues, and whether their experiences were positive, negative, or mixed, the predominant theme was that these relationships (or lack thereof) were an important factor in their lives. Sometimes families and partners served as resources, providing emotional support and/or help accessing services. A few reported that their families and loved ones were directly involved in the most recent decision to use PES. For example: “The only time I will go to the hospital is when I am being pushed from my family and friends and my girlfriend” (001); “She [my girlfriend] suggested that I go to Mass General, New England Medical Center or anywhere other than the VA this time” (002); and “I love my son, and he said ‘I think you're becoming manic, so I think that it's time I should bring you to the hospital.’ I said, OK, we'll find out” (008).

Some of these interventions were not welcome at the time, however: “My mom called the ambulance, the paramedics came, furthermore, my ex-convict cousin called the police and sent them” (016), “This last time at Beth Israel I went to the Emergency Room, ED on my own. But through the forced hand of my mother” (016) and

Well, at that time – the 4/20 – I was – my mother, my sister, and the ambulance

team. Only time that I was not willing to go. Well, my mother and my sister and my sister's boyfriend. Forgot he was there. And them and the emergency team – all of them – forced me into the ambulance because I didn't want to go (022).

Some described close relationships with family/significant others that provided a sense of connection and a vital source of support and encouragement.

And I love [my son]. We've had some bad times, with my wife, when we broke up and separated, and I'm trying to catch up with him now. You know, my wife died and I was holding back, I was hurt. I was really hurt, I was lost and confused, and I'm trying to bridge that gap now, so I'm trying to make a move towards him, and it's working out (008).

I mean, I have a better relationship with my mom than a lot of people do. Have a better relationship with my sisters than a lot of people do, so. I mean, \*\*\*. They understand what's actually happening to me. They there for me. You know. They always say, if you need anybody to talk to, just come (022).

Among those who discussed family, several specifically mentioned the lack of close family relationships as a negative influence in their lives. The lack of these connections was not only felt as a missing resource, but also exacerbated a sense of loneliness and isolation.

One of my issues is that I can never be alone I hate being alone I would get out of work at 5 o'clock in the evening since I'm divorced and I'll ride around the city until 2 in the morning. I just can't bring myself to go home (005).

I miss my family sometimes but I'm trying to do this on my own but it's a lonely, it's a lonely road you know. I am trying to get the best services I can in Boston right now (009).

Many descriptions of important familial and intimate relationships expressed a sense of inherent conflict. These relationships were complicated, often a source of support as well as a source of difficulty, as evidenced in this statement: "I love my family and I would love to call them when I am doing good and when I am proud of myself but I don't have any sense of pride right now" (013). Among those who did have spouses/significant others, these relationships were often fraught with emotional triggers. Divorces and abusive relationships were both mentioned as significant stressors: "Because my wife divorced me because of my drinking and I got so depressed after the divorce that I drank even more" (013) and,

It lasts, uh, a couple days at a time. It could just be, I get very down on myself, I get uh, no reason to uh, you know, I'm not working, I got no place to live, I'm divorced, problems with my family, it just seems that I keep creating more problems than I'm worth (010).

### **Semi-Formal Services**

Other resources that participants utilized were substance abuse support groups such as AA and NA. As one participant responded when asked what would help them use PES less, "like drug abuse right now and alcohol and if I stopped that everything else is okay as long as I go to AA or NA I'm ok talk to my sponsor you know and to see a therapist to just get my medication" (002).

While respondents found these groups to be largely helpful, a few mentioned that it was most effective as an auxiliary to psychiatric care, whether outpatient or PES. Even when sober or attending substance abuse groups, psychiatric symptoms could still present themselves. AA is explained by a participant, "Yeah to me it is very helpful but I need more than that" (011). Another participant stated,

Sometimes I get over it all by myself or through talking to a friend, sober friends. I go to AA meetings and sometimes that's helpful. But when I get really bad and sick and sad I go to the hospital emergency room (013).

As noted above, these groups can present considerable difficulties for those with dual diagnoses, as psychiatric medications are often discouraged. Finally, three participants mentioned other resources, such as church and art groups, as being helpful or as a desired resource.

Yeah, I feel safe. What I mean is, um, when I'm drawing, I know I'm free from trouble, um, I am, you know, I'm being good and in a safe environment, and everything is going good, you know. And everything is going the way it's supposed to. (020)

### **Formal Services**

The participants reported having few stable relationships with formal outpatient treatment providers. Eight of the eighteen participants reported having at least one formal treater but did not have any appointments scheduled with them. Another 6 participants had pending appointments. Finally, six participants identified no formal treaters. There

was no evidence of continuity or consistent care. Participants often spoke of wanting a therapist or a relationship with a therapist:

I have to check my paperwork, but I have to see if I have an appointment to see a therapist because I also need to continue my progress by seeing a therapist as often as possible (013).

I was in a program – a kind of hospital. It was called the partial program. And...I just go there like nine in the morning to like four in the afternoon. And like we talked to doctors, nurses, and like church people. You know, \*things\* like every day. And one-on-one, group counseling. And I stayed on my medication... I did good. Seems like, when we start... dealing with the Department of Mental Health... you end up doing bad or end up in the hospital or something happen to you, you know. But, you know, to stay better, you got to keep seeing \*\*\* regularly (009).

Many participants had struggled for years to maintain their mental health and believed they knew what was needed to be healthy however, had been either unable to access or maintain consistent therapy. Two participants expressed this as:

... I knew what I had done, with the not taking of the medication over the past six months, with the really not going to therapy appointments, ;cause I've been in therapy since I was nine years old (016).

Yeah, I called one day because I was really flustered, and I just wanted somebody to talk to, and I couldn't get in touch with my therapist or my psychopharmacist— Message (hint, hint) [*name removed*] counseling's wack. They are not proficient or efficient on any level (016).

Finally, participants often discussed their difficulties accessing services. This was related to many factors including financial barriers, insurance status, transportation and other factors. As one participant stated,

Because usually, when I was looking for a psychiatrist, they wouldn't listen to me because of my age. Because... I was always only eighteen, or, you know, I wasn't old enough. So they didn't see me as an adult. They saw me as still, like, a child. So... when I was looking for a psychiatrist and a therapist and I would leave messages... the only way that we got a call back was when my mom left a message (022).

## **Discussion**

The B-CAMHP study begins to fill an important gap in our understanding of the experiences of people who repeatedly use PES. While the study of repeat use of

emergency services has occurred, it did not include the experiences and perspectives of the service users themselves. This is particularly notable in research on the use of psychiatric as opposed to medical emergency services. These data suggest that interventions designed to reduce repeat use of PES must be broadly structured to address the issues we have identified in our research and not merely alter clinical models of care.

PES repeat users report that their lives are defined by instability in multiple domains. Certainly people who repeatedly use PES are psychiatrically unstable; however, the instability in the lives of our study participants is far more pervasive and far reaching. It encompasses finances, housing, family and community support. We also see a circularity between unstable mental health and unstable living patterns and unstable living patterns and unstable mental health.

Substance use and abuse was also revealed as a major part of the lives of many repeat PES users. This both exacerbates and is exacerbated by the instability in people's lives. Each of our respondents described substance use as both a precursor and result of psychiatric symptoms. Importantly, it was reported as one of the primary reasons for treatment seeking. These data suggest that more work is needed to design and make accessible services which acknowledge these complex webs of substance use and mental illness. This is true for both formal and semi-formal or self help services.

In addition to these key themes we have identified in the data the research team struggled to come to consensus with a way to present findings about the lack of hope found among the study participants. Specifically, we were struck by what appeared to be a lack of hope or discussion of wellness in their future. We noted that recovery was not discussed by any of the study participants however the group spent a great deal of time discussing how to understand this. In fact, the interview was not designed to explore participant's ideas of recovery or wellness, so perhaps our participants, if probed, would report a sense of hope or a recovery perspective. In analyzing these data and struggling with these concepts our use of a CBPR method was particularly beneficial. While we did not reach consensus as to how to understand wellness and recovery for people who are repeat users of PES, we feel confident in stating that these are concepts and ideas that should be pursued in future work.

## Conclusions

This is the first CBPR study of repeat users of PES to be conducted. While we have faced many challenges, and learned many lessons about conducting CBPR with mental health service users, we have demonstrated that it is feasible to do this type of work. We have successfully conducted a pilot study of 18 repeat users of PES. We have had service user participation in every stage of the research process. In fact, at every meeting, service users represented the majority of the research team.

While the previous research literature on repeat users of PES has focused on individual level characteristics, often diagnostic categories, which predict service utilization patterns, our findings suggest that while individual level factors matter, there are several other important factors which relate to repeat use of PES in our busy public PES. Based on these findings, the team has generated five recommendations to better meet the needs of people who repeatedly use PES.

- 1) Struggles with substance abuse and mental illness were a part of the lives of most of our study participants. In order to best meet the needs of people with dual diagnosis educational and training efforts for mental health and addiction providers should be developed which allow for cross-training of providers as well as educational efforts for service users. Many of our participants felt that the CSU was a place in which the staff was comfortable dealing with both mental illness and addiction and this contributed to their sense of comfort and wellness. More programs are needed which provide integrated dual diagnosis treatment.
- 2) We have learned that consistent, caring and respectful providers are needed to help our participants remain stable and avoid PES use. Efforts should focus on providing service users with consistent care, from providers who are knowledgeable about them, who can connect them with needed services and advocacy. Many of our systems do not allow for the building and maintenance of these types of important relationships.
- 3) Additional outreach about BEST services is needed to the community, including service users and providers. Our data suggest that despite current BEST outreach efforts, there remains a lack of knowledge about options available to service users other than the ER.

- 4) Our participants' lives are highly unstable in multiple ways, and this instability is compounded by their symptoms of mental illness. When people struggle with basic life needs, such as housing, it is difficult to maintain health. More work is needed to explore non-traditional housing models that work for people with multiple needs related to addiction and other health problems. Similar efforts are needed to create flexible and meaningful employment options which can respond to the high levels of instability people are faced with.
- 5) Mental health research should be informed by the perspectives of service users and their family members. Efforts should be made to increase the use of CBPR methods in mental health research as they have proven quite fruitful here. This study, of a most difficult to reach population, would not have been possible without our use of these methods and certainly our analyses and results would have been much less rich.

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