



Short report

Mental health of those directly exposed to the World Trade Center disaster: Unmet mental health care need, mental health treatment service use, and quality of life

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ABSTRACT

Mental health service utilization several years following a man-made or natural disaster can be lower than expected, despite a high prevalence of mental health disorders among those exposed. This study focused on factors associated with subjective unmet mental health care need (UMHCN) and its relationship to a combination of diagnostic history and current mental health symptoms, 5–6 years after the 9-11-01 World Trade Center (WTC) disaster in New York City, USA. Two survey waves of the WTC Health Registry, after exclusions, provided a sample of 36,625 enrollees for this analysis. Important differences were found among enrollees who were categorized according to the presence or absence of a self-reported mental health diagnosis and symptoms indicative of post-traumatic stress disorder or serious psychological distress. Persons with diagnoses and symptoms had the highest levels of UMHCN, poor mental health days, and mental health service use. Those with symptoms only were a vulnerable group much less likely to use mental health services yet reporting UMHCN and poor mental health days. Implications for delivering mental health services include recognizing that many persons with undiagnosed but symptomatic mental health symptoms are not using mental health services, despite having perceived need for mental health care.

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Introduction

Disasters such as the 1986 Chernobyl accident and 2001 attack on the World Trade Center (WTC) have documented long-term physical and mental health effects (Bromet, Havenaar, & Guey, 2011; Brackbill et al., 2009). In particular, the prevalence of stress disorders among Chernobyl clean-up workers remained high at 44% eight years after the event (Viel et al., 1997), as did post-traumatic stress symptom prevalence (23%) among directly exposed WTC disaster survivors up to six years after 9-11 (Brackbill et al., 2009). High prevalence of these illnesses years after a disaster translate into individual suffering and societal burden manifested by negative collateral effects on community and family intimacy as well as economic loss due to absence of income and treatment costs (Riggs, Byrne, Weathers, & Litz, 1998).

Although their effectiveness is unclear, early mental health interventions are usually implemented soon after disasters (Gray, Shira, & Litz, 2004). Following the 9-11 WTC disaster, public and

privately financed post-disaster mental health programs were implemented ranging from on-site crisis counseling to screening, referral and reimbursement systems (Felton, 2002). Despite this, large numbers of individuals did not avail themselves of these services (Stuber, Galea, Boscarino, & Schlesinger, 2006). In fact, immediate post 9-11 use of mental health services was surprisingly small as evidenced by a declining number of claims experienced between 9-11 and the first quarter of 2002 by one insurer of over 2 million New York City (NYC) residents (Green et al., 2006).

Given the high prevalence of persistent psychopathology five or more years after 9-11, it is important to understand the relationship between perceived need, quality of life, and healthcare utilization especially when it is frequently observed that people with mental health symptoms delay treatment (Wang et al., 2005) and that a majority of persons who have symptoms, do not seek help and have diminished functioning (Stuber et al., 2006). Perceived need or subjective unmet mental health care need (UMHCN) is a construct for measuring either choosing care but not receiving it because of financial or other barriers, or else not receiving expected care (Allin, Grignon, & Le Grand, 2010). Contrary to what might be expected, a cross-sectional Canadian population survey of perceived mental health care needs found that having a diagnosed

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mental health condition (e.g. depression, anxiety disorder, PTSD) and using mental health services were the strongest predictors of reporting an UMHCN (Nelson & Park, 2006). Prior studies have not evaluated how the presence of mental health disorder symptoms influence the perception of need, service use, and quality of life among those at risk for such disorders.

We use data from the World Trade Center Health Registry cohort to assess UMHCN post WTC disaster, in a population with a high prevalence of mental health symptoms 5–6 years after the event. We have two objectives. First, we describe the prevalence and predictors of UMHCN by demographics, social support level, WTC disaster exposure, quality of life, mental health status, and mental health service use. Second, to identify groups at risk of greater need and diminished quality of life, we evaluated the association between UMHCN and quality of life, mental health service use, social support, and 9–11 exposure with mental health status, defined by a combination of diagnosis status and presence or absence of current symptoms.

Methods

Study population

The Registry located in the New York City Department of Health and Mental Hygiene is a cohort study of 71,434 enrollees that prospectively monitors the physical and mental health of populations with reported exposure to the September 11 WTC attack and its aftermath. The present analysis is restricted to 46,226 persons who completed both an intake interview on enrollment in 2003–04 (Wave 1) and a follow-up questionnaire in 2006–07 (Wave 2) as described in detail elsewhere (Brackbill et al., 2009; Farfel, Digrande, Brackbill, Prann, Cone, Friedman, et al., 2008). Wave 1 provided data on gender, race/ethnicity, household income, exposure, and eligibility group membership. Data on perceived unmet health care needs, and other covariates such as social support, marital status, and current symptoms of PTSD and serious psychological distress (SPD) were obtained at Wave 2.

The Centers for Disease Control and Prevention (CDC) and the New York City (NYC) Department of Health and Mental Hygiene (DOHMH) institutional review boards approved the study protocol.

Measures

A detailed description of study measures is available in the electronic [Appendix A](#)

Unmet mental health care need (UMHCN) is defined as a response of not receiving needed “mental health care or counseling” during the last 12 months.

Socio-demographic variables included gender, age at Wave 2 interview, race/ethnicity, household income at Wave 1, and marital status.

WTC disaster exposure was the sum of twelve experiences grouped as none/low (0–1 experiences), medium (2–3), high (4–5), and very high (6 or more) consistent with Adams’s definition (Adams & Boscarino, 2006).

Social support had four categories: none, 1 to 2 sources, 3 sources, and 4 or more sources of support.

Probable Post-traumatic Stress Disorder (PTSD) was assessed with a 9–11 specific PTSD Checklist (PCL), a validated measure (McDonald & Calhoun). A cut-off score of 44 or greater indicated probable PTSD (McDonald & Calhoun, 2010).

Serious Psychological Distress (SPD) was based on the K6 scale, a psychometrically validated epidemiologic measure, using a cut-

off score of 13 (Kessler, Barker, Colpe, Epstein, Gfroerer, Hiripi, et al., 2003).

Mental health status was categorized based on having or not having a previously reported mental health diagnosis or symptoms indicative of PTSD or SPD. The categories were: diagnosed with current symptoms (D+S+); undiagnosed with current symptoms (D–S+); diagnosed but with no current symptoms (D+S–), and neither (D–S–). Diagnosed mental health conditions included generalized anxiety, probable PTSD, and depression with reported year of diagnosis between September 11, 2001 and December 31, 2005, so that diagnosis occurred before the assessed period of need and use of services (2006–2007).

Poor mental health days was defined as self-report of 14 or more days of poor mental health in the past 30 days, using the health related quality of life measure (Zahran, et al., 2005).

Any mental health service was considered to be an enrollee report of any mental health counseling, medication, or both in the preceding 12 months.

Data analysis

The final sample was 36,625 after excluding persons who reported a physician diagnosis of depression, anxiety, or PTSD prior to 9–11 ($n = 3819$), a diagnosis of depression, anxiety, or PTSD in 2006–2007 ($n = 833$), or were missing data for PTSD checklist or K6 (SPD screen) at Wave 1 or Wave 2 ($n = 4949$).

The first objective addressed UMHCN prevalence by demographic variables, social support, mental health status, 9–11 WTC disaster exposure, and mental health service using logistic regression to estimate adjusted odds ratios and 95% confidence intervals for the association of these characteristics with UMHCN.

The second objective involved multinomial logistic regression using mental health status categories (D+S+, D–S+, D+S–, D–S– [reference]) as multiple outcome levels. This technique is used when the dependent variable is categorical with more than two levels. It can simultaneously fit all levels of the dependent variable to provide estimated odds ratios. There are thus two implicit references in this type of analysis, one is a specified level of the categorical dependent variable (e.g. D–S–) and the other is the reference for the independent variable such as UMHCN relative to its reference (no UMHCN) (see Hosmer and Lemeshow, 2004).

All analyses were conducted using SAS version 9.2 (SAS Institute Inc., Cary, North Carolina).

Results

Over four percent (4.2%) of the study population reported UMHCN in the past 12 months (Table 1). The prevalence of UMHCN was higher among younger persons (e.g. 19–29 year olds 7.0% vs. 45–64 years olds 3.9%; adjusted odds ratio (AOR) = 2.3), and those with low incomes vs. high income (e.g. \$10–25,000, 8.6% vs. \$150,000, 2.2%, AOR = 1.6). UMHCN was prominently mentioned by those with 14 or more poor mental health days (16%) vs. fewer than 14 days (2.1%), AOR = 2.6, no sources of social support (13.1%) vs. 4 or more (2.9%), AOR = 1.6 and very high level of 9–11 WTC exposure (10.5%) vs. low/none (1.7%), AOR = 2.0.

Mental health status

In this analysis, we evaluated the relationship between subjective UMHCN and other factors and current mental health symptoms with and without a mental health diagnosis. Among those who had mental health symptoms at Wave 2 (28% of the total sample), 54% reported a mental health diagnosis in the period 9–11–01 to 12–31–05. Fig. 1 shows that a relatively high

Table 1
Prevalence and adjusted odds ratios (AOR) for unmet mental health care need (UMHCN) in the last 12 m: WTCHR, 2003–2007.^a

	N	%	% UMHCN	AOR ^c (95% confidence interval)
All ^b	36,625	100.0	4.2	
W1 recruitment method				
Self-ID	26,697	73.7	4.8	1.2 (1.0–1.4)
List	9628	26.3	2.8	1.0
W2 interview mode				
Paper	15,968	43.7	4.5	1.0 (0.9–1.1)
Web	16,000	12.7	4.5	0.7 (0.6–1.9)
CATI	4639	43.7	2.5	1.0
Gender				
Female	13,203	36.1	4.7	1.1 (0.98–1.3)
Male	23,422	64.0	4.0	1.0
Age at W2 interview				
19–29	1831	5.0	7.0	2.3 (1.8–2.9)
30–44	13,462	36.8	4.9	1.4 (1.3–1.6)
45–64	18,755	51.2	3.9	1.0
65+	2577	7.0	1.4	0.5 (0.3–0.8)
Race/ethnicity				
Non-Hispanic black	3689	10.1	3.9	0.8 (0.7–1.0)
Hispanic	3996	10.9	6.1	0.9 (0.8–1.1)
Asian	1985	5.4	4.4	1.1 (0.9–1.5)
Other	1147	3.1	6.3	1.3 (0.9–1.7)
Non-Hispanic white	25,808	70.5	3.9	1.0
2002 income				
10–25K	2437	6.7	8.6	1.6 (1.2–2.1)
25–50K	6156	16.8	6.0	1.5 (1.2–2.0)
50–75K	7358	20.1	4.3	1.2 (0.9–1.6)
75–150K	12,836	35.1	3.5	1.2 (0.9–1.4)
150K+	4323	11.8	2.2	1.0
Eligibility groups				
Residents	4645	12.7	4.2	0.9 (0.7–1.1)
Area workers	12,500	34.2	3.3	0.6 (0.5–0.7)
Passersby	1705	4.7	6.7	1.1 (0.9–1.4)
Rescue/recovery workers	17,709	48.4	4.7	1.0
Marital status at W2				
Never married	5914	16.3	5.4	1.2 (0.98–1.4)
Divorced/separated	3973	10.9	7.5	1.5 (1.2–1.7)
Widowed	748	2.1	4.5	1.3 (0.9–2.0)
Married	25,710	70.7	3.4	1.0
Poor mental health days				
'≥14 days'	5661	15.6	16.0	2.6 (2.3–2.9)
Less than 14 days	30,539	84.4	2.1	1.0
Social support at W2				
None	464	1.3	13.1	1.6 (1.2–2.3)
1 to 2 sources	5590	15.3	8.0	1.4 (1.2–1.6)
3 sources	11,893	32.5	4.3	1.1 (0.99–1.3)
4 or more	18,678	51.0	2.9	1.0
Status of mental health condition				
D+S+	3576	12.2	19.9	11.2 (9.2–13.7)
D-S+	3036	16.3	12.6	8.2 (6.8–9.9)
D+S-	3658	8.2	5.3	4.6 (3.8–5.8)
D-S-	26,355	63.3	1.0	1.0
Mental health service use				
Any	6669	19.0	9.7	0.9 (0.9–1.0)
Not reported	29,749	79.6	3.0	1.0
9-11 WTC exposure				
Very high	3345	7.5	10.5	2.0 (1.6–2.5)
High	8554	21.1	5.9	1.7 (1.4–2.1)
Medium	15,421	44.2	3.5	1.4 (1.2–1.7)
Low/none	9303	27.2	1.7	1.0

^a Excluded persons with physician diagnosed mental health conditions before year 2001 and between 2006 and 2007 or missing PTSD or SPD scores.

^b Missing: Income = 3515, eligibility group = 66, marital status = 280, WTC exposure = 2, mental health service use = 207.

^c Adjusted for all factors in the table.

percentage of persons with symptoms reported UMHCN (20% for D+S+ and 13% for D-S+) and poor mental health days (63% for D+S+ and 41% for D-S+) with big differences between mental health service use between those diagnosed and not diagnosed (e.g. 65% for D+S+ and 14% for D-S+).

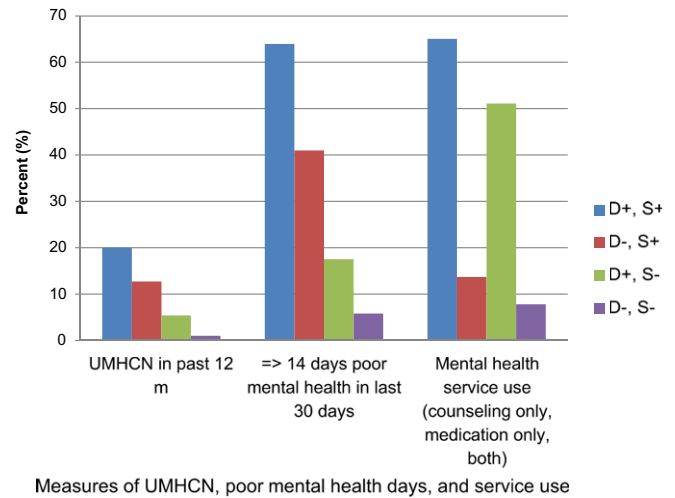


Fig. 1. Prevalence of unmet mental health care need (UMHCN), poor mental health days, and mental health service use by categories of mental health status.

In Table 2 we present the distributions of five critical variables (UMHCN, poor mental health days, social support, mental health service use, and 9/11 exposure) separately within each of the four mental health status categories: D+S+, D-S+, D+S-, and D-S-. Table 2 also shows adjusted odds ratios (AOR) and 95% confidence intervals (CI) for association of mental health status with each of these five variables, using the 26,355 asymptomatic persons with no reported mental illness diagnostic history (D-S-) as the comparison population.

UMHCN was strongly associated with being in the D+S+ group with an AOR = 10.0 (8.2–12.2) compared to D-S-. The associations between UMHCN with being in the D-S+ or the D+S- group were also statistically significant but not as strong with an AOR = 7.0 (5.8–8.5) for D-S+ and an AOR = 3.9 (3.1–4.8) for D+S-. Self-reported poor mental health days and lack of social support showed similar association patterns, with very strong associations also evident in the group that had both a diagnostic history and current symptoms (D+S+). For poor mental health days (≥14 days), there was an AOR = 13.4 (12.0–15.0) and for those persons without social support, there was an AOR = 7.4 (5.1–10.8) for association with D+S+ group compared to D-S- (Table 2). For both variables the AORs were lower but still statistically significant in the symptom-only group D-S+: 7.7 (7.0–8.5) and 5.2 (3.7–7.2) respectively, and lower still in the group (D+S-) with a prior diagnostic history that was symptom-free at Wave 2: 2.3 (2.0–2.6) and 1.5 (0.9–2.4), respectively.

Recent (past-year) utilization of mental health services or medication was also strongly associated with mental health status, with an AOR of 16.9 (15.2–18.4) in the D+S+ group relative to D-S-. However, the pattern for the D+S- and D-S+ groups was the reverse of that for unmet need and poor mental health days, being strongest for D+S- (AOR = 10.8, 9.9–11.8) and much weaker for D-S+ (AOR = 1.6, 1.4–1.8).

Finally, Table 2 shows dose-related associations of mental health status with both exposure to 9/11 experiences and lack of social support that have previously been reported to be strong predictors of PTSD. Among the D+S+ group the AOR for “very high” exposure was 22.7 (18.6–27.6), while it fell to 6.8 (5.7–8.1) among D-S+ and 4.6 (4.0–5.4) among D+S-.

Discussion

For survivors of the 9-11 disaster, the lasting impact of the trauma was still very apparent 5–6 years later, especially among

Table 2Multinomial adjusted odds ratios for association between selected factors and mental health status, WTCHR, 2003–2007.^a

Characteristic ^c	Total N 36625	Status of mental health condition: Self-reported diagnosis of anxiety, depression or PTSD (D) or screened by PCL and/or K6 (S)								
		D+, S+			D-, S+			D+, S-		
		n 3576	% 100.0	AOR (95% CI) ^b	n 3036	% 100.0	AOR (95% CI)	n 3658	% 100.0	AOR (95% CI)
<i>Unmet mental health care need in last 12 m</i>										
Yes	1551	713	19.9	10.0 (8.2–12.2)	382	12.6	7.0 (5.8–8.5)	195	5.3	3.9 (3.1–4.8)
No	34,927	2845	79.6	1.0	2630	86.6	1.0	3451	94.3	1.0
<i>Poor mental health days</i>										
≥14 days	5661	2262	63.3	13.4 (12.0–15.0)	1229	40.5	7.7 (7.0–8.5)	633	17.3	2.3 (2.0–2.6)
<14 days	30,964	1314	36.7	1.0	1807	59.5	1.0	3025	82.7	1.0
<i>Mental health service use</i>										
Any	6669	2327	65.1	16.9 (15.2–18.4)	416	13.7	1.6 (1.4–1.8)	1869	51.1	10.8 (9.9–11.8)
Not reported	29,749	1231	34.4	1.0	2600	85.6	1.0	1770	48.4	1.0
<i>Social support</i>										
None	464	156	4.4	7.4 (5.1–10.8)	95	3.1	5.2 (3.7–7.2)	23	0.6	1.5 (0.9–2.4)
1–2	5590	1015	28.4	2.8 (2.4–3.2)	892	29.4	2.7 (2.4–3.1)	421	11.5	1.1 (0.96–1.3)
3	11,893	1116	31.2	1.4 (1.3–1.6)	969	31.9	1.3 (1.2–1.4)	1243	34.0	1.0 (0.94–1.1)
4+	18,678	1289	36.0	1.0	1080	35.6	1.0	1971	53.9	1.0
<i>9–11 exposure categories</i>										
Low/none	9303	261	7.3	1.0	382	12.6	1.0	654	17.9	1.0
Medium	15,421	1069	29.9	2.5 (2.1–3.0)	1196	39.4	2.0 (1.8–2.3)	1497	40.9	1.6 (1.4–1.8)
High	8554	1245	34.8	7.4 (6.2–8.8)	1007	33.2	4.1 (3.6–4.8)	1048	28.6	2.6 (2.3–2.9)
Very high	3345	1001	28.0	22.7 (18.6–27.6)	451	14.9	6.8 (5.7–8.1)	459	12.5	4.6 (4.0–5.4)

^a Excluded pre-911 physician diagnosed mental health conditions, conditions diagnosed 2006–07, and those with missing PTSD and SPD scores.^b Adjusted for Wave 1 recruitment method, Wave 2 survey mode, sex, age at Wave 2 interview, race/ethnicity, 2002 income, and marital status.^c Missing: UMHCN = 147; mental health service use = 207; 9–11 exposure = 2.

those most intensely exposed. Survivors who lacked sources of social support and reported poor quality of life were also more prone to report an unmet mental health care need. On the other hand, perceived need of mental health services was not associated with actual service utilization. In addition, enrollees' subjective evaluation of their need for mental health care and quality of life were both associated in varying degrees with history of diagnosis of mental health conditions and current mental health symptoms. Specifically, those with symptoms indicative of PTSD or SPD reported higher levels of self-perceived poor mental health and lower social support, while having a prior mental health diagnosis was associated with both subjective unmet mental health care need and greater use of mental health services. Those with symptoms but no prior diagnosis are a particularly vulnerable population with both a diminished quality of life and perceived need for care that is much less likely to be receiving mental health care.

The continued reporting of perceived need for mental health care by those who also report a lack of social support and poor mental health quality of life suggests that these factors may mediate the long-term mental health effects observed in our studies (e.g. Brackbill et al., 2009) and others even on a national scale (Holman & Silver, 2011). WTC exposure was strongly associated with the severity of mental health issues (e.g. D+S+) similar to that reported two years after 9–11 using the same exposure metric (Boscarino, Adams, Stuber, & Galea, 2005).

These findings have implications for the long-term treatment and quality of life experience of disaster survivors who continue to have mental health sequelae. For diagnosed persons with ongoing symptoms, we can assume that diagnosis is the entry point for treatment, with sixty percent reporting some kind of mental health treatment in the last year. However, it is not clear whether persons with continued symptoms are more ill and in greater need of care, are non-compliant with care, or whether they are compliant but not receiving adequate care; any of these situations could result in a perceived lack of mental health care. Our subjective measure of UMHCN is likely composed of a combination of constructs including unmet need due to financial or other barriers or perceived inadequate care (Allin et al., 2010), so one or more of these reasons could apply to this D+S+ group.

Undiagnosed persons who continue to report untreated symptoms may number in the tens of thousands, if we project the prevalence found in our cohort to the estimated 409,000 persons directly exposed to the WTC disaster in NYC (Brackbill et al., 2009). These individuals may not be known to caregivers. Some (D–S+) may have visited a provider for physical health concerns without receiving a mental health evaluation or referral. Others may have been unable to locate a mental health provider or feared stigma related to receiving mental health care (Welch, Caramanica, Debchoudhury, Pulizzi, Farfel, Stelman, et al., 2012). In a study of factors related to mental health service use after the WTC disaster, Stuber et al. (2006) found that 64% of persons with symptoms did not seek help despite the fact that a majority of them (70%) had diminished functioning. Retrospective analysis of the National Comorbidity Survey showed that people with a diagnosable mental health condition have a median delay of 7 years before seeing a provider and only about 40% have provider contact within six years (Wang et al., 2005). In addition, some symptomatic people without a prior diagnosis of a mental health condition are not likely to perceive a need for treatment (Mojtabai, Olfson, & Mechanic, 2002).

Those who reported a diagnosis but did not subscribe to symptoms of PTSD or SPD reported less UMHCN and better quality of life, in combination with using services nearly as much as those who had a diagnosis and symptoms. It may be the case that the mental health care they received was effective or that symptoms among this group were less severe or resolved on their own.

Our findings underscore the challenges of reaching and treating a population exposed to a major disaster with long-lasting psychopathology regardless of the availability of treatment (Felton, 2002). Many may feel unwell for a good portion of the time, interfering with their ability to make and keep appointments and adhere to treatment. They also may lack social supports for seeking and adhering to treatment, and may even actively avoid treatment. Social support has been identified as one of the most important factors of reducing the impact of a disaster on survivors and appears to continue to be major factor in seeking mental health care (Shih, Liao, Chan, Duh, & Gau, 2002).

Strengths and limitations

The longitudinal design of the Registry along with this sample size of over 36,000 exposed persons enabled us to make comparisons between groups with and without reported diagnosis and symptoms of PTSD or SPD, both of which were measured with widely used, validated instruments. One limitation may be the 68.1% response rate at Wave 2, which could result in over-reporting of symptoms by affected individuals. However, there was no difference in either self-reported exposure (e.g. being injured or witnessing events) or post 9–11 depression, anxiety, or emotional problems as reported at Wave 1 between Wave 2 participants and non-participants, suggesting that differential symptom reporting is not subject to serious bias.

The overall prevalence of UMHCN in this cohort was similar to estimates of UMHCN in New York City (3.5%) and Ontario, Canada (4.5%) New York City, Community Health Survey: (Nelson & Park, 2006) using similar questions.

Implications

The implications for mental health service providers and policy makers include: First, a significantly large group of persons who have PTSD, depression, or anxiety symptoms report unmet mental health care need whether or not they are availing mental health services. Second, a significant number of undiagnosed persons also have symptoms indicative of PTSD or non-specific psychological distress. This group may be also hard-to-reach because of diminished quality of life and lack of social support. The Registry has a treatment referral program that encourages symptomatic registrants to seek care from the federal WTC Health Program (Welch et al., 2012). Policy makers associated with disaster-related mental health service provision can consider designing and implementing customized outreach programs for encouraging symptomatic but undiagnosed persons to seek treatment.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2012.12.016>.

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