

Baby or bathwater? Referrals of “non-cases” in a targeted early identification intervention for psychosis

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Abstract

Purpose: To explore the unintended impact of a targeted case identification (TCI) campaign for first episode psychosis (FEP) on people *not* experiencing FEP (“non-cases”) with respect to referral patterns and reasons for being a non-case. **Methods:** Sources of referral, reasons for being a non-case, and subsequent referral destinations of non-cases were examined before and after a TCI. **Results:** Following the TCI, a greater proportion of non-cases lived outside the study catchment area. A smaller proportion was referred by the parent hospital’s emergency room or had a substance-induced psychosis. **Conclusions:** TCIs for FEP may have unintended effects, with implications for early case identification and early intervention services.

Keywords: Early case identification; non-cases; first episode psychosis; early intervention services

1 Several targeted case identification campaigns (TCIs) aimed at informing health professionals
2 and the public about first episode psychosis (FEP) have been conducted [1,2] so that individuals
3 experiencing a FEP are more efficiently referred to specialized early intervention services for
4 psychosis [3,4]. While most TCIs have no clear impact on referral rates of people experiencing a
5 FEP to early intervention services, some TCIs have decreased the duration of untreated psychosis
6 for help-seekers [1].

7 Most work on TCIs has focused on their target referrals: FEP cases. However, an
8 unintended consequence of TCIs may be that individuals distressed for reasons other than a FEP
9 are referred to early intervention services. Such instances could arise, for example, when referral
10 sources are unsure whether help-seekers are experiencing a FEP instead of chronic psychosis,
11 sub-threshold conditions or non-psychotic disorders. Furthermore, help-seekers who do not meet
12 treatment criteria (e.g., living out of sector, previous treated episodes) may nonetheless be
13 directed to early intervention services after a TCI.

14 While FEP cases have typically been viewed as the proverbial baby amidst the bathwater
15 of help-seeking “non-cases” [5], non-cases are still consequential from the perspective of mental
16 health services design and delivery. Whereas a direct referral of cases experiencing a FEP to
17 early intervention services is thought to shorten their help-seeking process [6], referral of non-
18 cases to FEP services could represent an unnecessary lengthening of already long care pathways
19 for non-cases since they are not being referred to services tailored to their needs, potentially
20 resulting in increased suffering and disengagement from care [6-9] in those already vulnerable to
21 adverse outcomes [10,11].

22 Only one report has investigated non-cases, focusing on their diagnostic profiles and
23 referral rates [5]. No studies have explored how a TCI alters referral patterns of non-cases to

early intervention services. Given this, we examined whether a previously reported TCI [12] impacted 1) the proportion of referrals to the early intervention service who were deemed non-cases; 2) reasons for being considered a non-case; 3) referral sources of non-cases to early intervention service, and 4) the types of services non-cases were subsequently directed to.

Method

Setting and sample

The study was carried out by the Prevention and Early Intervention Program for Psychoses in Montreal (PEPP-Montréal), the only early intervention service treating FEP within an urban catchment area serving approximately 300,000 people. Individuals were accepted for treatment if they were experiencing a FEP not attributable solely to substance use or to an organic brain condition (e.g., epilepsy); were between the ages of 14 and 30; had not previously taken antipsychotic medication for more than 30 days; and had an IQ above 70. Help-seekers were screened for the above criteria by a screening clinician and a psychiatrist within 72 hours. Those accepted to PEPP were followed for up to two years [13]. Non-cases were referred to services deemed more appropriate to their needs.

Study Design

The overall aim of the intervention was to provide education to medical and community referral sources about the signs and symptoms of early psychosis, as well as the benefits of early intervention. A full description of the TCI has been provided elsewhere [12]. The study consisted of *pre-intervention*, *intervention*, and *post-intervention* phases. The *pre-intervention* phase occurred between January 2003 and December 2005. During this phase, relevant organizations and health services in the PEPP catchment area were made aware of the services offered at PEPP. Participants recruited during this phase served as a historical control group.

During the *intervention* phase (January to June 2006), a TCI based in the PEPP catchment area was provided by a senior PEPP clinician accompanied by PEPP research and clinical staff. The intervention used films either in English or French showing the onset and course of untreated FEP within a family context, which then became a topic of discussion using principles of academic detailing [14]. The intervention was conducted in acute care hospital services ($n = 3$), school health and counseling services ($n = 7$), community health and social service centers (known in Québec as Centre Local de Services Communautaires, CLSCs; $n = 9$), and other relevant groups such as church services ($n = 4$).

During the *post-intervention phase* (June 2006 to May 2009), booster sessions were provided every 6 months to organizations and services which had received the intervention. Booster sessions were designed to elicit knowledge gaps from the intervention phase and remind individuals of the clinical characteristics of FEP as well as the advantages of early treatment.

Materials

Systematically collected administrative data were used for this study, which were based on notes taken by an intake clinician at PEPP, including sociodemographic information, the source of referral to PEPP, the reasons for not being accepted to PEPP, and type of service referred to.

Analysis

Main analyses were performed using Chi-square and Fisher's exact tests. Exploratory post-hoc tests following each significant omnibus test were computed using two-sample tests of proportions.

Results

1) Number of non-cases referred to PEPP

Overall, 868 referrals were screened for FEP between 2003 and 2009. Of these, 505 did not meet admission criteria across the pre- and post- intervention phases, and were considered *non-cases*. 299 were considered *cases* meeting PEPP's admission criteria and received up to two years of treatment at PEPP, of which 64 either refused follow-up ($n = 52$) or elected to pursue other services ($n = 12$).

The proportion of non-cases referred to PEPP increased following the TCI [*pre* $n = 198$ non-cases out of 335 referrals (59%), *post* $n = 307$ non-cases 463 referrals (66%), $Z = -2.08$, $P = .02$]. The average age of the overall sample ($n = 505$) was 21.88 ($SD = 5.12$) and the majority were male ($n = 295$, 58.4%). The TCI had no effects on age or gender of the non-cases referred to PEPP.

2) Reasons for being considered a non-case following the TCI (Table 1a)

Changes in the reasons for not being accepted to PEPP following the TCI were observed ($\chi^2(6) = 37.50$, $P < .001$) (Table 1a). There was a significant decrease in the proportion of non-cases who were experiencing a solely substance induced psychosis [*pre* $n = 10$; *post* $n = 4$] ($M_{diff} = .044$, $Z = 2.67$, $P = .008$). The intervention also drew a greater proportion of individuals living outside the study catchment area [*pre* $n = 19$; *post* $n = 93$] ($M_{diff} = -.21$, $Z = -5.13$, $P < .0001$).

3) Sources from which non-cases were referred to PEPP following the TCI (Table 1b)

An overall change in referral sources of non-cases to PEPP following the intervention ($\chi^2(5) = 18.07$, $P = .003$) was observed. Specifically, the proportion of referrals from the emergency room of the parent institute that were non-cases [*pre* $n = 53$; *post* $n = 42$] decreased following the TCI ($M_{diff} = .13$, $Z = 3.47$, $P < .001$).

4) *Services non-cases were directed to following the TCI (Table 1c)*

No change in referrals to clinical or social services occurred following the TCI (Fisher's exact test $P = .55$).

Discussion

This study explored changes in the referrals of individuals not experiencing an FEP or not meeting service criteria (non-cases), before and after a TCI. While the purpose of the TCI was to increase the penetration rate of untreated FEP to PEPP and to reduce the delay in treatment by simplifying pathways to care [12], we also observed a small yet significant increase in the proportion of non-cases referred to the early intervention service.

Referrals of non-cases may occur because TCIs may inadvertently lower thresholds to clinicians referring help-seekers with non-psychotic symptomatology or secondary etiology (e.g. a primary substance-induced psychosis) to FEP services [15], or because TCIs can increase community awareness of resources at early intervention services [16]. While symptomatology can evolve between the time of referral and the time of assessment [17], PEPP's direct and rapid referral system is designed to minimize this possibility [13].

We observed that a lower proportion of non-cases were referred from the parent hospital emergency room, while a greater proportion were referred from outside the catchment area following the TCI. This suggests that awareness of PEPP services may have spread both within and outside the intervention sites, although perhaps in different ways. Referral sources located near PEPP may have adhered more closely to specific inclusion criteria following the TCI; this is reflected in reductions of those not meeting program inclusion criteria (e.g. >30 days of antipsychotic use, outside of the age 14-30 range, etc). On the other hand, distal referral sources may have become aware of PEPP services but less cognisant of its catchment-based criteria. In

1 the latter example, referral sources outside catchment may have sent cases to PEPP because of
2 difficulties in accessing mental health care within their own catchment [18], and/or because they
3 knew that help-seekers would in all cases be guaranteed at least a rapid assessment from PEPP.
4 Consistent with this, the vast majority of non-cases sent to PEPP were thought to require
5 subsequent referral to clinical (rather than social) services both before and after the TCI.

6 The overall results of this study highlight the potential unintended effects of TCIs. While
7 the increased proportion of non-cases is statistically significant but small (from 59% pre-
8 intervention to 66% post-intervention), the increase in absolute numbers (from 198 to 307 over a
9 3 year period; or ~36 per year) could place an additional strain on screening resources and
10 clinician time, potentially resulting in further delays with corresponding lengthening of pathways
11 for non-cases and even cases. This highlights the need for greater access to mental health
12 screening and supports across diagnoses, and underscores the potential value of a diagnostically-
13 agnostic intake point.

14 One limitation of this study was that its historical control design means that changes in
15 referral patterns could be due to factors other than the TCI itself. While basic demographic
16 characteristics do not appear to have influenced the results, other potentially relevant factors
17 remain unexamined; future studies on this topic (such as time-series analyses to examine overall
18 versus more time-specific trends) could address this gap. A second limitation reflects the
19 potential generalizability of our findings: early case identification campaigns may differentially
20 impact referrals sources and pathways to care that are idiosyncratic to the local health system
21 (with its primary, secondary and tertiary components) within which they are conducted.

22 In prioritizing rapid evaluations for *all* youth they come into contact with [19], early
23 intervention services are beginning to move away from diagnostically-driven silos and to see

non-cases as *also* being babies rather than bathwater [20]. In concert with this, our findings suggest that future generations of TCIs efforts should perhaps follow suit: by providing education and outreach for a broad range of mental health conditions affecting youth, across diagnoses and levels of severity.

Table 1: Study Results

1a) Reasons for being a non-case**	Pre (n = 174)	Post (n = 291)
Not first episode psychosis	68 (39.08%)	112 (38.49%)
More than 30 days of antipsychotic receipt	41 (23.56%)	52 (17.87%)
Living outside of sector**	19 (10.92%)	93 (31.96%)
Lost contact with person	8 (4.60%)	8 (2.75%)
Outside of age range	15 (8.62%)	10 (3.44%)
Solely substance-induced diagnosis**	10 (5.75%)	4 (1.37%)
Other	13 (7.47%)	12 (4.12%)
1b) Source of referral to PEPP**	Pre (n = 195)	Post (n = 291)
Emergency Room**	53 (27.18%)	42 (14.43%)
Other hospital services	55 (28.21%)	104 (35.74%)
Community organizations	8 (4.10%)	7 (2.41%)
CLSCs, GPs, private clinic	12 (6.15%)	29 (9.97%)
Self or family	62 (31.79%)	91 (31.27%)
School services and others	5 (2.56%)	18 (6.19%)
1c) Subsequent referral from PEPP	Pre (n = 42)	Post (n = 140)
Clinical services (hospital services, health clinic, therapist or private health professional)	41 (97.62%)	138 (98.57%)
Non-health services (community organizations, school services)	1 (2.38%)	2 (1.43%)

Note. CLSC's refer to community health clinics; AP refers to antipsychotic medication; * = $P < .05$; ** = $P < .001$

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