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## Title:

Early Intervention for Psychotic Disorders: Real-life Implementation in Hong Kong

# **Running Title:**

Early Psychosis Intervention in Hong Kong

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# Abstract

Hong Kong is among the first few cities in Asia to have implemented early intervention for psychosis in 2001. Substantial changes in psychosis service have since taken place. We reviewed available outcome data in Hong Kong, with reference to the philosophy of early intervention in psychosis, discussing experience and lessons learned from the implementation process, and future opportunities and challenges. Data accumulated in the past decade provided evidence for the benefits and significance of early intervention programme: patients under the care of early intervention service showed improved functioning, milder symptoms, and fewer hospitalizations and suicides. Early intervention is more cost-effective compared with standard care. Stigma and misconception remains an issue, and public awareness campaigns are underway. In recent years, a critical mass is being formed, and Hong Kong has witnessed the unfolding of public service extension, new projects and organizations, and increasing interest from the community. Several major platforms are in place for coherent efforts, including the public Early Assessment Service for Young People with Psychosis (EASY) programme, the Psychosis Studies and Intervention (PSI) research unit, the independent Hong Kong Early Psychosis Intervention Society (EPISO), the Jockey Club Early Psychosis (JCEP) project, and the postgraduate Psychological Medicine (Psychosis Studies) programme. The first decade of early intervention work has been promising; consolidation and further development is needed on many fronts of research, service and education.

Key words: Psychotic disorders, schizophrenia, early intervention

#### Early Intervention for Psychotic Disorders: Real-life Implementation in Hong Kong

A decade has passed since the first introduction of a specialized early intervention (EI) service for psychosis in Hong Kong. The launch of the Early Assessment Service for Young people with psychosis (EASY) programme in 2001 gave impetus to a series of new local development: extension of existing service, new projects (e.g., the Jockey Club Early Psychosis project, JCEP) and independent organizations (e.g., the Hong Kong Early Psychosis Intervention Society, EPISO) continue to unfold, adding momentum to early psychosis work in terms of clinical intervention, research, public awareness and professional training. This article summarizes 10 years of early psychosis work in Hong Kong, evaluating available outcome data with reference to the philosophy of EI in psychosis, reviewing the experience and lessons learned from the implementation process, and discussing future opportunities and challenges.

# 1. Principles and Structures

# 1.1 Pre-EI Situation in Hong Kong

Hong Kong has witnessed substantial changes in psychosis service since the turn of the millennium. During the period preceding EASY, the average patient with psychotic disorders in Hong Kong would present to public psychiatric service with duration of untreated psychosis (DUP) of 1.5 years (Chen et al. 2005). Quality of life was low during the DUP (Law et al. 2005), with disruptions and impairments in a range of life domains. Access to public psychiatric service required referral from a general practitioner; more often, however, service contacts were crisis-driven inpatient hospitalizations through Accident and Emergency Departments (AEDs) and police intervention, which might require compulsory admission and even restrains, making the presentation itself a traumatic experience. After discharge, the patient would be managed under a highly saturated general psychiatric outpatient service, with infrequent follow-ups, brief consultation time, and limited access to non-medication supports (Hui et al. 2008; Wong et al. 2008). This happened against a background of heavy stigmatization, discrimination, and a lack of knowledge in the community, and concealment of the illness was the rule among patients and families (Chung and Wong 2004). Secondary complications including occupational, social and family functioning impairment, psychiatric complications and other risks were common.

# 1.2 Rationales and Goals in EI Movement

Compared with other areas in medicine, EI is a relatively new concept in psychotic disorders, partly due to the previous pessimistic attitude towards treatment outcome. This attitude has been challenged by a series of studies in recent decades, which showed that recovery is possible and that early outcome predicts long-term outcome (McGlashan 1986; Thara et al. 1994; Mason et al. 1996; Harrison et al. 1996; Carpenter and Strauss 1991; Harding et al. 1987). These research efforts have led to the development of the critical period hypothesis, suggesting maximum plasticity (deterioration or amelioration) in the early phase of psychosis, during which biological and psychosocial influences have the greatest impact; this is followed by a plateau in long-term outcome (Birchwood, Todd, and Jackson 1998).

This insight highlighted the importance of early identification and intervention for secondary prevention in psychosis. On the other hand, the damage inflicted on a person's quality of life by untreated psychosis demands in itself timely intervention to stop

unnecessary suffering. It was out of these considerations the World Health Organization and the International Early Psychosis Association (IEPA) issued the *Early Psychosis Declaration* (World Health Organisation and International Early Psychosis Association 2004) and the *International Clinical Practice Guidelines for Early Psychosis* (International clinical practice guidelines for early psychosis 2005), emphasizing the need for specialized comprehensive programmes for early detection and treatment of psychosis by increasing community awareness, improved access, engagement and treatment, promoting recovery and ordinary lives, engaging and supporting families, and training for practitioners and community workers. Ultimately, EI movement aspires to detect at-risk individuals before onset of a fullblown illness, with possibility of developing satisfactory interventions for primary prevention.

EI for psychotic disorders has since advanced substantially, with introduction of specialized programmes in many parts of the world. In Hong Kong, the EASY service marked the beginning of a movement towards focused early psychosis intervention. The aims are to (1) reduce treatment delay by making available more accessible services and prodrome monitoring, and by destigmatizing psychosis through public awareness works; (2) achieve the best possible clinical outcome during the critical period by providing phase-specific care tailored to the needs of first-episode patients; and (3) establish a high-quality intervention model through developing a team of professionals with high level of skills and knowledge in early psychosis, and by the use of data-driven intervention initiatives as an integral component of management.

# 1.3 EI Service Structures and Development in Hong Kong

A brief overview of the EI services in Hong Kong for the period 2001-2011 is summarized in Figure 1.

<insert Figure 1 about here>

# 1.3.1 The First Milestone: EASY in 2001

The EASY service is a territory-wide initiative from the Hong Kong Government to alter the pathway to care, optimize treatment and raise public awareness of early psychosis under the public healthcare system. The major undertakings can be summarized as follows with deliberations on resources and goals (for details, see Wong et al. 2008):

- Formation of multidisciplinary teams comprised of psychiatrists, nurses, social workers and a clinical psychologist, with close community collaborations serving catchment areas covering the entire population;
- Development of a management protocol, the Psychological Intervention Programmes in Early Psychosis (PIPE) (So, Wong, and Chong 2002), specifically for the programme;
- Set up of an easily accessible channel allowing self-referral and direct service contact, with a hotline managed by trained case managers for initial screening assessment, followed by timely diagnostic assessment by psychiatrists in low stigmatization settings, with non-cases referred to appropriate services or monitored for possible onset;
- Provision of 2-year phase-specific case management for first-episode patients aged between 15 and 25 years old;

- Introduction of a new Chinese translation for "psychosis" (*Si Jue Shi Tiao*) emphasizing reversibility, for effective communication in awareness campaigns; and
- A wave of intensive media exposure and public education activities during programme launch.

The entire programme has a staffing of 10 psychiatrists responsible for clinical assessment and diagnosis, outpatient management, networking with local units and agencies, and lead educational programmes; 15 community psychiatric nurses responsible for case management, structured telephone screening, assist in running clinics, community work, educational programmes and group work; five medical social workers to support cases; and a clinical psychologist to provide case management, community work and specific therapies. They are divided into four teams serving four catchment areas in Hong Kong with a total population of 7 million and expected new cases of 700 per year. EASY also receives support from non-government organization (NGO) partners for day activities, vocational programmes, provision of normalized settings, outreach programmes, community work and group works for families.

#### 1.3.2 Gaining Momentum: Recent Developments

Until recently, adult-onset patients in Hong Kong were not receiving specialized EI service due to resources limitation. However, while it is acknowledged that psychosis onset peaks at early adulthood, about half of psychotic disorder nevertheless express itself only after the age of 25 years (Hafner et al. 1993). To fill this gap, a 5-year early psychosis project for adult patients, JCEP, hosted by Psychosis Studies and Intervention (PSI) Unit at the University of Hong Kong was made possible through a funding from the Hong Kong Jockey Club Charities Trust in 2009. JCEP has recently completed case recruitment and entered the follow-up phase. It comprises the following three components, which are executed in collaborations with local NGOs:

- Research: A randomized controlled trial (RCT) comparing functioning outcome of 2year versus 4-year case management with health economic analysis;
- Service: Phase-specific case management intervention for 1000 first-episode patients aged between 26 and 55 years receiving public psychiatric service; and
- Education: Regular gatekeeper training for frontline workers in contact with psychosis patients, and awareness programmes in the community for general public.

JCEP also provides an important platform for building expertise in EI for psychosis, with direct interchange between research and service for the development of evidence-based intervention models. The JCEP intervention model utilizes elements of life coaching, cognitive-behavioural therapy (CBT) for psychosis and case management tailored to the patients' stage and needs. Within 2 years of JCEP project commencement, the Government concurred on the service direction and injected resources in 2011 for extending the public EASY service to first-episode patients aged 25 years or above.

These new developments imply increased demand for EI professionals. While both JCEP and EASY conduct regular in-house trainings, the PSI team has offered in 2011 a new postgraduate programme in Psychological Medicine (Psychosis Studies) for more structured training. The programme covers basic concepts such as epidemiology and psychopathology, neurobiology and cognitive dysfunctions in psychosis, as well as specific skills such as

pharmacological, psychosocial and case intervention for psychosis. The first batch of Master programme students is expected to graduate in 2013.

Another important addition to the local picture of early psychosis work is the Hong Kong EPISO. EPISO is a charitable organization founded in 2007 by a group of enthusiastic professionals and community members to combat stigmatization through public awareness campaigns and to transfer scientific and clinical knowledge through educational activities to frontline workers. Workshops and scientific symposia are also organized regularly to provide training for professionals from various sectors. In its public awareness approach, EPISO is mindful of rebuilding a youthful and attractive image for early psychosis with which young patients and community people would identify themselves, for example with celebrity endorsement in popular events such as concerts, film premiere, and secondary school drama workshops.

#### 2. Lessons and Experiences

Among the abovementioned EI platforms in Hong Kong, more experience has been accumulated from the EASY programme and the following discussion is focused more on the EASY experience, with reference to JCEP and EPISO where information is available.

#### 2.1 Processes and Outcome of EI Service

Before service extension in 2011, the EASY programme covered a population of approximately 1.5 million aged between 15 to 25 years (Wong et al. 2008). Each year, an average of 3000 hotline enquires were received, around 1000 diagnostic assessments carried out, and about new 600 cases included in the programme. Main sources were from both within the hospital system (inpatient 26%, outpatient 25%) and general public (relatives 23%, school 8%, self 6%). Each team has a caseload of approximately 360 new and follow-up cases. However, the average caseload per case manager is high (around 1:80 to 1:100).

Outcome studies, however, have been able to demonstrate effectiveness of the EASY programme even at such high case ratio. Using a historical control design, it was has found that patients who received EI service had better functional outcome and reduced hospitalization in 3 years (Chen et al. 2011). This territory-wide case-control outcome study compared 700 consecutive EASY patients with 700 patients who received standard care, who were matched in diagnosis, age, and sex. The EI group had better occupational functioning, fewer and shorter hospitalization, milder positive and negative symptoms, fewer completed or attempted suicides, and were better engaged (all p<0.01). In particular, average duration of hospitalization over 3 years reduced from 114 days to 62 days with the EI service. The rate of relapse and DUP, however, were unchanged.

The cost-effectiveness of the EASY programme has recently been studied in another historical control study comparing direct cost for EI and standard care over 24 months (Wong et al. 2011). The EASY programme was shown to be more cost-effective in reducing hospital admissions and improving clinical symptoms. Direct costs investigated in this study include inpatient bed days, outpatient contacts, medication utilization, and other professional service utilization including social workers, clinical psychologists, community psychiatric nurses, and AED visits. Results suggest that the extra costs in medication and contacts of the EASY programme are being offset by decreased costs in other domains such as inpatient costs, AED service need, community psychiatric nurse service and medical social worker attendance. Indirect costs were not included in the analysis.

The evidence provided robust support for EI in psychosis in Hong Kong: without taking into account indirect costs, the EASY programme is already superior to standard care in resources requirement, while patients receiving EI have better clinical and functioning outcome among other benefits. It makes a strong case for further exploration of the optimal intervention model with detailed health economic analysis to find out the most cost-effective ways of EI in psychosis. Data from the JCEP project shall be able to address this and provide further insight in the near future.

#### 2.2 Public Awareness, Destigmatization and Early Detection of Psychosis

The "new" Chinese translation for psychosis, *Si Jue Shi Tiao*, has now been around for 10 years. It emphasizes dysregulation of thought and perception, implying reversibility. The term is well received by the public, being regularly used in the locality without a heavily stigmatizing connotation; a very illustrative example is the publication of a book titled *Wo De Si Jue Shi Tiao* (i.e., *My Psychosis*), a personal account of the illness by a patient using her real name (Chiu et al. 2010). While there is an apparent acceptability of the term by the public, evidence from formal evaluation is needed to judge the impact of renaming on destigmatizating and promoting awareness and early detection of psychosis.

As noted above, data from the historical control study have failed to demonstrate an overall reduction in DUP with the introduction of EASY (Chen et al. 2011). It is conceivable that the EASY programme, with improved accessibility, might have captured a number of patients previously hidden from service with long DUP, and longer-term studies will be able to tell apart this effect. On the other hand, a local study prior to EASY on factors affecting DUP has found that family experience of psychosis greatly reduces DUP (225 vs. 546 days, p<0.01), which is likely a result of better knowledge about potential symptoms and their significance in those with exposure (Chen et al. 2005). With the EASY programme, this difference disappeared with a shorter DUP in patients with and without family experience, and may suggest better awareness in the general public comparable to individuals with previous family exposures.

In terms of destignatization, Hong Kong still has a long way ahead. A public attitude phone survey conducted in 2009 found that, among 1016 respondents, misconceptions and discriminations were still pervasive. Majority of the general public views patients with early psychosis as "having multiple personalities", being strange and annoying; they are unwilling to date someone with psychosis, and employers would give a lower priority to applicants with psychosis. Exposure to negative news reporting appears to be an important factor affecting the level of stigma in Hong Kong (HKU survey reveals misconceptions and lack of awareness towards psychosis 2009).

Both EPISO and JCEP have substantial input in public awareness work in response to this survey finding. EPISO works closely with mass media, involving radio and TV partners for various campaigns, while also targeting young people directly through a series of secondary school tour in the form of drama workshop: from 2010 onwards, 19 schools have been visited with a total number of participants of around 5500. JCEP works steadily at the community level, including an annual art competition that engages the public. A short movie and essay competition in 2011, for instance, has attracted a number of high quality entries demonstrating genuine understanding and empathy for psychosis in the community.

A follow-up public survey is planned in 2013 when the effect of these destigmatization and awareness campaigns can be more rigorously evaluated by detecting changes in public attitudes after 5 years.

## 3. The Future

Amongst the first few cities in Asia implementing EI for psychosis, Hong Kong has gone through many challenges and struggled with limited resources available in this area. The reassuring news is that data thus far provided solid evidence for the benefits and significance of local EI programmes. In recent years, a critical mass is being formed, with increasing interest from different sectors, as reflected by new developments and inputs from the government, NGOs and funding bodies. This momentum needs to be sustained with a series of further works, which can be outlined as follows:

- 1. Knowledge consolidation and transfer: A set of clinical guidelines with reference to locally relevant data needs to be developed; the pearls of clinical experience and wisdoms from frontline workers gained through years of focused early psychosis work should be collected and passed on systematically;
- 2. Further integration of research and clinical work: More interaction between EI service and data should be made possible by developing data-driven intervention initiatives as an integral component of early psychosis management;
- 3. Perfection of service model: Refinement based on evidence of the duration of critical period, with possibility of individualized intervention, and exploration of the most effective intervention model and case ratio should be carried out through detailed research to inform future resources allocation;
- 4. Professional development: A system of training, supervision, and staff development should be in place as EI for psychosis continues to grow as a professional field;
- 5. Exploration on preventive intervention: Forward movement of early detection towards primary prevention should be piloted with prodrome studies and services
- 6. Mobilization of community resources: New taskforce should be developed as an addition to growing service demand; with sufficient training, volunteer programmes with community, patients, and carers involvement may provide important help;
- 7. Continued work on public awareness and destigmatization, with more creative and informed strategies

All these developments will require focused research effort in early psychosis to provide a rich knowledge base about the illness. In conclusion, EI for psychosis by a specialized team has proven efficacy in Hong Kong, saving resources in the long run. The first decade of EI work in Hong Kong has been promising, and solid further development is needed on many fronts of research, service and education.

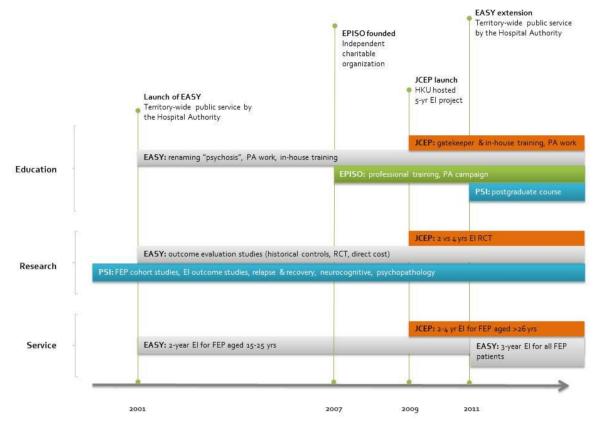
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## Figure 1. Specialized EI for psychosis structures in Hong Kong (2001-2011).

EASY = Early Assessment Service for Young people with psychosis

EPISO = Hong Kong Early Psychosis Intervention Society

JCEP = Jockey Club Early Psychosis project

PSI = Psychosis Studies and Intervention programme, The University of Hong Kong

EI = early intervention

FEP = first-episode psychosis

RCT = randomized controlled trial

PA = public awareness