Part 2: Discharge and Step-Down in Coordinated Specialty Care (CSC) for Persons with a First Episode of Psychosis

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Today’s Presentation

- Overall Objective – Continue discussion of issues that should be addressed regarding transition from FEP programs
- Four Related Presentations
  - Summary from Part 1 Transition Webinar – David Shern
  - Some Additional Considerations Regarding Longer Term Outcomes – Lisa Dixon
  - Results from the National Evaluation of the 10% Set Aside Program for First Episode Psychosis – David Shern
  - Implications of these results for future research, policy and practice – Steve Dettwyler
- Questions and Discussion
Summary of Issues from Part 1

• Early Benefits of First Episode Programming May Not Last
  – But it is complicated.

• Ashok Malla’s trial data indicated benefits of services extended from 2 to 5 years on symptom remission and attrition from services.

• Two examples of transition strategies
  – Creating a companion or extension program.
  – Implementing a systematic stepdown process.
Considerations/Reflections

• Complexity of Existing Literature: Is there evidence of persistence of CSC beyond end of treatment?
• If not, what strategies can promote persistence of benefits?
  • Some version of ongoing specialized (?)High quality) treatment
• Findings of MHBG and moving forward
The OPUS Studies

- OPUS is groundbreaking EIS consisting of assertive community treatment, family involvement and social skills training.
- Follow up of individuals in OPUS 1 largely found loss of benefits at 5 and 10 years (though not completely!) (Bertelsen et al. 2008)
- OPUS 2 randomized individuals who received ~2 years of OPUS to 3 more years of OPUS vs usual services. Minimal differences at 5 years. But both groups retained benefits! Increased quality of usual care (Albert et al. 2017)
• EASY Studies
  – First study randomized pts who had completed two years of “EASY” to one year of ongoing EASY or TAU. Pts who had an additional year of EASY did better than pts who had TAU. (Chang et al. 2015)
  – Then, for 2 years, all pts were then provided with TAU. Differences between the two groups evaporated. (But it looks like control got better while EASY group stayed same or slightly worse.) (Chang et al. 2017).
Sustainability of treatment effect of a 3-year early intervention programme for first-episode psychosis

Wing Chung Chang, Vivian Wing Yan Kwong, Emily Sin Kei Lau, Hon Cheong So, Corine Sau Man Wong, Gloria Hoi Kei Chan, Olivia Tsz Ting Jim, Christy Lai Ming Hui, Sherry Kit Wa Chan, Edwin Ho Ming Lee and Eric Yu Hai Chen

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Complexity of Existing Literature

Social & Occupational Functioning Assessment Scale

Role Functioning Scale

(a) Intervention group
Control group

(b) Intervention group
Control group

(c) Baseline 6 months 1 year 2 years 3 years

SOFAS score

RFS total score
• Prevention and Early Intervention (PEPP) Studies
  – First study showing that individuals receiving 5 years of EIS had persistent benefits (Norman et al. 2011)
  – Study that randomized individuals who completed 2 years of PEPP to 3 more years or usual services found increased time in remission from positive and negative symptoms in 5-year group (Malla et al. 2017)
  – Another analysis showed persistent improvement in negative symptoms over 2 years and then over 5 years (expressivity) with no difference between groups (Lutgens et al. 2019)
Negative Symptoms (Expressivity) Improves Over the 5 Years

**Fig. 8.** Expressivity over the 5-year critical period. b(0) = baseline at randomization

**Fig. 9.** Motivation over the 5-year critical period. b(0) = baseline at randomization.

How to interpret these findings?

• There is clear value for some, if not most, individuals of continuing aspects of EIS beyond the end of the time-limited program.

• The nature of the alternative matters! If “usual care” is high quality care that provides evidence-based approaches, there may be less differential value of EIS.

• EIS alone may change the trajectory for some individuals for some outcomes, regardless of what comes next.

• There is clear heterogeneity of needs and outcomes.
Clinical Strategies to Promote Existing Benefits

• Remember that CSC was built upon the scientific literature regarding evidence based practices developed for the care of people with schizophrenia as adults—see Schizophrenia PORT (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2800150/)

• And adapted for young people

• Therefore, it stands to reason that the key components of CSC should be available for all individuals diagnosed with these disorders
Phase 3: Transition Planning

• Work with the team is time-limited: approximately two years for most participants.

• The Primary Clinician helps the participant and family prepare for transition in the following ways:
  o Equip them with knowledge about the mental health care system and available resources for future goals and plans
  o Develop a comprehensive plan for transition with them
  o Encourage strong relationships with new treatment providers
• Very clear need for access to person-centered, recovery-oriented services
  – Psychiatric medications
  – Family supports
  – Psychotherapy
  – Case Management
  – Supported Employment/ Education
  – Peer supports?
Clear need for communication and transparency around this
Ultimately dependent on financing mechanisms
Need to stop saying “They need” and start asking “Who needs what?”
  – Not just after CSC, but during CSC
  – There will not be a one-size fits all solution
Trials testing web-based online strategies (e.g., HORYZON)
Selected Results Addressing Transition from the National Evaluation of the 10% Block Grant Set Aside Program
National Evaluation of 10% Set MHBG Set Aside

Collaboration of three federal agencies

SAMHSA

NIH National Institute of Mental Health

Assistant Secretary for Planning and Evaluation
• Westat is conducting the evaluation in collaboration with NRI and the National Association of State Mental Health Program Directors (NASMHPD).
• The Research Team

Evaluation Design Overview

• **Mixed-methods design**: qualitative & quantitative data

• **Site Survey**: provides an overview of CSC programs nationally

• **Outcomes analysis**: to examine the client level outcomes on symptoms, functioning and quality of life.

• **Fidelity assessment**: to document each site’s fidelity to the coordinated specialty care (CSC) model

• **Process assessment**: to document the environmental context in which CSC is implemented
The purpose is to gain a better understanding of CSC programs nationally and the services that they offer

Obtain information on topics such as:
- How the program identifies and recruits participants
- Treatment services and supports offered by the program
- The typical duration of care
- What outcome measures programs use to document impact
• Purpose is to more fully examine the context in which sites are delivering CSC.

• Semi-structured in-person interview with:
  – Program administrator at each site
  – CSC team leader and other CSC staff members
  – Clients in the CSC program
  – State behavioral health authority representative (phone)
What We’ve Learned from the MHBG 10% Evaluation

• From National Survey of MHBG Funded Programs (88% response rate)
  – OnTrack, Navigate and EASA represent 73% of the Programs
  – 91% Report length of stay between 1 and 3 years
Variability Regarding Time Limits in the Programs

- From the 36 Sites more intensively studied
  - 19/36 (53%) 2 years as a target with flexibility to extend; flexibility very variable
    - Of these, 3/19 were initially 2 years fixed but changed owing to the need for greater flexibility
  - 10 (28%) typical/allowable to serve clients as long as 3-5 years
  - 3 (8%) No fixed program length (‘average’ length not stated);
    - includes new programs that have not yet dealt with challenges involving discharge/not yet developed policy
  - 4 (11%) 2 year fixed
    - Of these, 3 originally had greater flexibility but has been scaled back to keep program more transitional
Many program participants were unclear on time limits
  – 24% Did not know if treatment was time limited
  – 32% Clearly understood remaining time
  – 44% Thought there was no fixed length

About half of clients reported no discussion with their clinicians about transition
  – This was related to length of time in enrollment – those with longer enrollment were more likely to have discussed transition
Participant Feelings About Transition

- 26% of clients reported concerns with transition
  - sad, anxious, fear loss of support, loss of relationships with program
- 48% were ambivalent
- 26% were optimistic

Half of the programs were part of larger agencies and offered internal continuity of care

- 17% had some continuity of relationships with CSC staff
- None served all of the discharged participants
Challenges

• Poor engagement with standard outpatient services
  – Disenroll after 2 no-shows
  – Little assertive outreach
• Standard services often more pessimistic about recovery than CSC Services
• More intensive service (stepping up) depressing to clients who then terminate care
• Difficult to find private psychiatrist comfortable with prescribing clozapine and long acting injectables.
• Case management services not available to private pay clients
• Young people who didn’t want access to case management but wanted psychiatric services.
Issues that Have Emerged Regarding Transition Services

• Conceptualizing discrete endpoints and transitions as opposed to variable supports within a program
  – Supported Housing Example

• How best to titrate services to individual needs while promoting maximal independence from the system
  – Building stable informal supports

• Continuity of relationships
  – Prescribers and Clinicians
• Structural Issues
  – Programs that are part of larger agency vs free-standing
  – Rural – Urban Differences

• Financing –
  – Differing intensity at differing points in treatment
  – Limited resources
  – Difficulty financing supported employment/education

• Policy
  – Fixed program length
  – Not allowing dual enrollment across programs
• Science to service
  – Block grant built on the RAISE study
• Rapid growth of teams, nation wide (Westat map)
  – About 290 teams serving about 10,000 people (10% of need)
• Well supported models, variations on a theme - CSC models in use
• Outcome data from the evaluation showed that the programs work in terms of participant clinical and functional outcomes
Federal Considerations

Number of Evidence-Based CSC Programs Implemented Nationally

- FY 2014: 37
- FY 2015: 53
- FY 2016: 140
- FY 2017: 214
- FY 2018: 265
• With programs graduating people the question is what is next?
• Goal to consolidate gains
  – Maintain the trajectory of recovery.
• Not sure about how to assure these outcomes.
Research Questions

• What are the critical treatment and support components to maintain recovery path?
  – Personal goals and strengths/challenges
    • Ongoing needs for supported employment and education
  – Including the role of the informal support system?
    • Family involvement may be important
  – Continuity with caregivers

• What types of measurement approaches do we need to best target services and supports?

• Can fidelity measurement be used to identify differential effects of program components?
Research Questions

• How do we finance these programs?
  – Differential rates for persons as they progress through the program?
    • Implications for case rates?
  – Can we pay for the essential elements?
    • Supported Education and Employment can be challenging

• Can we change the fixed staffing models?
  – Size the teams based on the characteristics of the treatment population.
  – Will this work in rural settings?
Helpful Material


• Annotated List of all NASMHPD TA Materials https://www.nasmhpd.org/sites/default/files/Overview_Links_All_FEP_TA_Products_9-28-18_0.pdf