Recovery Outcomes & Experiences following Early Psychosis: Implications for Psychiatric Mental Health Nurses

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Overview of Presentation

1. Provide a brief description of the quantitative & qualitative methods & highlight the findings
2. Describe how the 2 sets of findings were integrated.
3. Discuss results of the synthesis of the 2 data sets & how the results inform our understanding of recovery
4. Using the study findings, highlight areas for increased nursing involvement in promoting full, timely recovery.

Study Description and Methods

The Study Site

PIER program (Psychosis Intervention Early Recovery) , a service of the Regional Health Authority in Eastern NL, Canada:

- is a specialized community-based mental health program focused on the recognition, assessment & treatment of individuals experiencing a 1st episode of psychosis;
- has 3 admission criteria: i) first time psychosis; ii) age b/t 16 & 50, and iii) less than 6 months of antipsychotic treatment.
- has an interdisciplinary team providing a range of services to individuals and families

Introduction to the Study

This mixed methods study explored the recovery outcomes and experiences of individuals who participated in a specialized early psychosis (EP) program. It was comprised of 2 components:

- i) a large quantitative study that assessed recovery outcomes over the 3-year Rx period. Two recovery measures were developed and used to determine rate, timing, & nature of recovery reached by 260 participants, and
- ii) a small qualitative study that explored the meaning of recovery as lived by individuals & family members.

Results of the 2 study components were integrated & synthesized to better understand the nature of recovery following EP

Research Questions

- What are **the rate and timing** of recovery following a first episode of psychosis?
- What are the **recovery experiences** of individuals and families following a first episode of psychosis?

Quantitative Component

Prospective cohort study examining time-to-first recovery [how many & how quickly do individuals recover following early psychosis?]

- Secondary analysis of a clinical program database consisting of a range of clinical scales collected over the 3-year program
- 308 individuals admitted consecutively to EP program over 9 year period (Jan 2001 – Dec 2009);
- 260 (85%) had appropriate admission data for inclusion in study

Outcomes of Interest

To answer the research question re: rate & timing of recovery, 2 target events were examined:

1. **Partial Recovery (PR)** measured by 3 criteria:
   - Symptom Remission: (i) Mania, and (ii) Psychosis
   - Adequate Daily Functioning
2. **Comprehensive Recovery (CR)** measured by 4 criteria:
   - Symptom Remission (both manic & psychotic)
   - Adequate Daily Functioning
   - Quality of Life

Thresholds were defined for each criterion; each criterion had to be achieved concurrently for the recovery event to be identified.

Program Scales Used for Operational Measure: Partial Recovery

1. Positive and Negative Syndrome Scale (PANSS)

- 30 items that evaluate positive, negative & other symptoms of psychotic episodes (Kay, Fiszbein & Opler, 1998; 1997). [Score of '3' or less on 8 of 30 items]

2. Young Mania Rating Scale (YMRS)

- Contains 11 items to assess the severity of mania but not depression [Score of '5' or less on all items]

3. Global Assessment Scale

- Single item rating scale for evaluating the overall functioning of an individual during a specified period (usually 1 week prior to administration). [Score of '61' or higher]

Program Scales Used for Operational Measure: Comprehensive Recovery

Comprehensive Recovery (CR) included the 3 scales used to measure Partial Recovery (PR) plus one additional scale, the Quality of Life Scale ([QLS] Heinrichs & Carpenter, 1984).

- CR represented a broader understanding of recovery, more aligned with the view of individuals & families living with illness than the traditional health system view (represented by PR).
- The scale assesses an individual's social and occupational functioning by examination of personal experiences, interpersonal relationships & occupational roles; [Score of '4' or more on all 21 items]

Data Analysis

Descriptive Statistics

Survival Analysis Methods

- **Kaplan-Meier statistics**
  - Survival curve and hazard function
- **Cox Regression**
  - Multivariate impact analysis

The Qualitative Study Component

The 2nd component was a descriptive phenomenological examination of the recovery experience for individuals & family members

- Was an attempt to enhance understanding of recovery by exploring scientifically what the recovery experience was like for individuals & families.
- The goal was to illuminate the essential structure or meaning of the phenomenon to reveal a description that reflects the core psychological constituents of the human experience (**not** the individual experience).

Qualitative Methods & Analysis

Participants

- Three individuals and 3 family members who had participated in the early psychosis program

Data Collection

- Face to face semi structured interviews

Analysis

- Giorgi's 4-step methodology was used to analyse the interview data

Study Results: Both Components

RESULTS: Quantitative then Qualitative

Demographic Characteristics At Program Entry

Characteristics		Males n=188 (72%)	Females n=72 (28%)	TOTAL n=260
AGE:	≤ 24 years	n = 125	n = 35	n = 160 (62%)
	≥ 25	n = 63 (34%)	n = 37 (51%)	n = 100 (38%)
AVE AGE at 1st Contact		24.2	27.9	25.0
*EDU:	< high school	53(28%)	31(43%)	84 (32%)
	high school	68(36%)	16(22%)	84 (32%)
	> high school	57(30,%)	25(35%)	82(32%)*
*EMP:	employ/student	58 (31%)	28 (39%)	86 (33%)
	had worked	61(32%)	18 (25%)	79 (30%)
	never worked	56 (30%)	23 (32%)	79 (30%)*
*LIV CIRC: with parents		128 (68%)	33 (46%)	161 (62%)*
*MARTIAL: single		179 (95%)	51 (71%)	230 (89%)*

* Some missing data

Clinical Characteristics at Program Entry

Clinical Characteristic		Total Population
DIAGNOSIS	Schizophrenia Spectrum	103 (40%)
	Affective Psychosis	60 (23%)
	Other Psychosis	97(37%)
*COMORBID	Psychiatric	158 (61%)
	Physical	36 (14%)
SUB USE	None	64 (25%)
	Alcohol	45 (18%)
	Marijuana only	15 (6%)
	Alcohol + marijuana	82 (32%)
	Other	51 (20%
*FAM HX	None	46 (18%)
	1st degree relative	86 (33%)
	Other relative	66 (25%)

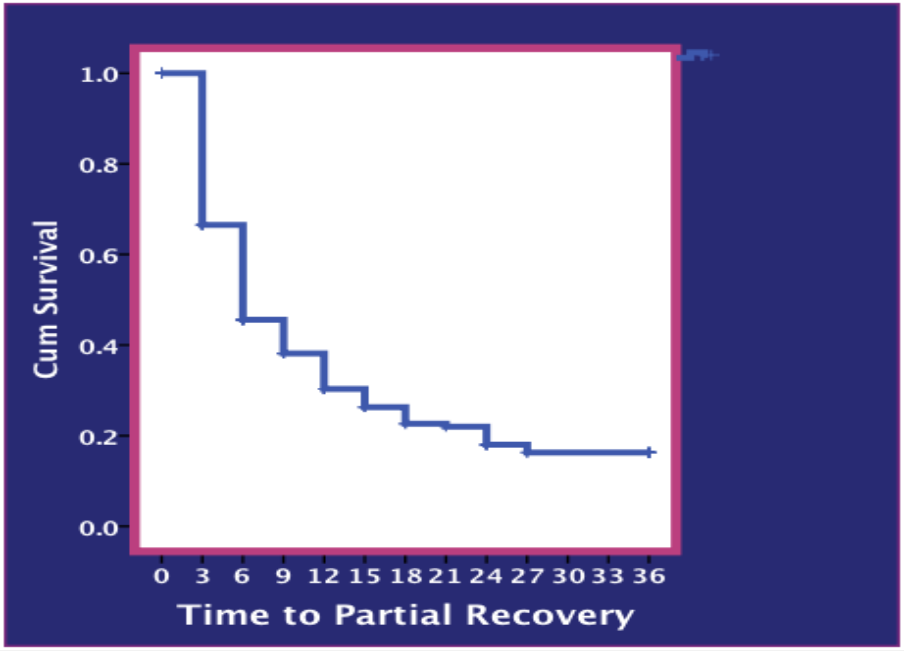
*some missing data

Partial Recovery Results

174 of eligible participants (73%) achieved partial recovery over the 3-year program

- 122 recovered in the first 12 months
- Significant improvement was shown in symptoms, and daily functioning
- Median time for partial recovery = 8.3 months
- Mean time was 12.6 months
- 62 individuals or 26% of the cohort , however, did not meet the threshold for PR over 36 months.

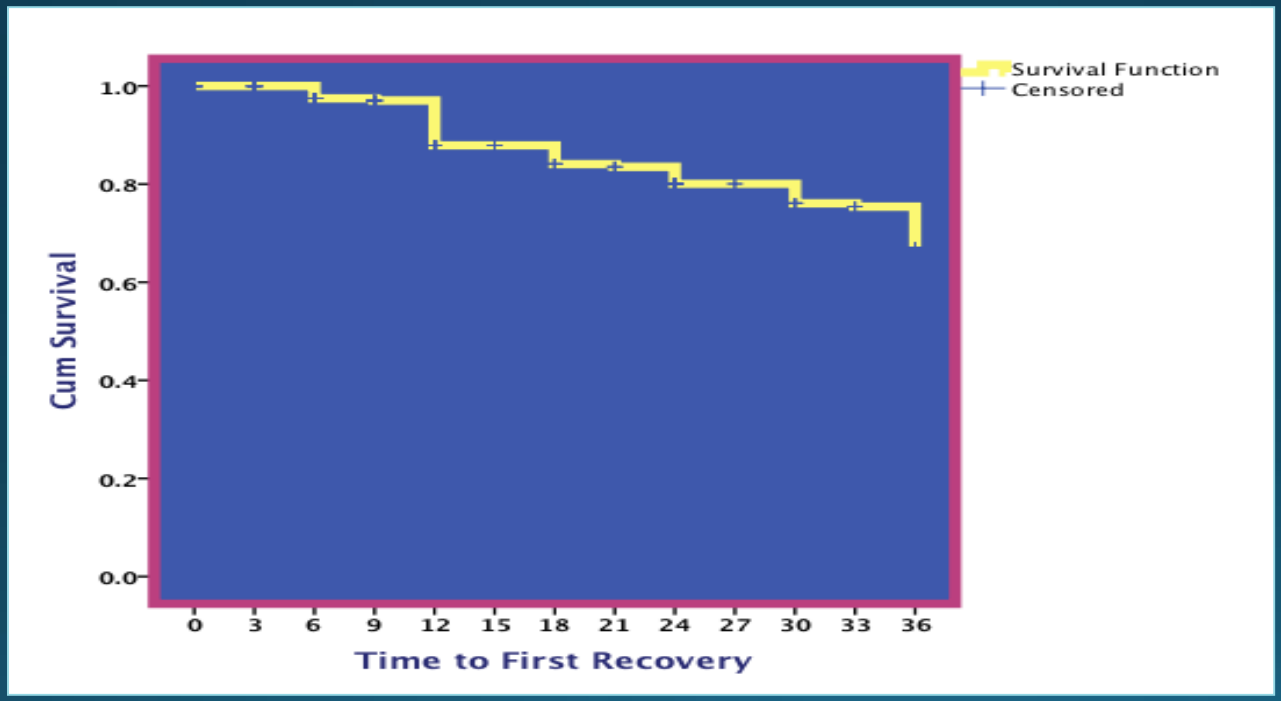
Time to Event: Partial Recovery



Comprehensive Recovery Results

- 59 or 22.7% of the cohort achieved comprehensive recovery;
  - A small number (n=7) recovered in the first 12 months;
  - The largest number of recoveries occurred in Year 2 (n=27, 46%) and 25 individuals achieved comprehensive recovery in Year 3 (42%);
  - 60% of the 59 maintained recovery for 6 months or more.
- It was clear from these results that issues related to quality of life were a major barrier to achieving a full and satisfying recovery following EP.
  - Symptom remission and the return of better daily functioning were not enough.

Time to Event: Comprehensive Recovery



Qualitative Findings

Participants

- Three young men between the ages of 23 and 36 who had participated in the early psychosis program; and,
- Three mothers of 3 young men who had attended the early psychosis program;
  - there was one mother-son dyad among the participants.
- The six participants provided in-depth descriptions of their recovery experiences resulting in 128 pages of text.
- Data analysis reduced the in-depth situated descriptions to a general structure that included three main constituents.

Essential Constituents of Recovery

1) Exchanging one nightmare for another

Three elements give meaning to the beginning period of recovery following a 1st psychosis:

- *The Frightening Unknown* reflects how the individual & family begin recovery.
- *The Short-lived Transition* depicts the pathway to & nature of contact with the mental health system.
- *Ongoing Uncertainty* illustrates the disappointments & frustration that result from frequent treatment modifications. Side effects & symptoms prove equally difficult.

Essential Constituents of Recovery

2) The Tension between Resistance and Acceptance

- Emotional struggles reflects the toll of psychosis
  - Determination not to give up
- Ascribing meaning to illness
  - Recovery plans

3) Taking Life Back, Slowly

This final constituent is characterized by the ever changing degree of illness activity. Three elements emerged:

- Determining new directions
- Moving toward independence, and
- Getting on with it.

The Third Set of Results

Data Integration & Synthesis

Data Integration

The main study finding of the quantitative component was the intense struggle of individuals to develop a satisfying quality of life. It impeded recovery.

- The phenomenological results were used to expand and better understand the nature of the struggle.

Participant scores on the 4 subscales of Quality of Life Scale were reanalysed & grouped from low to high as 'poor', 'fair', good' & 'at par' for 5 time periods in the program.

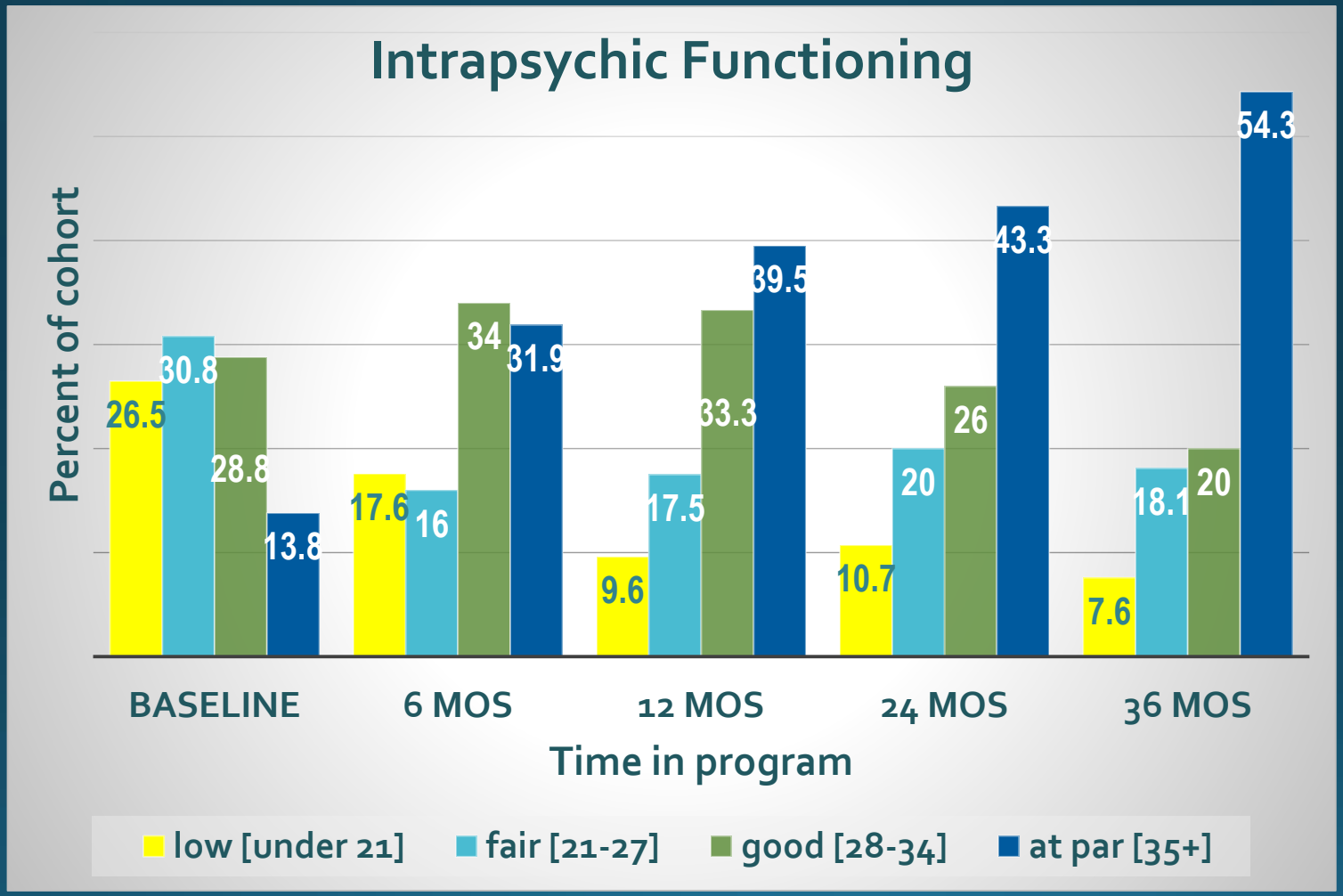
- Trends over time were noted; strength & challenge were identified.
- The phenomenological findings were then integrated with the 'qualitized' QLS results.
- A more holistic, textured view of recovery was generated through the integration of findings.

Quality of Life: Intrapsychic Subscale

This sub-scale assessed the psychological dimensions of cognition, conation & affectivity.

- 7 items explored the client's sense of purpose, motivation, curiosity, empathy & ability to experience pleasure
- On program admission (baseline), 56% of the cohort were assessed as having moderate to severe intrapsychic difficulty . By 12 months that number decreased to 27% and remained relatively stable over the next 2 years.

Intrapsychic Subscale Categorization



Qualitative Findings: Intrapsychic Functioning

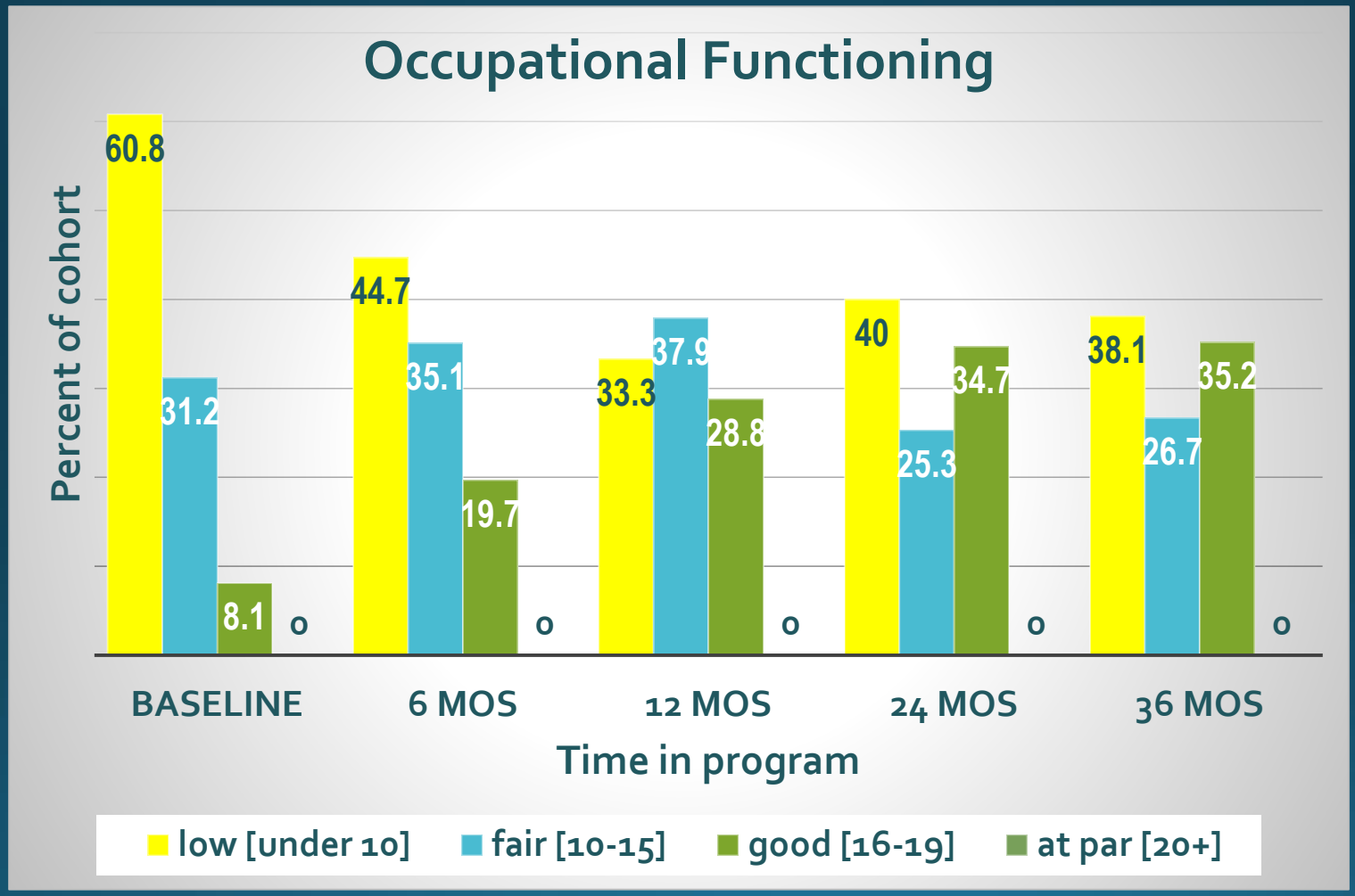
- Participant descriptions revealed challenges rooted in the intrapsychic dimension. They were seen as delaying/ limiting full recovery.
  - One young man attributed his lack of motivation & drive to his illness which meant they were out of his control. It fortified his belief that he was a sick person
  - One mother observed that her son lost his personality when he became ill. He showed little emotion & had minimal emotional interactions with his parents for several years.
  - One participant was ambivalent about his future & was indecisive about a number of possible options. He had little sense of direction.
  - However, determination to put the illness in its place was a positive psychological attribute expressed by all participants.

Quality of Life: Occupational Subscale

This subscale addressed the roles of employee, student & parent/homemaker.

- 4 items assessed the extent of occupational functioning, the level of achievement, degree of underemployment & satisfaction derived from the role.
- 92% of participants were experiencing difficulty with role functioning on program entry. That number was reduced to 71% at 12 months & showed only a small change over the following 24 months.
- At the end of the 3-year program, 65% continued to experience significant challenges in role productivity.
- Worthy of note, at no time in the program was any individual assessed as having impairment-free functioning in this domain of living.

Occupational Subscale Categorization



Qualitative Findings: Occupational Role

Psychosis was described as provoking major disruptions in role functioning. It delayed recovery & increased dependency.

- School & work were abandoned.
  - 1 client participant who had been working part-time & completing a university degree left both when he developed psychosis. He stayed on social assistance for over 4 years before re-entering the workforce.
  - 1 mother described having to fight with the school to get permission for her son to complete high school following a long period of illness.
- Interference of symptoms & side effects was a contributing factor as it undermined the confidence of the young adults & kept them close to home.

Framework for Integration of QSL & Recovery Constituents

INTRAPSYCHIC

a) Influences meaning given to illness;
b) Influences completion of age-appro tasks; c) Impacts emotional aspect of relationships;
d) Bolsters determination to manage illness.

INTERPERSONAL

a) Personal support & sharing are resources for dealing w illness.
b) Spotlighting illness beliefs as health facilitating.
c) Family & social network as key to independence.
d) Role of the mental health system.

OCCUPATION

a) Role interruption due to 1st psychosis.
b) Barrier to independence
c) Educational & volunteer endeavours
d) The influence of an illness focus.

ACTIVITIES

a) Access to age appropriate technology & activities;
b) Music & television provide a connection to the world.
c) Lack of age appropriate social & community activities

What Did Data Integration Achieve?

- It demonstrated complementarity of much of the quantitative & qualitative data; but it also highlighted family and other issues, important to the participants, that were not a focus of the quantitative data.
- It provided an organizing framework to add to our understanding of why comprehensive recovery following early psychosis was such a lengthy, difficult process.
- It can guide nursing interventions with individuals & families to promote timely, full recovery.
- It broadened and deepened knowledge of how recovery is lived over time. It captured the challenges presented by the social dimension of mental illness. It revealed what remained for individuals to manage when symptoms remission and satisfactory functioning were supposedly re-established.

Study Findings: Significance for Nurses

- More action is needed to facilitate a stronger, quicker recovery for individuals & families.
  - Factors related to emotional struggles, the lack of a social network & need to redevelop life's goals highlight are just some of the areas where the influence of PMH nurses could be beneficial to recovery.
  - Formalizing phase-specific interventions aimed at strengthening personal capacity for active recovery also have priority.
- The plateau in recovery that occurs after the initial 9-12 months in the early psychosis program needs examination and, likely, new interventions to advance healing.
  - Nursing interventions related to the promotion of health-facilitating illness beliefs, for example, have been shown to relieve suffering in individuals & families experiencing illness.

Study Findings & Significance for Nurses

- The social impairment resulting from psychotic illness was clearly illustrated in both the quantitative and qualitative findings. The social isolation that follows is painful & unacceptable. It can be changed & improved by nurses.
  - Building close, trusting relationships with individuals & families has great value & will remain an essential part of nurses' work.
  - Creating opportunities to bring young people together & foster peer relationships is a priority for this population
- Further development and explication of the role of PMH nurses in early psychosis is also necessary as the contribution of nurses to the health and well being of the early psychosis population is not yet well known.

Thank You