Knowledge Exchange in the Mental Health Arena: The CREST.BD experience

NEXUS Spring Institute
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Bipolar disorder

- Uniquely complex condition
- Remarkably little previous qualitative, mixed method or participatory research
- Most previous research conducted within the framework of a traditional medical model
- Little focus upon recovery or quality of life
Quality of life

- No accepted definition of what constitutes QoL
- Multi-dimensional
- Dynamic
- Highly subjective
Quality of life in the Michalak household
How is QoL understood by people with BD?

Qualitative interviews with individuals with BD (n=35), their caregivers (n=5) or experts in BD (n=12) about determinants of QoL in BD

- Routine
- Social support
- Identity
- Spirituality
- Independence
- Stigma

First turning point in the journey…
recognition of the need for a team approach
Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD)

Team planning funding received in 2007
Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD)

**British Columbia based team members**
- Erin Michalak
  - Team Leader
  - Quality of life, psychosocial functioning
- Jehannine Austin
  - Genetics, genetic counseling, knowledge translation
- Sandra Hale
  - Recovery, knowledge translation
- Catriona Hippman
  - Genetics, genetic counselling
- Rachelle Hole
  - Qualitative research
- Raymond Lam
  - Clinical and neurobiological factors
- Mark Lau
  - Cognitive behaviour therapy
- Victoria Maxwell
  - Consumer perspective, knowledge translation
- Jamie Livingston
  - Stigma
- Barb Pesut
  - Spirituality, religion and health, qualitative research
- Melinda Suto
  - Leisure, qualitative research
- Ivan Torres
  - Cognitive and neurobehavioural factors
- Lakshmi Yatham
  - Neurobiology and treatment of BD
- Allan Young
  - Neurobiology and treatment of BD

**Canadian team members**
- David Kreindler
  - Mathematical modelling, clinical applications of handheld computers
- Roumen Milev
  - Stigma, psychiatric perspective
- Sagar Parikh
  - Knowledge translation, continuing professional development, health services

**International team members**
- Steve Hinshaw
  - Stigma, adolescents with BD
- Sheri Johnson
  - Reward sensitivity, life events, cognitive factors, personality
- Greg Murray
  - Psychosocial treatments. quality of life, circadian factors
- Samson Tse
  - Psychiatric rehabilitation, gambling, Asian health
- Eric Youngstrom
  - Youth with BD, assessment factors, quantitative methods
- David Miklowitz
  - Family environmental factors, family psychoeducation

**Who we are**
CREST.BD is a network of individuals who have come together to focus upon the study of psychosocial issues in bipolar disorder (BD).

**Why we believe the study of psychosocial issues is important**
Bipolar disorder is a disabling psychiatric condition that affects half a million Canadians. Advances in medication management of BD have been encouraging. However, it has become increasingly apparent that psychosocial factors have a crucial role to play in how the condition manifests.

This is a rapidly emerging field, but research to date has been fragmented. We believe that the time is right to bring together a cohesive, multidisciplinary group of individuals to focus research efforts in this area. Our aim is to create a network of people who are more than the sum of their parts; a team that can significantly further our understanding of psychosocial issues in BD.

**Core Values**
1. A strong consumer focus
2. Emphasis upon refining understanding via individual difference interactions
3. Translation upon wellbeing and growth
4. Emphasis upon refining understanding via individual difference interactions
5. A focus upon under-studied populations

**Examples of CREST.BD research projects**
- Quality of life in BD: Predictors, structures and outcomes
- A focus upon under-studied populations

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**Quality of life, stigma, and BD: A collaboration for change**
This study will educate consumers and healthcare providers simultaneously about a) The importance of stigma, both internal and external in BD (how to recognize internalised and externalised stigma and how to deal with it) and b) The importance of using QoL as an outcome measure in BD. Strategies we will use to educate include: presentations, teaching events, manuals, courses, developing online interventions, providing supervision for new scales and interventions.
CREST.BD: geographic spread
2007 team planning weekend…
Plenty of heated debate...

Victoria Maxwell gives her two cents worth
CREST.BD core values

- Strong consumer focus
- Emphasis upon wellbeing and growth
- Emphasis on methodology and measurement issues
- Emphasis upon refining understanding via individual differences (e.g. age, gender, ethnicity, personality)
- A focus upon under-studied populations (e.g., rural/remote, indigenous/migrant populations, elderly/youth with BD)
- Think global, act local stance: strong connections to international groups, but the understandings will be brought to bear on the specific context of BC
An example of a CREST.BD study
‘Wellness in BD’

**Aim:** To determine the self-management strategies used by high functioning individuals with BD

**Method:** Participant choice of semi-structured individual interview or focus group

**Data analysis:** Via NVivo, multidisciplinary team of 4 individuals

**Methodological approach:** Combination of narrative, content and quantitative analysis
Results

Data analysis revealed 5 themes:

1. Self-management strategies
2. Accepting BD, not being defined by it
3. Social support
4. Focus on personal growth
5. Stigma
Knowledge Exchange activities...


Hosted by: Dr. Erin Michalak, PhD, Assistant Professor, Mood Disorders Centre, Department of Psychiatry, UBC and Dr. Allan Young, MB, PhD, Professor, UBC Department of Psychiatry, LEVER Chair in Depression Research and Co-Director, Institute of Mental Health. In conjunction with: The CREST BD team, the UBC Department of Psychiatry and the UBC Institute of Mental Health

Topics:
- Medication treatment strategies for BD: Dr. Allan Young
- Psychosocial self-management strategies for BD: Dr. Erin Michalak
- Question and answer panel: Allan Young, Erin Michalak and members of the CREST BD team (an interdisciplinary team dedicated to the study of psychosocial issues in BD)

July 10th, 2007, 7:00pm
UBC Robson Square Theatre, 899 Robson St., Vancouver
corner of Robson and Howe.
Please pre-register for this event as seats are limited.
Send your name and $5 registration fee (cheque or money order, cheques to be made out to the UBC Mood Disorders Centre - waived in cases of financial hardship) to:
UBC Mood Disorders Centre
Altn. Heather Armstrong
Room 2CT-2256 Wesbrook Mail
Vancouver, B.C. V6T 2A1

For more information, please contact Heather Armstrong at 604.822.0046 or via email at hla@interchange.ubc.ca
Other forms of KE....

- Website
- Regular newsletters
- CREST.BD ‘Consumer Group’
- Peer researcher network
- Opening up data to consumer group
2008 CIHR-funded community consultation day

Attended by 48 people: 30 consumers with BD (or their family members) and 18 team members.
A second turning point in the journey... focus upon stigma
Are you interested in helping shape the future of research into bipolar disorder?

Stigma, discrimination and bipolar disorder: A community consultation event

Join us for a one-day event designed to:

1) Allow the Collaborative REsearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD), and people with BD, their family members and community representatives to network

2) Help CREST.BD develop a program of research into stigma and BD.

If you experience BD, have a family member who experiences the condition or you are associated with a community group and would like to get involved, please contact Erica Amari for further details at 604 822 7247 or erica.amari@ubc.ca

To register online, visit http://intranet.ca/event_registration

Location:
Cecil Green Park House
University of British Columbia
6251 Cecil Green Park Road
Vancouver, B.C. V6T 1Z1

Date:
Thursday March 12th, 2009

Time:
10:00 – 4:00 pm (lunch provided)

Travel and out of pocket expenses associated with attending the event will be reimbursed.

Many people living with a mental illness report that the stigmatization of mental illness causes them more suffering than their disease itself (Mental Health Commission of Canada)

Mastering Mood Disorders: Identifying and Overcoming Stigma and Discrimination

A one-day CREST.BD/CANMAT CPD event
Saturday, March 14th, 2009
UBC Robson Square, 800 Robson St., Vancouver
8:30am – 4:15pm

Course Directors: Dr. Erin Michalak and Dr. Sagar Parikh

Conference Summary
Mood disorders disable more Canadians than any other disorder, but often treatment is not sought nor entirely effective. Research indicates that experiences and perceptions of stigma are common in depression and bipolar disorder, and this affects help seeking as well as acceptance of mood disorders as a health condition by the public. These findings have led the Mental Health Commission of Canada to identify stigma as one of the top three priority areas in improving mental health outcomes. This year, CREST.BD, CANMAT and the UBC Department of Psychiatry have come together to create a conference to focus on stigma and discrimination in mood disorders. Join us at this one-day education event, and learn from international leading experts in stigma research.

CREST.BD stands for Collaborative the REsearch Team to study psychosocial issues in Bipolar Disorder, an international group of mood experts - both health care professionals and consumers. CANMAT stands for the Canadian Network for Mood and Anxiety Treatments, an organization of many of Canada’s leading mood and anxiety specialists who collaborate in research, education, and producing treatment guidelines.

Who Should Attend
- Researchers
- Psychiatrists, Family Practitioners
- Psychologists, Social Workers
- Nurses, Occupational Therapists
- Counsellors, Therapists, other Mental Health Professionals
- Consumers and Family Members
- Educators and other Stakeholders

Register Now
To register online please visit: http://intranet.ca/event_registration

For further information please contact Erica Amari at:
T: 604-822-7247
E: erica.amari@ubc.ca
Converging paths

- Findings from our mixed methods and CBR research indicate that stigma is paramount in determining QoL in BD
- Platform for our future program of consumer-centric, ‘integrative KT’ research

- Large CIHR operating grant
- CIHR ‘Knowledge to Action’ grant
CIHR KTA application:  
“QoL, stigma and BD: A collaboration for change”

- **Aims:** Educate consumers re. how to recognise internalised stigma, deal with it, recognise and respond to public stigma
- **Aims:** Educate provider re. stigma, both internalised and public, how to facilitate treatment plans for reducing internalised stigma
- **Methods.**
  1) Develop, disseminate and evaluate a presentation by Decision Maker to dramatically illustrate how internalised and public stigma manifest
  2) Establish a community consultation panel; variety of other forms of KE
Lessons learnt along the journey

- A different kind of research process
- Takes time (higher risk for early career researchers), commitment, passion, defending
- Issues around data/resource ownership can be significant
- Funding bodies have some way to go
- High relevance as research questions reflect the needs of the community
- Creative and pragmatic implementation of results can occur
- Research community is invested in the process – can pay dividends
Feel free to contact me!
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