

Searching for order in disorder: Self-management education for persons with bipolar disorders and their informal caregivers

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Promotie

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Joint degree
Radboud Universiteit &
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Aanleiding (wat is ‘zelfmanagement’?)

- Vermogen eigen gezondheid te monitoren om kwaliteit van leven te vergroten (Barlow et al., 2002).
- Complexe verzameling aan ondersteunende interventies en monitoringsinstrumenten (Clark, 2013).
- Als losstaande componenten effectief, maar grote variatie in uitkomsten (Holman & Iorig, 2000; Trappenburg et al., 2013).
- Geen verklaring voor werkingsmechanisme achter het integrale leerproces (Perry et al., 1999; Scott et al., 2007).



Zelfmanagement bij een bipolaire stoornis

- Onderdeel van behandeling in multidisciplinaire richtlijn (Kupka et al., 2015).
- Valt binnen verpleegkundig taakgebied (Coster & Norman; 2009).
- Grotendeels instrumenteel vormgegeven (o.a. LCM en vroegsignalering)
- Mist aanknopingspunten WAT zelfmanagement inhoud en HOE zelfmanagement te bevorderen.



Vraag en doel van het onderzoek

Welke leermechanismen liggen ten grondslag aan zelfmanagement bevorderende interventies?

Doel is tweeledig:

- 1) Het gebruik/nut van stemmingmonitoringinstrumenten.
- 2) Leerervaringen van patiënten, naasten en verpleegkundigen.



I Monitoring de basis van zelfmanagement

Research Paper

Attitudes of Patients With Bipolar Disorder Toward the Life Chart Methodology: A Phenomenological Study

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Laura J. Kramer³, and Peter J. J. Goossens⁴

Abstract

BACKGROUND: The Dutch guideline for bipolar disorder (BD) recommends the use of the Life Chart Methodology (LCM) to help patients to monitor fluctuating mood patterns. But in practice patients show ambivalent attitudes toward this instrument. **OBJECTIVE:** To describe attitudes and motivations of patients with BD for (non-)using the LCM. **DESIGN:** A phenomenological study with unstructured in-depth interviews of 14 patients with BD. Patient narratives were audio-taped, transcribed verbatim, analyzed, and coded inductively. **RESULTS:** The results show that despite variability in perceptions and willingness to work with the LCM, the general attitude toward this instrument was a recognized value for using the LCM. However, the emotional impact of daily mood charting was experienced as a substantial burden, particularly during the early stages of diagnosis. **CONCLUSION:** The impact of the diagnosis of BD needs to be taken in account when introducing the instrument for the first time to a patient.

Keywords

bipolar disorder, life chart methodology, self-management, patients' attitudes

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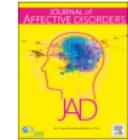
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Research paper

The user experiences and clinical outcomes of an online personal health record to support self-management of bipolar disorder: A pretest-posttest pilot study

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ABSTRACT

Background: Self-management comprises knowledge, behavior, activities and resources providing people with bipolar disorder (BD) control over fluctuating mood and activity-patterns. The 'Self-management and Dialogue in Bipolar Disorder' project entailed the tailoring of an online personal health record (PHR) originally designed for the chronically ill to monitor condition and share information with their clinician to people with BD (PHR-BD). The aim of this study was to evaluate the feasibility, utility and user-experiences of participants with BD,

Analoge stemmingsmonitoring

Design: kwalitatief, N=14; BI = 92,8%

- Attitude positief/nut beaamt
- Confronterend/emotioneel belastend
- Lastig te personaliseren
- Vatbaar voor sociaal wenselijk gebruik
- Wens digitalisering LCM

NIMH-LCM™ Self/PROSPECTIVE Ratings: The LCM-S/P™

Name _____ Month _____ Year _____

LCM-S/P™ Version 2-02

Days of Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Medication Name	Enter total # of tablets TAKEN per day																														
Lithium																															
Tegretol																															
Depakote																															
Please track all medications that you are currently taking.																															
Days of Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Hours of Sleep																															
Dysphoric Mania (✓) If Yes																															
Mania																															
SEVERE	Essentially Incapacitated or Hospitalized																														
MODERATE	GREAT Difficulty with Goal-Oriented Activity																														
LOW	SOME Difficulty with Goal-Oriented Activity																														
LOW	More Energized & Productive with Little or No Functional Impairment																														
MILD	Little or No Functional Impairment																														
LOW	Functioning with SOME Effort																														
HIGH	Functioning with GREAT Effort																														
SEVERE	Essentially Incapacitated or Hospitalized																														
Days of Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
MILD	Baseline																														
Depression																															
TRACK COMORBID SYMPTOMS HERE																															
Number of Mood Switches / Day																															
Mood (0 - 100)																															
0 Most Depressed Ever																															
50 Balanced																															
100 Most Manic (Activating) Ever																															
Please circle the days of your medication period.																															
Days of Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

Digitale stemmingsmonitoring

Design: pre-post test, N=39 (66);
BI=76%

- Geen stat. Significant effect op MANSA, NEL, IDS-SR, ASRM, OQ-45, GAF, CGI-BP
- Monitoring + vroegsignalering meest gebruikte modules
- Interface in-uit zoomen en integratie instrumenten
- Wens applicatievorm



II Zelfmanagement: een drievoudig perspectief

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Identifying and describing patients' learning experiences towards self-management of bipolar disorders: a phenomenological study

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Keywords: bipolar disorders, community mental health services, learning experiences, phenomenology, qualitative research, self-management

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Accessible summary

- Existing evidence suggest that patient education in promoting self-management strategies of bipolar disorder (BD) is effective. However, results across the full range of service users with BD vary. Learning experiences of service users look to be a crucial factor to take into account when designing, delivering, and evaluating effective interventions that promote self-management in chronic illness. What learning activities service users actually undertake themselves when self-managing BD that might explain varying success rates, and guide future self-management educational programmes has not been examined.
- Unlike previous studies that suggest that outcomes in self-management depend on individual learning activities, the current study found that learning to self-manage BD takes place in a social network that functions as a learning environment in

Research Paper

Informal Caregivers' Learning Experiences With Self-Management Support of Individuals Living With Bipolar Disorder: A Phenomenological Study

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Abstract

BACKGROUND: The degree of informal caregiver involvement influences the self-management of individuals living with bipolar disorder (BD). **OBJECTIVE:** This article aims to provide a description of informal caregivers' learning experiences in self-management support of BD in order to guide professionals in tailoring future psychosocial and psychoeducational interventions. **DESIGN:** In-depth open interviews with 10 informal caregivers of patients with BD who followed treatment in the context of specialized outpatient bipolar care were conducted. **RESULTS:** Four learning phases emerged from the phenomenological analysis describing the informal caregivers learning process: (1) understanding BD, (2) overcoming the dilemmas in self-management support for individuals living with BD, (3) dividing tasks and responsibilities, and (4) acquiring a personal definition of self-management support for individuals living with BD. **CONCLUSION:** By grasping the concept of BD, informal caregivers gradually learn how to overcome dilemmas resulting from living with someone with BD, and how to control the expression of emotions. They learn to reflect on the nature of conflicts and how to share the responsibilities of illness management with individuals living with BD and professionals. Mastering these skills eventually allows them to define and delimit their supporting informal caregiver role in the self-management of BD. **PRACTICE IMPLICATIONS:** Our findings provide information regarding the educational needs of informal caregivers to tailor counseling, and psychosocial and psychoeducational interventions in specialized outpatient care for individuals living with BD.

Keywords

bipolar/mood disorder, families of the mentally ill, psychoeducation, research, qualitative, self-management

Background

Self-management of a chronic illness is one part of the treatment in the chronic care model and part of the definition of health as stated by the World Health Organization (Huber et al., 2011; Wagner, Austin, & Von Korff, 1996). Self-management improves outcomes and reduces the

involved in their treatment (Lorig & Holman, 2003; Newman, Steed, & Mulligan, 2004). The primary goal of self-management education is to increase the individual's ability to overcome the negative consequences of living with a chronic condition and maintain a satisfactory quality of life (Barlow, Wright, Shasby, Turner, &

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Self-Management Education for Bipolar Disorders: A Hermeneutic-Phenomenological Study on the Tacit Knowledge of Mental Health Nurses

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ABSTRACT

Background: Self-management of bipolar disorder (BD) education is a complex nursing intervention in which patients and informal caregivers are taught to be actively involved in self-monitoring and self-regulating activities. Some studies question if nurses are sufficiently equipped to deliver these educational tasks. Other studies suggest that nurses have gathered their knowledge implicitly by experience, but to date, this tacit knowledge is not described from the experiences of mental health nurses (MHNs) in ambulant BD care.

Objective: To detect the tacit knowledge used by MHNs by interpreting their experiences in delivering self-management education to people with BD and their informal caregivers.

Methods: A phenomenological-hermeneutic study amongst MHNs ($N=9$) from three ambulant BD care clinics in the Netherlands. Face-to-face, open-in-depth interviews guided by a topic list, were conducted and transcribed verbatim prior to the hermeneutical analysis.

Findings: We found five categories resembling the complex character of self-management interventions provided by MHNs: Building a trustful collaboration, Starting a dialogue about needs and responsibilities, Explaining BD, Utilizing mood monitoring instruments, and Conceptualizing self-management of BD.

Conclusion: Eventually MHNs use tacit knowledge to cope with situations that demand an outside-the-box approach. Self-management education is partially trained and partially mastered through experience.

Practice implications: In order to facilitate long-term self-management of BD, the collaboration of a supporting network is essential.

Introduction

Self-management of BD is a continuous learning process of self-regulation, active involvement, and reflection that demands proper educational guidance and support to

Een drievoudig kwalitatief perspectief

Patiënten (N=16; BI= 56%)

- (H)erkenning
- Informatie
- Ziektemanagement
- Leven met bipolaire kwetsbaarheid

Naasten (N=10)

- Informatie
- Dilemma's
- Taken/verantwoordelijkheden
- Roldefinitie

Professionals (N=9)

- Samenwerking
- Dialoog zoeken
- Uitleggen
- Gebruik instrumentaria

Zelfmanagement: een drievooudig perspectief

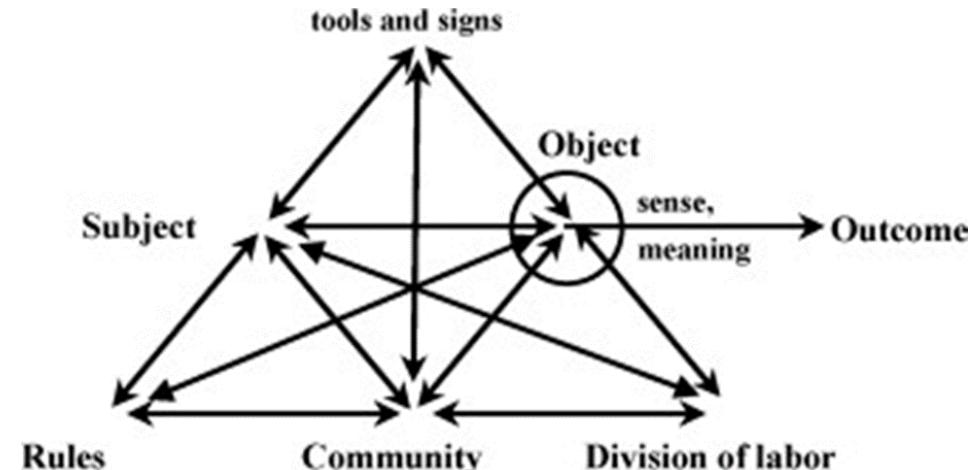
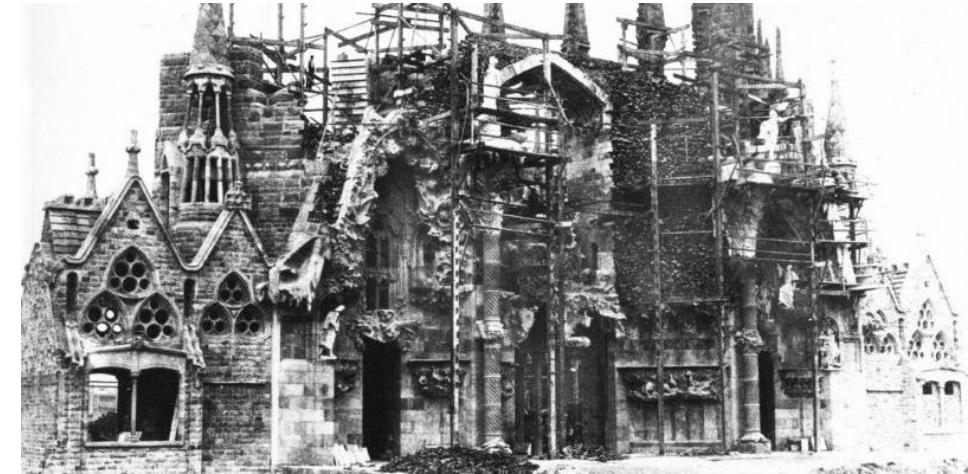
- Asynchroon leerproces
- Personaliseren concept ZM
- Wederkerigheid en vertrouwen
- Inzet netwerk als vangnet
- Zeker geen panacée

“[...] despite all efforts, it is a sword of Damocles hanging above my head, some kind of unpredictable wild animal, a predator, that is watching me closely waiting to strike me at any given time. [...]”

[citaat, cliënt7]

Aanbevelingen voor de praktijk

- Vermijd discussie (diagnose) zoek de dialoog
- Ondersteuning waar nodig/zolang het nodig is, maar niet langer
- Timing en personaliseren instrumenten
- Focus op netwerk leren (Engeström & Sannino, 2010).



Aanbevelingen voor vervolgonderzoek

- Replicatie kwalitatieve studies (multidisciplinaire steekproef)
- Begripsvorming zelfmanagement binnen GGZ (Eckman, 2012).
- Experimentele studies interventies om zelfmanagement en welbevinden te bevorderen
- Naturalistische implementatie/evaluatie mobiele applicaties



Het uiteindelijke resultaat

Vragen/opmerkingen?

Interesse in een hardcopy, mail naar:

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SEARCHING FOR
ORDER IN DISORDER:
SELF-MANAGEMENT EDUCATION FOR
PERSONS WITH BIPOLAR DISORDERS
AND THEIR INFORMAL CAREGIVERS

Literatuur

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