

PSYCHOGERIATRIC NOTE

Perspectives on recovery by older persons with bipolar disorder, their caregivers, and mental healthcare professionals: an exploratory approach using focus groups and social dialogue

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Although bipolar disorder (BD) has been understood classically as a cyclic disease with full recovery between manic and depressive mood episodes, the long-term outcome has been associated with cognitive deficits, impaired psychosocial functioning, and premature death.¹ Due to ageing of the population the absolute number of older persons with BD will rise in the next decades¹ with substantial burden for their caregivers.²

Acknowledging that recovery is defined more broadly than the absence of mood symptoms,³ insights regarding perspectives of recovery and expectations of mental health care (MHC) are urgently warranted to meet the needs of this growing complex patient group.

To this aim, we set up a qualitative exploration of the different perspectives on recovery and the role of MHC by patients, informal caregivers, and mental healthcare professionals in focus groups followed by social dialogue. The study was conducted in 2016 from March to July. All older persons with BD ($n = 14$) were euthymic with a mean Center for Epidemiologic Studies Depression Scale (CES-D)-score of 3.2 (standard deviation (SD) 2.1) and a mean Young Mania Rating Scale (YMRS)-score of 1.6 (SD 2.0). The average age was 68.5 years (range 62–80, SD 5.1) and 57% were female. Thirty-six percent had BD type 1. The mean Global Assessment of Functioning (GAF)-score was 65.4 (SD 6.9). Caregivers of older persons with BD ($n = 3$) were 64.3 years old (range 62–67, SD 2.5) and 67% female. Professionals (community nurses: $n = 4$, psychologists: $n = 5$, psychiatrists: $n = 5$ and managers: $n = 4$) had a mean age of 48.7 years (range 30–64; SD 11.0), and 71% were female. They had been working in outpatient clinics for old age psychiatry on average for 18.4 years (range 2–32 years; SD 9.3).

The focus group discussions were semi-structured, guided by an independent moderator (AvL, MT, BR),

and lasted approximately 2 h.⁴ Focus groups provide room to collectively brainstorm and discuss about new ideas and solutions. A focus group started with a mind-map and participants were asked to share their first ideas and associations with the concept of Recovery.

Participants pointed out that recovery is very personal, yet overarching themes could be identified. Community nurses mentioned similar recovery themes as patients and caregivers; moreover, they used mostly the same words to define these recovery themes. With open coding, 28 recovery themes were identified (Table 1) that could be related to the five recovery components within the universal conceptual framework: Connectedness; Hope and optimism about the future; Identity; Meaning and purpose in life; and Empowerment (giving the acronym CHIME).⁵

Next, members of each focus group joined the social dialogue session. The purpose of a social dialogue is collective consultation and negotiation, sharing ideas, informing each other, exchanging perspectives and establishing a deep conversation.⁶ All recovery themes, written on small cards, were categorized according to their role within MHC in the following categories: I. Sufficiently provided by MHC; II. Desirable part of MHC; III. Supporting role for MHC; IV. Informative and advisory role for MHC; V. No role for MHC. The results were collected in one large table on the wall. Next, in three subgroups recommendations were formulated to improve recovery-oriented care for older persons with BD. The social dialogue ended with pitches of these suggestions for improvement.

According to patients, their caregivers, professionals, and managers, recovery in older persons with BD is more than reducing clinical symptoms but contains elements of improvement of personal and social functioning and quality of life. This is in accordance with current

Table 1 Recovery themes as indicated in focus groups clustered according to the CHIME-model

CHIME-factors	Recovery theme	Role for mental health care				
		I	II	III	IV	V
Connectedness	Reciprocal social relations	2/14	2/14	2/14	4/14	4/14
	Close social network	0/12	2/12	2/12	4/12	4/12
	Sexuality and intimacy	0/14	6/14	4/14	2/14	2/14
	Being part of society	0/12	4/12	4/12	4/12	0/12
	A place to call home	0/14	4/14	4/14	2/14	4/14
	Feeling safe	2/16	6/16	6/16	0/12	2/16
Hope and Optimism	Hope and Optimism for the future	2/12	0/12	0/12	8/12	2/12
Identity	Confidence in self	4/12	0/12	4/12	4/12	0/12
	Acceptance of self	4/16	0/16	4/16	4/16	4/16
	Own identity	4/12	0/12	2/12	4/12	2/12
	Acceptance of disease	6/10	0/10	0/10	4/10	0/10
Meaning in life	Dealing with stigma [†]	2/14	6/14	2/14	4/14	0/14
	Having a goal or challenge	4/12	0/12	8/12	0/12	0/12
	Day schedule	8/12	4/12	0/12	0/12	0/12
	Spirituality	4/14	0/14	0/14	2/14	8/14
	Part of society	0/12	2/12	2/12	4/12	4/12
	Significance in life	0/12	6/16	6/16	4/12	0/12
Empowerment	Personal strength	4/16	2/16	4/16	2/16	4/16
	Personal growth	0/12	2/12	4/12	2/12	4/12
	Sense of independence	2/12	2/12	2/12	2/12	4/12
	Self-management	2/12	6/12	0/12	2/12	2/12
	Making independent decisions	4/8	2/8	0/8	0/8	4/8
	Optimize health	4/16	6/16	0/16	2/16	4/16
	Personal care [†]	0/10	2/10	2/10	0/10	6/10
	Financial independence	0/8	2/8	2/8	4/8	0/8
	Guard own boundaries	6/14	4/14	0/14	0/14	4/14
	Knowledge about the disease [†]	8/14	6/14	0/14	0/14	0/14
	Acknowledgement [†]	6/12	0/12	0/12	2/12	4/12

[†] These recovery themes were only mentioned in focus groups with patients and caregivers, not in any focus groups with professionals. I. Sufficiently provided by Mental Health Care. II. Desirable part of Mental Health Care. III. Supporting role for Mental Health Care. IV. Informative and advisory role for Mental Health Care. V. No role for Mental Health Care. In the first column are the CHIME factors. In the second column are the recovery themes as indicated in the focus groups clustered according to the CHIME factors. In columns I–V the results of the social dialogue are presented, and every participant indicated the role for Mental Health Care for the different recovery themes. The total number varies, as participants could not always decide on a role for each theme.

opinions about recovery and recovery-oriented MHC. Most recovery values as identified in our study on older persons with BD could be categorized within the CHIME model. Of note, this model relates to working age groups.

The recovery value ‘Hope and Optimism’ was not mentioned in our groups as a recovery theme that should be addressed by MHC. It is possible that this recovery value is of less importance with duration of disease or with aging.

Questions remain as to how MHC can provide the environment for patients to achieve recovery in all dimensions. If recovery is defined as more than clinical recovery and broadened to functional, soci(et)al and personal recovery, the role for MHC and professionals will change accordingly. A team consisting of professionals with different backgrounds will help ensure that the various aspects of recovery will be

attended to, as recovery-oriented care is dependent on individual motivation and expertise on the part of both patient and professional.⁷ In our focus groups only the community nurses defined similar recovery values as patients, moreover using similar language. It is possible that community nurses are trained to approach recovery in a more holistic way, making them highly valuable in a multidisciplinary team that wants to provide recovery-oriented care.

Focus groups with patients, caregivers, professionals, and managers provided us with an efficient opportunity to find a common language on the topic ‘recovery’ and to get insight into the gaps between care as demanded and care as provided, as well as into the expectations of various groups. The age-specific aspects of recovery warrant further study in order to generate services that work well for older people.

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DISCLOSURE

All participants provided informed consent, and the study was approved by the Medical Ethical Committee of Amsterdam UMC, location VUmc. The authors have no potential conflicts of interest to disclose.

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