Health outcomes, community resources for health, and support strategies 12 months after discharge in patients with severe mental illness

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KEY MESSAGES

1. Social functioning and general psychopathology were predictors of quality of life (QOL) 12 months after hospital discharge in patients with severe mental illness (SMI).
2. Patients rehospitalised for relapse were associated with non-compliance with prescribed treatment, poor physical health, and inadequate personal and community living skills.
3. A dynamic interplay of the empowering/disempowering experiences with regard to spark of hope to carry on with life, a desire to move from institutional to community living, redefining oneself, a willingness to volunteer, and engagement in treatment that enhance or hinder recovery resulted in improved/deteriorated QOL in community living or readmission.
4. Clinical and personal recovery in patients with SMI is complementary.
5. Empowerment is the key to personal recovery.

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Introduction

In 2009, a recovery-oriented multidisciplinary case management model was developed for patients with severe mental illness (SMI). In 2010, the Hospital Authority launched the Personalised Care Programme (PCP) to provide a patient-centred service to enhance recovery in the community. Quality of life (QOL) is a main outcome measure. Based on the human functioning perspective, patients with SMI can live in the community with a self-perceived high QOL if they experience less severe symptoms, are able to perform adaptive functioning, receive appropriate help, and if their family caregivers do not perceive the burden of care to be too overwhelming. Personal recovery is defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles … [in order to live] a satisfying, hopeful and contributing life even with the limitations caused by illness".[1] Thus, patients with SMI can live in the community with a self-perceived high QOL if they are engaged in a dynamic interplay of individual and environmental characteristics that enhance recovery. From an ecological perspective, individuals have innate potential that contribute to behavioural variability. In this study, environments refer to the inter-relationships between individuals with SMI and their family, neighbourhood, and the psychiatric, general health care, social welfare, and community support services.

Methods

This prospective cohort study was conducted from April 2010 to October 2012. Patients with SMI, their family caregivers, and various stakeholders (including service users and psychiatric and community-based service providers) were included. A total of 347 patients diagnosed with SMI admitted to Castle Peak Hospital were assessed at discharge (T1) [n=347], and 2 months (T2) [n=271], 6 months (T3) [n=180], and 12 months (T4) [n=180]. Only 103 patients completed assessments in all four time points. In addition, 126 caregivers were interviewed at T1 of whom 76 completed the interview at T2, 33 at T3, and 22 at T4. Only 13 completed all interviews in all four time points.

A total of 99 participants were interviewed: 40 patients with SMI, nine family caregivers, and 50 service providers from both the public sector and non-governmental organisations. Of those who completed interviews in a minimum of two time points, 11 had a positive change and 12 had a negative change in World Health Organization QOL scores. Fifteen were hospitalised within 6 months of discharge, of whom six were discharged a second time to a half-way house.

The QOL of patients with SMI was measured using the World Health Organization QOL – Brief Form; the mental health state was measured using the Positive and Negative Syndrome Scale; functional level was measured using the Specific Level of

Functioning Scale; care needs were measured using the Camberwell Assessment of Need; and Family caregivers' burden was measured using the Family Burden Interview Schedule. Consistency was ensured across assessors through inter-rater reliabilities and regular checks. Qualitative interview was used to elicit narratives about mental illness, treatment, community living, and barriers or facilitators to recovery. Interviews with service providers focused on the care challenges as well as their views on strategies and resources for mental health and interdisciplinary services.

Results

Predictors of quality of life

Physical illness significantly affected QOL in terms of physical health, general psychopathology symptoms, level of functioning, and care needs (Table 1). Patients with family caregivers had better QOL (P=0.029), fewer symptoms (P<0.001) and unmet needs (P=0.024), and better social functioning (P=0.014) and community living skills (P=0.001) than those without. Patients with repeated hospitalisation had a significantly poorer level of functioning in self-maintenance and community living skills than those without. Patients' perceived QOL was positively associated with their level of functioning and negatively associated with their negative symptoms, general psychopathology symptoms, unmet needs, and total number of needs.

From T1 to T4, patients experienced an increase in their symptoms and a decrease in their specific level of functioning. Change in their overall

TABLE 1. Correlations between quality of life, symptom severity, functioning level, care needs, and family burden

Outcome	**World Health Organization Quality of Life-Brief version**					
	Total score	**Overall quality of life**	**Social relationship**	**Environment**	**Physical health**	**Psychological health**
Positive and Negative Syndrome Scale						
Total score	-0.279†	-0.151†	-0.111*	-0.233†	-0.306†	-0.268†
Positive symptoms	-0.088	-0.026	-0.005	-0.113*	-0.088	-0.090
Negative symptoms	-0.174†	-0.101	-0.124*	-0.120*	-0.147†	-0.168†
General psychopathology symptoms	-0.322†	-0.178†	-0.115*	-0.265†	-0.375†	-0.307†
Specific Level of Functioning Scale						
Total score	0.230†	0.062	0.188†	0.145†	0.211†	0.192†
Self-maintenance	0.206†	0.085	0.158†	0.142†	0.248†	0.119*
Physical functioning	0.235†	0.189†	0.103	0.141†	0.348†	0.182†
Personal care skills	0.105	-0.033	0.145†	0.090	0.072	0.023
Social functioning	0.319†	0.161†	0.284†	0.181†	0.250†	0.300†
Interpersonal relationships	0.292†	0.132*	0.308†	0.137*	0.199†	0.278†
Social acceptability	0.213†	0.154†	0.051	0.207†	0.257†	0.194†
Community living skills	0.121*	-0.012	0.090	0.085	0.121*	0.095
Activities	0.089	-0.003	0.051	0.079	0.069	0.090
Work skills	0.116*	-0.016	0.097	0.069	0.132*	0.076
Camberwell Assessment of Need						
Total No. of met needs	-0.178†	-0.146†	-0.164†	-0.105	-0.130*	-0.169†
Total No. of unmet needs	-0.391†	-0.259†	-0.305†	-0.295†	-0.362†	-0.301†
Total No. of needs	-0.361†	-0.259†	-0.299†	-0.250†	-0.308†	-0.300†
Family Burden Interview Schedule						
Total score	-0.012	0.090	0.015	0.054	-0.119	0.006
Financial burden	-0.050	0.056	-0.017	-0.052	-0.111	0.012
Effect on family routine	0/019	0.085	0.015	0.069	-0.048	0.022
Effect on family leisure	0.015	0.132	0.055	0.085	-0.118	0.017
Effect on family interaction	-0.038	0.085	-0.007	0.049	-0.098	-0.066
Effect on family physical health	0.079	-0.050	0.028	0.081	0.032	0.107
Effect on family mental health	0.000	-0.003	0.042	0.149	-0.193*	-0.009

* P<0.05
† P<0.01

QOL was not significant, except for improvement in psychological health and environment. Between T1 and T2, negative symptoms (P<0.001) and general psychopathology symptoms (P=0.002) increased significantly, whereas self-maintenance (P=0.001), social functioning (P<0.001), and community living skills (P<0.001) decreased significantly. The total number of unmet needs remained similar over the 12-month period, and was mostly related to finances, psychological distress, looking after the home, sexual expression, child care, psychotic symptoms, and physical health.

Social functioning and general psychopathology were the two predictors of patients' QOL. General psychopathology had the most significant negative impact on QOL at T1 and T2, whereas social functioning had the most significant positive impact on QOL at T3 and T4. Of the 180 patients who completed the T4 assessment, 94 experienced an improvement in their perceived QOL from T1 and 86 had no improvement, with negative symptoms being the only predictor. Self-perceived QOL was positively associated with functioning but negatively associated with symptom severity and unmet care needs. This supports our hypothesis that patients with SMI can live in the community with self-perceived high QOL if they have less symptom severity, improved adaptive functioning, and support for their care needs.

TABLE 2. Empowering and disempowering experiences that enhance or hinder the recovery process of patients with severe mental illness

Components of the recovery process	Empowering experiences	Disempowering experiences
Spark of hope to carry on with life (existential encounters with life-affirming events resulting in cognitive efforts to renew one's will to live)	- Genuine kindness and empathetic caring in encounters with family, friends, service providers, and others, leading to an awakening of hope in life - Existential encounters with nature or spirituality inspiring a spark of hope in life	- Confronted with indignities that hurt one's sense of integrity and dignity, and provoke harmful thoughts or harmful behaviours towards oneself/others
Desire to move from institutional to community living (expression of a wish to reclaim control of one's life by recouping one's strength and ability to care for oneself and live independently)	- Desire to reclaim control of one's life by taking personal responsibility for one's own care - Family commitment to support individuals by focusing on their strengths and desire to engage in new roles in life	- Cognitive difficulty in recognising one's illness - Engaging in behaviour that outwardly demonstrates one's readiness for independent living with the aim of fulfilling the 'standard criteria' for discharge - Unfriendly and sceptical neighbours
Redefining oneself (self acceptance and self-adaptation through goal-directed thinking in living with the mental illness)	- Narrative of self-transformation to renegotiate the identity shattered by mental illness. The narrative illuminates goal-directed thinking to define needs and future plans - Narrative of self-acceptance and self-adaptation in living with the mental illness	- Narrative of the self as a victim of mental illness where one's recovery depends on others or where one perceives no relation between one's own behaviour and outcomes - Estranged from family and relatives, resulting in social isolation and a lack of confidence that one would be accepted by other people - Holding a stigmatised view of oneself, which diminishes one's self-esteem and causes one to doubt one's ability to find a job, earn a livelihood, and take care of one's family
Gaining a sense of normalcy in activities of daily living (knowing how to self-manage the resources and options that are available for independent living in the context of a supportive family relationship and a friendly community)	- Acquiring the resources to self-manage one's life. Such resources include finances, housing, healthcare, and employment opportunities - Experiencing love and belonging with family and friends, neighbourhood, and community - Developing capacities for achieving one's goals, such as occupational training, emotion and anger management, health self-management, arts and crafts work, and personal hobbies	- Difficulties achieving stability in housing and finances, suffering from physical health problems, having a difficult relationship with family and friends, and living in an unfriendly neighbourhood
Willingness to volunteer (meaningful community engagement by offering help to the needy or contributing to peer support services)	- Offering help and support to in-patients, thereby gaining recognition from others as well as enhanced self-esteem - Gaining a sense of belonging and meaningful community engagement by becoming actively involved in volunteer services and self-help group activities - Expressing a sense of contribution and value to society	- Service providers' rigid sense of role and boundaries negatively affect individuals who may wish to also play a helping role - Inadequate professional support for self-help groups
Engagement in treatment (being engaged in the recovery process by moving from being a passive recipient to an active participant in managing one's treatment)	- Moving from being a passive recipient to an active participant along the iterative treatment trajectory - Having a positive therapeutic alliance with service providers - Demonstrating capabilities in medication self-management - Enhanced self-efficacy by participating in psycho-education seminars and health self-management workshops - Experiencing shared power in mutual support groups	- Being disengaged in treatment planning - Being disengaged from the prescribed treatment regimen, resulting in a deterioration in one's level of functioning and mental alertness

Predictors of hospitalisation

Respectively at T2, T3, and T4, 9.1% (32/347), 11.8% (41/347), and 12.7% (44/347) of patients were hospitalised for relapse, and 22, 16, and 20 of them were interviewed. Reasons for hospitalisation included irregular drug compliance/refusal of medication and irregular/defaulted follow-ups. Non-hospitalised patients had significantly better community living skills (Z=-3.057, P=0.002) and personal care skills (Z=-2.498, P=0.012) at T2, skills in activities (Z=-2.538, P=0.011) and personal care skills (Z=-2.538, P=0.011) at T3, and QOL-environment (Z=-2.439, P=0.015) at T4 than hospitalised patients. Increase in non-compliance with medication and the number of unmet needs predicted hospitalisation of 16 participants at T3. Increase in frequency of hospitalisation and poorer physical health predicted hospitalisation of 20 participants at T4.

TABLE 3. Empowering strategies and community resources for mental health that support the recovery process

Recovery process	Empowering strategies	Community resources for mental health
Spark of hope to carry on with life (existential encounters with life-affirming events resulting in cognitive efforts to renew one's will to live)	- Capacity-building activities to enhance resilience and learn hopefulness. - The conscious use of patient-centred and strengths-focused communication by service providers to promote hopefulness and enhance empathetic interactions.	- Opportunities to engage in outdoor activities, enabling contact with refreshing surroundings and nature. - Opportunities to participate in social or religious groups that promote the social inclusion of individuals with mental illness and provide a sense of belonging.
Desire to move from institutional to community living (expression of a wish to reclaim control of one's life by recouping one's strength and ability to care for oneself and live independently)	- Respectful collaboration between individuals, family caregivers, and service providers in discharge planning, which supports and encourages functional as well as existential recovery. - Encouragement, tolerance of risk, and respect for the individual's choice shown by service providers, balanced with duty-of-care obligations. - Development and consolidation of skills for self-efficacy and management, such as behavioural skills in stress reduction, symptom identification, and medication management.	- Integrating in-patient and community psychiatric care to provide continuity of services, supporting individuals in their efforts to live independently. - Availability and access to a half-way house or long-stay home.
Redefining oneself (self-acceptance and self-adaptation through goal-directed thinking in living with the mental illness)	- Development of a positive therapeutic alliance in formulating individualised service plans. - Development of the individual's existing strengths, resources, and skills to promote and facilitate the process of redefinition. - Involving family members in their role as caregivers by providing support and facilitating the development of effective skills in coping and adapting to living with mental illness.	- Access to and availability of social and welfare resources to meet the needs of individuals in the areas of housing and financial security, health care, occupational opportunities, and personal needs. - Access to community resources for promoting mental health and well-being, including the development of meaningful social relationships, engagement in activities for personal growth, and enjoyment and achievement of goals. - Availability of appropriate and varied occupational training and employment opportunities. - Access to social networks that provide support and a sense of community to individuals with SMI throughout their illness trajectory. - Public education for promoting understanding, awareness, and acceptance; removing stigma; and changing negative attitudes about mental illness
Gaining a sense of normalcy in activities of daily living (knowing how to self-manage the resources and options that are available for independent living in the context of a supportive family and a friendly community)	- Building upon the capacity of individuals and caregivers to find everyday solutions to everyday problems through training in social and interpersonal skills, psycho-education, family/personal therapy, stress management, problem-solving skills, and occupational training. - Partnership and communication between different social sectors and services that adopt empowering options in crisis interventions.	
Willingness to volunteer (meaningful community engagement by offering help to the needy or contributing to peer support services)	- Engagement and training of peer specialists and volunteers as part of the mental health care system. - The belief, respect, and commitment of service providers to power sharing and flexible boundaries for the 'helper role'.	- Incorporation of a participatory practice approach to existing community-based mental health wellness services. - Embracing the philosophy of peers as experts in their illness to provide support to others in recovery and promote mutual helping relationships.
Treatment engagement (being engaged in the recovery process by moving from being a passive recipient to an active participant)	- Positive therapeutic alliance, active collaboration and shared decision making between individuals and service providers in designing service or treatment plans about medication, health behaviour for well-being, crisis plans, advance directives, enduring powers of attorney, recovery plans, and risk safety plans (WHO, 2010). - Case management using the model of flexible assertive community treatment including collaboration and communication between multidisciplinary teams, in line with individual needs of service users. - Use of balanced advance directives and community treatment orders that respect individual autonomy and preferences for treatment while carrying out safe and effective interventions in times of relapse.	- Availability of case-managers, providers, and effective services in the community to identify risks and carry out care plans for individuals. - Availability of and access to resources that promote self-efficacy in illness management through psycho-education and community-based programmes to consolidate and support treatment engagement. - Promoting and supporting peer support groups and shared power in partnership with psychiatric and community MH service providers as well as governmental MH policy makers.

The perceived care burden of family caregivers

The three major burdens of care on family caregivers were financial burden, effects on family routine, and effect on family interaction. The family caregivers of patients who were hospitalised for relapse reported a higher level of family burden.

The multi-faceted recovery process

The six iterative components of recovery were: a spark of hope to carry on with life, desire to move from institutional to community living, redefining oneself, gaining a sense of normalcy in activities of daily living, willingness to volunteer, and engagement in treatment (Table 2). Empowering process promoted progress and was a buffer for disempowering experiences, whereas disempowering process hindered progress or triggered a relapse.

Association between recovery process and health outcome

Interplay between empowering and disempowering experiences and patients' health outcome involved (1) community living and positive QOL change, (2) community living and negative QOL change, and (3) hospitalisation within 6 months of discharge. A positive QOL change involved patients' active engagement in treatment, positive alliance with community service providers, receiving occupational training and financial stability, reconciliation with family members, social support, friendly neighbourhood, and maintaining personal hobbies and religious practices. Negative QOL change involved challenges in adjusting life with mental illness, poor physical health, noisy or inconsiderate neighbours, sense of loneliness owing to estrangement from family, low self-esteem, and doubt about their ability to live independently.

Four patterns of events that led to hospitalisation within 6 months of discharge included (1) cognitive difficulty in recognising their illness, but a desire to move to community living resulted in outward behaviour masquerading as readiness to be discharged; (2) being confronted with indignities that hurt their sense of integrity and dignity and triggered harmful thoughts towards oneself or others; (3) disengagement from the prescribed treatment regimen that resulted in deterioration in level of functioning and mental alertness; and (4) the iterative trajectory of chronic mental illness that required self-acceptance and insight for triggers of symptoms and relapse that may require voluntary hospitalisation.

Empowering strategies and mental health resources

Based on the empowering and disempowering experiences of patients in relation to the recovery process, the views of family caregivers and service providers, including psychiatric and non-governmental organisation service providers, were elicited from the interviews (Table 3).

Discussion

Our study results are consistent with those of other longitudinal studies in other countries.[2,3] Non-compliance with medication regimen, deterioration in self-perceived QOL, physical health, and frequency of hospitalisation were predictors of readmission. This is consistent with findings in another study.[4] Personal recovery is a multi-faceted process that comprises six components. This concurs with the findings of other qualitative studies.[5] Empowerment is the key to personal recovery. Results of this study can be used to re-create environments and practices that promote and nurture the recovery process.

Limitations of study

Owing to the higher than expected attrition rate of both patients and family caregivers at T3 and T4, generalisation of results was compromised with the estimated power of 0.65, and attrition bias could not excluded. Further, patients with SMI who received psychiatric treatment and required no hospitalisation, or those with substance abuse were not represented in this cohort sample.

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References

1. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. Psychosoc Rehabil J 1993;16:11-23.
2. Gorna K, Jaracz K, Rybakowski F, Rybakowski J. Determinants of objective and subjective quality of life in first-time-admission schizophrenic patients in Poland: a longitudinal study. Qual Life Res 2008;17:237-47.
3. Sim K, Chua TH, Chan YH, Mahendran R, Chong SA. Psychiatric comorbidity in first episode schizophrenia: a 2 year, longitudinal outcome study. J Psychiatr Res 2006;40:656-63.
4. Cougnard A, Parrot M, Grolleau S, et al. Pattern of health service utilization and predictors of readmission after a first admission for psychosis: a 2-year follow-up study. Acta Psychiatr Scand 2006;113:340-9.
5. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. Br J Psychiatry 2011;199:445-52.