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Interdisciplinary Rehabilitation to Facilitate Recovery of People Living with Long-Term Schizophrenia in Developing Countries

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Abstract

Schizophrenia is characterized by irregular, alternating episodes of exacerbation and remission of psychotic symptoms. The occupational care for people living with long-term schizophrenia (PLWS) after medical treatment, for re-engagement into work, leisure, and daily-living activities, still needs attention. Personalizing follow-up care of PLWS can improve the medical-psychosocial level of patient with differing medical, physical, and psychosocial effects from their treatment exposures. This chapter highlights the call for an individual care approach that is often lacking in resource-limited countries with additional burden from entrenched stigma. Patient categorization for PLWS may be a cost-effective step forward to overcome the less effective, one-size-fits-all approach. The need to address personalized assessment of risk exposure and to remediate its consequences on function, recovery, and quality of life calls for a better interdisciplinary-care approach, and a renewed investment to ensure occupational performance after recovery. Medicine is initial, but personalized rehabilitation is warranted for much improved functioning and better quality of life. Research is also needed to evaluate and document the effectiveness of various models of interdisciplinary care for PLWS that have been developed but may not be tested/evaluated and also on models tested effective but on other long-term nonphysical conditions.

Keywords: schizophrenia, work, leisure, daily-living activities, interdisciplinary, personalized, categorizing care, occupational therapy

1. Background

Schizophrenia is recognized as a severe brain disease, with 1% of any population predicted to develop schizophrenia during their lifetime [1]. The prevalence (i.e., the number of cases in a

population at any one time point) and the incidence (i.e., the number of new cases annually) of schizophrenia is about 1% and about 1.5 per 10,000 people, with onset occurring typically during adolescence, at between 18 and 25 for men and between 25 and 35 for women [2]. The prevalence of schizophrenia in less developed countries was significantly lower than in the developed countries [3], but this difference could be due to underreporting [4]. This condition has been reported as highly unlikely to have a uniform etiology, because of the diversity of the aetiological factors involved, and the characteristically irregular and alternating episodes of exacerbation and remission of psychotic symptoms [5]. Therefore, it is considered the most disabling of all the major mental disorders and interferes with an individual's ability to think, feel and to receive, to understand sensory information, and/or how to behave appropriately.

The debilitating, public health burdens of schizophrenia also seem greater in less developed countries. About 85% of the world's population are in the 153 low- and middle-income countries [6], where 80% of people living with mental disorders reside. Mental illness accounts for 8.8% in low-income and 16.6% in lower-middle-income countries, of the total burden of disease [7, 8]. Living in a world distorted by hallucinations and delusions [9], people living with schizophrenia may feel frightened, anxious and confused, as they experience hearing voices (not heard by others), or believing that other people are reading their minds, controlling their thoughts or even trying to harm them. Their disorganized speech and behavior can be incomprehensible and may even be frightening to others. These encounters also worsen the entrenched stigma against people living with schizophrenia (PLWS), which increases the burden of care. This issue of PLWS experiencing stigma because of their illness is an ongoing battle in both developed and developing countries. They faced discrimination from many aspects of their lives including education, work, relationships and access to health-care services [10]. Studies on determinants of quality of life in schizophrenia found that gender, positive and disorganized symptoms of schizophrenia, and cognitive and physical impairments are the most important predictors of quality of life of a group of people with schizophrenia in Malaysia [11]. This issue calls for a better integrated care and a concerted public health de-stigmatization module to educate and reach more communities. It is therefore critical that medical treatment is provided with interdisciplinary rehabilitation care to address and impact these irregular, alternating episodes of exacerbation and remission and social stigma on their level of functioning in their daily living.

Occupational participation has a critical role in the recovery and functioning of people with schizophrenia. People living with schizophrenia look for treatments that relieve active symptoms and to improve their abilities to function at work, school and in their everyday lives. Research evidence suggests that occupational rehabilitative intervention can increase the likelihood of obtaining a competitive job with a positive impact on work hours, but it is often insufficient to enable optima work participation for people living with schizophrenia, and comprehensive, individualized treatments are necessary to address functional deficits which are a barrier for labor sustainability and their job performance [12]. The occupational rehabilitation for people living with long-term schizophrenia still needs attention and improvement to facilitate better social adjustment and reengagement into work, leisure and daily-living activities. However, the individual care approach is often lacking in resource-limited, developing

countries where society's entrenched stigma on mental illness aggravates and complicates the recovery of PLWS. The need to address personalized assessment of risk exposure (from long-term treatment and psychosocial exposures) and to remediate its consequences on function, recovery and quality of life warrants a renewed investment to ensure performance beyond recovery. Patient categorization for PLWS may be a step forward to overcome the less effective, one-size-fits-all approach. Therefore, this chapter highlights the call for a need to categorize care towards personalizing follow-up rehabilitation care of PLWS to improve their specific medical and psychosocial needs for each individual patient who presents with differing side effects from their long-term treatment and the long-term exposures to their environments.

Medical treatment through the use of antipsychotic medication alone in long-term schizophrenia is often not enough for the characteristically irregular and alternating episodes of exacerbation and remission of illness in schizophrenia [5]. Improving and scaling up mental health services in developing countries requires flexible policies [13], to overcome limited resources, effective inter-professional communication and evidence-based training—both in numbers and in quality university-based training for the severe shortage of health professionals like occupational therapists.

A timely initiative for developing countries with low resources is towards the development of category patient-centered, rehabilitation services—beyond the initial phase of recovery from medical treatment. Categorization of care may be a focused way to address the complex range of needs from the individual's physical health, psychosocial, financial and occupational needs in people living with schizophrenia. It is universally accepted that the standard of care for people with schizophrenia should include the combination of antipsychotic medication and psychosocial interventions [14], but in many countries, this equation is neglected due to low manpower and resources. A more concerted plan to intervene by focusing on the category of needs of people living with schizophrenia may be more cost-effective than a “one-size-fit all” approach. Categorize care for PLWS is, in simpler term, about reappraising and re-addressing, and regrouping care needs to overcome the limitations from a “one-size-fit-all” approach. The principles are based on enabling PLWS to make informed choices, received personalized care, within a philosophy of recovery and well-being [14]. Categorizing these psychosocial-care interventions can be enhanced in context-appropriate ways to offer support to PLWS such as to (1) manage with negative/positive symptom and (2) deal with negative social reactions, including from family members and occupational needs [15]. Three principles of personalized care identified—(1) categorizing care, (2) early interdisciplinary intervention and (3) comprehensiveness of care—are important concepts when the therapists attempt to rehabilitate the client (as the expert patient), in line with the patient self-management approach for chronic disease [16].

2. Categorizing care to target better functioning and quality of life

Categorizing rehabilitation care for PLWS aims to ensure sustained recovery and improve their quality of living. With a target to increase the individual's level of functioning, the rehabilitation goal is to nurture the strengths and specific life skills, and to be able to live as

independently as possible in the community [17]. The intervention targets at building up their strengths and reducing their deficits, and as such, the features of intervention program must be comprehensive, continuous, coordinated and all encompassing, to ensure better quality of living. With this, a need for more precision into the categorization of patient living with schizophrenia is warranted. This approach does require a paradigm shift in the culture of psychiatry interdisciplinary care, whereby health professionals collaborate closely towards implementing evidence-based findings (from epidemiologic knowledge and risk assessment tools) to develop a tailored, individual follow-up, and abandoning a generic approach for all people with schizophrenia. Medical and psychosocial care should eventually move into personalized precision approaches, as are recommended for all other chronic diseases too. Therefore, a care that intersect between evidence-based medicine and value-based medicine may prove to be more supportive of the patient's entitlement to autonomy, reflecting a truly commendable shift from focusing almost exclusively on a patient's clinical condition to considering him/her as a person [18]. It also sets the tone for a tailored, personalized and valued patient-centered care [19] that warrants careful identification of individual disorders, individual risk and functional needs. Studies are needed on what and how to categorize individual needs of PLWS across the spectrum of medical, psychosocial and occupational health status for a rehabilitation pathway to ensure multidimensional/comprehensive therapy where the occupational therapist can focus on value intervention to improve functional abilities and illness recovery [19]. Nevertheless, this chapter hopes to stimulate new discussions so that more studies are needed to evaluate what and how to categorize for personalized and valued care for better quality of life in people living with schizophrenia.

3. Early intervention interdisciplinary approach care

People living with schizophrenia may not present as a life-threatening condition, but early intervention should still be emphasized. Some people have only one such psychotic episode; others have many episodes during a lifetime, but even in the multi-episode group, they can lead relatively normal lives in between. Thus, any delay in medical treatment plays a significant role in the long-term outcome of these patients. The longer the duration of untreated illness, the more difficult it is to treat the patient and results in more permanent disabilities. Many have continuous or recurring pattern of illness and may not fully recover and typically requires long-term rehabilitation. Coping and self-management is needed with the symptoms of schizophrenia as they can be especially difficult for family members [16]. The numerous psychological, social and occupational dysfunctions experienced by people living with schizophrenia warrant greater comprehensive and an early therapy management, to facilitate their social functioning, and ensure a continuum of care from the hospital to their homes and community, or on the job. The occupational therapist, mental health counselors, social workers and working interdisciplinary with the psychiatrists treating these PLWS must be aware of the range of symptoms interfering with functions, so that evidence- and valued-based care can be considered for each individual.

4. Comprehensiveness of care

Comprehensiveness is defined by the institute of medicine in 1996 as “the provision of integrated, accessible health-care services by clinicians for addressing a large majority of personal health-care needs [20], but it is often refers to the bio-psychosocial or whole-person approach, that view patient as body and soul from a social context [21]”. The increase in complexity of care, attending to co-morbidities and the evolution of interdisciplinary models of care calls for all health team to sustain such responsibilities and to provide better interdisciplinary care. In the comprehensive occupational therapy programs for people living with schizophrenia, the interventions planned are along the goal-directed use of time, energy and interest, with a comprehensive focus to foster adaptation, participation and performance by minimizing pathology and promoting the maintenance of health. However, in developing countries, there is a lopsided emphasis for medical personal over health-care professionals, and the low manpower of rehabilitation therapists is a significant issue for most developing countries. In Malaysia, a medical supremacy approach and an entrenched medical governance model for its health-care delivery system perpetuate the lingering issue of manpower shortages and low university-based program for training qualified occupational therapists.

5. Symptoms interfering with functions

People living with a diagnosis of schizophrenia encountered numerous dysfunctions from a serious mental illness with a very broad range of symptoms, which includes (1) “positive symptoms” (abnormal experiences), such as hallucinations (seeing, hearing, feeling something that is not actually there), delusions (false and usually strange beliefs) and paranoia (unrealistic fear); (2) “negative symptoms” (absence of normal behavior), such as emotional withdrawal and lack of motivation and enjoyment; and (3) cognitive dysfunction (problems with concentration, learning abilities and memory) [1, 2]. These symptoms also occurred with a disorganized and abnormal thinking, behavior and language. Often, they can become emotionally unresponsive or withdrawn, with the experience of progressive personality changes leading to a breakdown in their relationships with the outside world. Apart from stigma [15], the lack of insight of PLWS may be key factor contributing to the refusal of medical treatment and also medication non-adherence. At the Permai Hospital (a large mental institution in Malaysia), 54% of the patient with schizophrenia had poor insight [22], and a comparison study between patients with schizophrenia and other mood disorders psychosis found that schizophrenia patients had the worst insights—where the level of impairment of insight was associated with the functionality of patients [23]. Therefore, social isolation or withdrawal, along with the poor insights, unusual speech, thinking or behavior may precede, be seen along with or appear later on in the course of the illness. Some less obvious symptoms such as loss of interest, low energy, absence of warmth and care, and lack of humor are all dysfunctions that do not presently respond well to medications. These symptoms add to the distress for the schizophrenia sufferer and their

families. In less-developed countries, the stigmatization phenomenon (from lack of awareness) aggravates the great distress to themselves and their families. Although the outlook for people living with schizophrenia has improved over the last 25 years, this is true only in developed countries. More research is needed as the current research has gradually led to new and safer medications and unraveling the mysteries behind the causes of the disease, but the occupational rehabilitation needed to enable people to live and function with a better quality of life is still needed.

6. Physical rehabilitation

Among people living with schizophrenia, physical fitness is a fundamental rehabilitation and self-management intervention, as it preserves a sense of physical wellness and mental well-being. The sufficient amounts of moderate daily exercise also form part of a healthier daily routine and facilitate sleep pattern. Research evidence has more often than not highlighted that physical health and mental health are intertwined [24]. As schizophrenics become withdrawn and unsociable, their desire to exercises wanes. Obesity and metabolic syndrome are among the major medical co-morbidities in schizophrenia, with evidences of relationship between weight gain or metabolic syndrome and antipsychotic medications [25–27]. A study on weight changes among first-episode schizophrenia 1 year after the initiation of antipsychotic medications reported that patients treated with olanzapine had the largest mean weight gain (14+ 10 kg) with treatment [28]. Patients treated with the antipsychotics trifluoroperazine, flupenthixol decanoate and clozapine are to be associated with the highest prevalence of metabolic syndrome [29, 30]. In addition, even the normal weight people with schizophrenia have higher visceral fats compared with normal weight healthy control subjects [31], and physical activity such as simple regular walking is important and beneficial to the body composition and quality of life of PLWS [32].

7. Psychosocial rehabilitation

People with schizophrenia become ill during the critical career-forming years of life (18–35 years old), which makes them, less likely, as a group of young adults to be able to complete their certification degrees or vocational training needed for skilled work. Many have difficulty with communication, motivation, self-care and relationships with others. Together with the antipsychotic medicines to treat the symptoms of the illness, counseling and social support from family, friends and health-care services is also a vital part of therapy. Thus, many of them not only faced dysfunction from thinking and emotional difficulties but they have dysfunctions from a lack of social and work skills and experience as well. With social rehabilitation, PLWS can be very much focussed on internal processes that his/her external social world collapses [24], with a loss of self-esteem [33]. Social engagement is a longitudinal predictor of objective and subjective health [34]. In fact, evidence points to the fact that any person who is socially incompetent due to mental illness is unable to function smoothly in society because of feelings of low self-esteem, isolation and anger [35].

8. Cognitive rehabilitation

All domains of cognition are affected in schizophrenia, with verbal and visuospatial memory, attention, executive function and speed of processing most profoundly being affected [36–38]. Verbal memory represents one of the most affected cognitive domains in schizophrenia, and the impairments are the most profound [39]. Of the three symptoms domain, on positive, negative and disorganization symptom, cognition is the strongest predictor of functional outcome [40]. Cognitive deficits are closely linked to activities of daily living (ADL) and have been shown to interfere with daily functioning including activities of daily living [41], employment and quality of life [42–44]. Green et al. [45, 46] pointed out that four specific neurocognitive domains were significantly associated with functional outcomes: executive functioning, immediate verbal memory, secondary verbal memory and vigilance. Dysfunctions in activities of daily living (ADL) have been predictive of future cognitive impairment, independent of current cognitive status or depression [47, 48]. Among all ADLs, bathing impairment may have the highest risk of future institutionalization [49]. With the acknowledgement that some ADL dysfunctions are more predictive of long-term institutionalization, policymakers can plan ahead of the resources to target these declines with occupational therapy and nursing services that has implication for future program spending on long-term-care services. Functional impairment leads to an acceleration of cognitive decline [41, 48]. Therefore, any strategy to increase or maintain cognitive functioning can enable people to remain functionally independent in medical management (which is important for people living with schizophrenia) and ensure independence in their daily living [48].

9. Daily-living performance

Activities of daily living (ADL) are a part of everyday self-care activities that are important for health maintenance and independent living [41, 48, 49]. A major goal of occupational therapy rehabilitation is to enable people to develop independent living skills—for personal daily care of oneself and independent community living. ADL dependence is correlated with increased health-care costs, an increased risk of mortality, poorer quality of life and institutionalization [50–52]. Self-care including oral health has often been neglected—a cohort study on 543 people with schizophrenia found that the mean decayed-missing-filled teeth was at a high 20.5, almost double as that of the general population which was only 11.7 [53]. Wey et al. also found that higher decayed-missing-filled teeth scores were significantly associated with both older age ($p < 0.001$) and longer illness duration ($p \leq 0.048$) [53]. Leisure time is another key area of rehabilitation focus for people living with schizophrenia, who are often limited in their financial capabilities and may find it hard to know what to do with the spare time on their hands. Initial assessment must be made to determine what new skills are needed, and then from there, a program could be developed and individualized for that client [54]. Lalonde [16] reported that the leisure desires and needs of schizophrenics determine the range of activity and how they use time effectively. PLWS should be encouraged to begin/continue participating in meaningful social recreational/community activities because social engagement can help slow down the onset of ADL disability [55]. However, it is also timely for clinicians to

attend to the underlying factors that worsen ADL performance (but can be treated early such as depression, resistance to care and pain), because ADL impairment has significant ramifications for patients and leads to institutionalization and caregiver burnout.

10. Work rehabilitation

Worldwide, psychiatry disorders comprise about one-third of the burden of illness in young adulthood [56], because about 75% of adult mental health problems manifest around early adulthood [57]. Untreated mental health problems and disorders in adolescents and young adults are strong predictors of poor vocational achievements, problematic interpersonal and family functioning. Most schizophrenia rehabilitation programs need a vocational component. Financial stability is a crucial part of the rehabilitation of these young adults—and having some money in one's pocket is a potent source of self-esteem [58]. Work (paid or volunteer tasks) can become monotonous and unchallenging, but for people with schizophrenia, work can provide a social or an occupational environment/routine that is familiar and safe. A study on the quality of life of community-based chronic schizophrenia patients in Penang (Malaysia) found that people with schizophrenia experienced discrimination, social isolation and workplace exploitations [59]. A large study across 26 countries reported that 64% of PLWS (n = 469) who apply for work, training or education were discriminated [59–61]. Employment (and a task-orientated-coping style) has been found to be positively correlated with a better quality of life [62], whereby social relationship was the most impaired aspects of well-being [63] in this group where social functioning is often at risk [10]. Importantly, employment has been showed to be positively correlated with a better quality of life [64]. In short, work as a medium of rehabilitation can build up their work skills and good work habits [54], providing them with a sense of belonging, finance, meaning and purpose in life. Supported employment, a type of psychosocial therapy that offers job training, integrated together with work-related social skills training, has been used to enhance vocational and non-vocational outcomes for people with schizophrenia in mainland China [65]. Supported employment has been reported to be effective in various international settings and has a beneficial impact on competitive employment rates for about 2 years irrespective of economic conditions [66].

11. Interdisciplinary rehabilitation for schizophrenia

In the past, rehabilitation for people living with schizophrenia (PLWS) in developing countries with low resources has focus primarily on a one-size-fits-all approach, with integration of psychosocial interventions to enable these persons to engage in their highest possible level of independent functioning. Schizophrenia has been commonly associated with impairments in social and occupational functioning due to a combination of positive (hallucinations or delusions, disorganized speech) and negative symptoms (such as a flat affect or poverty of speech) and impairments in cognition (e.g., attention, memory and executive functions) [9]. In recent decades, the introduction of better, newer, more

well-tolerated antipsychotic medications has opened up possibilities for more patients to participate in psychiatric rehabilitation programs including overall patient-self-management and supported employment. The rehabilitation goals have shifted towards a better level of symptom control and management, and a greater level of subjective life satisfaction and quality of life. Therefore, an early interdisciplinary approach to plan personalized- and categorized-care intervention is based on categorizing users into smaller clusters according to their needs in line with a need-based approach to recovery [15, 18]. The therapists need to establish the level of concerns for the particular intervention—and decides with the other health-care practitioners and with clients' inter-discipline. Specific occupational therapy intervention is needed and calls for greater research as well as clinical implementation to help define the category of care packages according to the needs of occupational therapy service users and the adapted OT intervention in mental health—a preliminary framework presented in **Table 1** [63, 67]. More work and research are needed

The OT service category	Definition	Level of concerns (low, mid, high)
1. Patient self-efficacy —to engage in basic self-care, work and leisure	Adapting activities to match current abilities and thus support engagement, Focus on personal assets and resources rather than deficits only	[] [] []
2. Behavioral activation (re-motivation process)	Building enjoyment in activity engagement to make spontaneous choices to participate in self-care, leisure and work.	[] [] []
3. Self-management education to activate patients in symptom management	Increase understanding of managing the condition, and monitoring symptoms and managing changing emotions while developing coping skills	[] [] []
4. Lifestyle adjustment	An intervention that is focused on developing/ establishing daily routines, roles and responsibilities in a graded pattern of intervention, leading to a structured daily routine of self-care, productivity (work) and leisure which support the delivery of life roles	[] [] []
5. Lifestyle management	Interventions focus on promoting health and prevention of ill health. Health promotion topics, that is, smoking cessation, healthier eating, mental well-being, increased physical activity addressed as part of enhancing the quality of life.	[] [] []
5. Environmental modification and assistive technology to support engagement in activity	Support with environmental modification and assistive technology and establishing a sense of purpose/direction and satisfaction in functioning in new and unfamiliar physical and social environments	[] [] []
6. Developing social relationships and networks	Building supportive social relationship at home and social engagement at the community	[] [] []
7. Enablement: back to work/meaningful occupation	Sheltered employment and into supportive employment and open employment	[] [] []

PLWS, people living with schizophrenia.

Table 1. Clustering of category of occupational therapy care progressing at a different level for PLWS.

to ensure outcome-based recovery approach. Psychosocial category of care that includes more community-based interventions must include home-based component, psychoeducation and family involvement, and some of cognitive retraining have been recommended as feasible in low-middle-income countries and self-management intervention skills training [15, 68]. In people living with schizophrenia, further category of care such as the supported employment for those who are trained with social skill has been found to be helpful in providing sustainable employment [69, 70]. The goal of interdisciplinary rehabilitation is aiming towards recovery, by facilitating and optimizing people living with long-term schizophrenia experienced by themselves as they become empowered to manage their lives. This is the rehabilitation pathway that allows them to achieve a meaningful life and one that contributes to a positive sense of belonging in the community—one that allows them to live independently, not just to exist. It calls for experts in the area of rehabilitation—in particular, the occupational therapists, psychologist and psychiatrists to collaborate directly with the “client” or the expert patient.

12. Summary

Indeed, medication is an initial must for every individual afflicted with schizophrenia, but it is by no means a cure and warrants customized rehabilitation to improve quality of life. Patient categorization for people living with long-term schizophrenia is a step forward to overcome the less-effective, one-size-fits-all approach. With more occupational therapist and psychiatrists now compared to decades ago, the rehabilitative care for PLWS needs more attention and should be improved. Occupational practice guidelines target at outcome-focused-care and interdisciplinary-care planning. It is a practice guided by the Model of Human Occupation to craft a framework that enables people to move forward—by addressing practical daily issues and gaining the needed confidence as goals are planned and achieved, and benefit from. Occupation-focused practice can transform people living with schizophrenia’s daily experience of their situation, both as a patient in recovery and as a holistic human being, gradually establishing themselves as valued members of the community. Personalizing follow-up of PLWS can improve the medical and psychosocial care for each individual patient (with differing medical, physical and psychosocial exposure). In addition, personalizing care may also help reduce the entrenched stigma of psychiatry illness that still persists in many Asian cultures. There is a need to address specific (treatment, physical, psychosocial) exposures and examine combination therapies in line with developing guidelines for categories of PLWS and to evaluate the sustainability of gains beyond the rehabilitation intervention period.

In conclusion, more research work is still needed to evaluate and document the effectiveness of various models of interdisciplinary care and categorizing care for PLWS which have been developed but may not be tested/evaluated. The model tested to be effective but on other long-term non-physical conditions may also be translated and adapted for testing to ensure cost-effective deliveries. Much work is needed along a common battery of measurements (including tools for risk exposure assessments) for better comparisons across interventions and across sub-categories of PLWS. However, in resource-limited countries, strategies that

call for the social engagement of communities to support in the management of disability towards recovery and working closely with patients (and their activated families) may be ecologically more feasible. Future research should also examine the interdisciplinary partnership and communication, as well as with the community partners.

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