'Family centric rehabilitation' for persons with mental illness in India

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'Family centric rehabilitation' for persons with mental illness in India: Conceptual framework using evidence-based case studies ’

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Abstract:	Purpose of the study In India, people live in a collective society wherein family members are integral to care provision for Person with Mental Illness. Psychiatric rehabilitative models are individual-centric, focusing on individual level skills (emotional, social, self-management and vocational) and development to enhance successful community reintegration. If the entire family is considered a unit for rehabilitation, i.e. family rehabilitation, the possibility of empowering the family to function effectively is higher despite the illness. The objective of the case study is to conceptualize the framework ‘Family centric Rehabilitation from evidence based case studies. Methods Case study design Results Family centric rehabilitation can be conceptualized as ‘a process that facilitates families, dysfunctional due to PMI, to reach their optimal level of independent functioning by harnessing resources available within the community’. Family rehabilitation focuses on enhancing the global functioning of the “family unit”, in essence all members, rather than just the PMI. Strategies deployed include concurrently addressing and minimizing anticipated challenges across domains including medical, psychosocial, vocational as well as economic, thereby aiding in recovery of the family unit as a whole. Conclusions Family centric rehabilitation is a culture specific important concept which aims to provide the optimal level of functioning of all family members and can contribute to the family achieving self-sustenance, a sense of autonomy and empowerment.
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IMPLICATIONS FOR REHABILITATION

1. Family rehabilitation is a new culture specific concept in the field of rehabilitation which aims to help the family achieve self-sustenance, a sense of autonomy and empowerment.
2. Family rehabilitation is conceptualized as 'a process that facilitates families, dysfunctional due to PMI, to reach their optimal level of independent functioning by harnessing resources available within the community'
3. Family rehabilitation encompasses individual rehabilitation goals which help in improving functionality of individuals within the family system.

'Family Centric rehabilitation' for persons with mental illness in India: Conceptual framework using evidence-based case studies'

Abstract

Purpose of the study: In India, people live in a collective society wherein family members are the primary caregivers for the person suffering from mental illness (PMI). Psychiatric rehabilitative models are individual-centric, focusing on individual level skills (emotional, social, self-management and vocational) and development to enhance successful community reintegration. If the entire family is considered to be a unit for rehabilitation, i.e. family centric rehabilitation, the possibility of empowering the family to function effectively is higher despite the illness. The objective of the case study is to conceptualize the framework 'Family centric Rehabilitation'.

Methods: Case study design

Results: Family centric rehabilitation can be conceptualized as 'a process that facilitates families, dysfunctional due to PMI, to reach their optimal level of independent functioning by harnessing resources available within the community'. Family centric rehabilitation focuses on enhancing global functioning of the "family unit", in essence all members, rather than just the PMI. Strategies deployed include concurrently addressing and minimizing anticipated challenges across domains including medical, psychosocial, vocational as well as economic, thereby aiding in recovery of the family unit as a whole.

Conclusions: Family centric rehabilitation is an important culture specific concept that aims to provide optimal level of functioning of all family members and can contribute to the family achieving self-sustenance, a sense of autonomy and empowerment.

Key Words: Family Centric, Family Rehabilitation, Mental Illness, Psychiatric Rehabilitation

'Family centric rehabilitation' for persons with mental illness in India: Conceptual framework using evidence-based case studies'

I. Introduction

In India, unlike in several high-income countries, people live in a collective society, wherein family members are the primary caregivers for most persons with mental illness (PMI). Interdependence and concern for one another are key elements of Indian family system (Chadda and Deb, 2013; Singh, 2010) that play a vital role in the recovery of PMI compared to western countries (Thara, 2004). In the process of caregiving, family members often experience physical, emotional and financial strain contributing to their burden. Several studies among caregivers of persons with mental disability have highlighted the role of various emotional issues such as depression and stress and their quality of life (Adelman et al., 2014; Bastawrous, 2013; Raj et al., 2016; Reine et al., 2003; Stanley et al., 2017). Financial burden contributes significantly to family burden as the time warranted for caregiving often hinders caregivers from taking on full-time employment, that could otherwise have relieved the same (Nair et al., 2018). Rehabilitation of PMI can alleviate family burden only to a limited extent. However, if the entire family is considered as a unit for rehabilitation, i.e. family centric rehabilitation, the possibility of empowering the family to function effectively is higher.

World Health Organisation's(WHO) definition of Psychosocial Rehabilitation states that 'it is a process that facilitates the opportunity for individuals who are impaired, disabled or handicapped by a mental disorder- to reach their optimal level of independent functioning in the community'("Psychosocial rehabilitation: A consensus statement," 1997). Consequently, most psychiatric rehabilitative models are individual-centric, focusing on individual level skills (emotional, social, self-management and vocational) development to enhance successful community reintegration. The psychosocial approaches adopted in psychiatric rehabilitation involve mobilising community resources to create opportunities, manage stigma and enhance

social support for the PMI at all levels of the system (Drake et al., 2012; Falloon et al., 1999; Saunders, 2003). The concept of considering the family as unit for designing rehabilitation interventions has not been studied in a collectivistic society like India. This paper elucidates the above using two case studies, putting forth an innovative concept of "family centric rehabilitation''. The two cases (family with PMI or FMI) presented in this paper were attended to by the Psychiatric Rehabilitation Services (PRS) team, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore, India. PRS is a multidisciplinary team of mental health professionals that include psychiatrists, psychologists, psychiatric social workers, and psychiatric nurses, working to promote reintegration of PMI with mainstream society through services such as day-care, pre- vocational training, inpatient care and out-patient care.

2. Case Illustration:

2.1. Family 1:

A family of four, inclusive of parents and their two sons, from a lower socio-economic status, Muslim religious background, urban Bangalore was referred to PRS, NIMHANS in April 2016. Three of the four family members (mother, a 55year old lady; 1st son aged 30 years and 2nd son aged 27 years) were diagnosed with schizophrenia with suspected mitochondrial disorder. The father, the only healthy member and breadwinner of the family, aged 62 years worked as a seller of scrap items.

A situation analysis of the home environment during a visit identified that the entire family lived in extremely deprived state within a dilapidated one-room home that was uninhabitable. There was no safe drinking water or sanitary facility in the house. The floor of the house was littered and unhygienic, rooms completely covered with dust and windows broken. As the mother was ill and unable to cook food or clean the house, the father brought food from the street or nearby home to feed the family members. The neighbours were not very forthcoming to help the family.

The psychosocial challenges faced by the family were (1) untreated mental illness in multiple family members, (2) lack of permanent and hygienic shelter, (3) unemployment due to mental illness in both sons, (4) extreme poverty, (5) lack of social support, (6) lack of awareness about help-seeking behaviour for mental illness and (7) lack of awareness of government social security benefits for PMI.

2.1.2. Strategies for dealing with Psychosocial problems:

2.1.3. Improving family's health: The case (FMI) was transferred by adult psychiatry to PRS. Initially, the PRS team focused on addressing the complex health care needs of the family. The two sons, initially received in-patient care by the adult psychiatry unit using a combination of pharmacotherapy (aripiprazole 5mg with lorazepam 6 mg) and electroconvulsive therapy given their profound catatonic state whilst the mother received pharmacotherapy (chlorpromazine) via out-patient care. Mitochondrial disorder evaluation was conducted following a neurological consultation, given the history of illness in multiple family members on the maternal side and profound protracted symptoms of catatonia in both sons. Skeletal muscle biopsy and genetic analysis for mitochondrial cytopathy were conducted for diagnostic confirmation and treated with vitamin supplements as mitochondrial cocktail. The final diagnosis - Organic schizophrenia like psychotic disorder (ICD-10) with Mitochondrial cytopathy was made for all three of the family members. The family was psycho-educated about the illness and need for medication adherence to maintain recovery.

2.1.4. Managing poverty of the family: Since the family lived in poverty, with father as the only earning member, they were unable to meet their basic needs for food, clothing and shelter. They did not possess a government subsidy card i.e. Below Poverty Line Card (BPL) to avail free treatment or rations. The PRS team facilitated in waiving-off inpatient treatment charges and coordinated access to free medications for PMI in the family in collaboration with a Non-Governmental Organisation (NGO). The NGO also committed to provide weekly maintenance

to meet food related expenses and to improve the living conditions. Additionally, the team facilitated national identity card (Aadhar), disability assessment and certification for all the three family members. This facilitated the FMI availing disability pension, acquiring concessional bus-pass and Below Poverty Line (BPL) card to avail entitled Government benefits including free rations which was coordinated by PRS. This was done in liaison with various government departments and authorities. The above ensured that the FMI received necessary financial support to relieve associated distress.

2.1.5. Improving competency and optimum level of functioning: Vocational training and supported employment was planned for both the sons to improve their individual capacities to work. The first son was initially encouraged to attend day-care at the (PRS), to structure his day and provide goal-directed engagement for a duration between 12 weeks, helped in improving the day structure and prevocational training skills. Subsequently, supported employment was organized in the hospital horticulture department, wherein he was appointed as trainee for one month and transitioned to salaried employment. To enhance vocational gains, weekly worksite visits were conducted by PRS team to address issues related to compliance, self-care, interpersonal relationship with co-employees, difficulties and concerns. Consolidation of vocational gains occurred via remuneration, demarcating clear job description, ensuring flexibility of duty as well as duty hours and reporting to a single person in the office. Challenges encountered by PRS team included his difficulty in adhering to the work timings occasionally, and domain of decreased motivation. Given gains achieved, the PRS team made consistent attempts to keep him motivated and continue his employment. The above initiative offered the opportunity, motivation and permitted time for the father to get the second son a job in a local furniture shop, thereby translating to three of four members being gainfully employed and overdue respite for the primary caregiver, the father. Improvement in

mother's symptoms and personal hygiene helped her contribute to the household chores especially in maintaining the house and cooking for the family members.

2.1.6. Improving Social Support: The PRS team in the second home visit team interacted with extended family members and neighbours to enhance secondary support systems for the FMI. The paternal aunt and her family stayed in the same locality. Following an interaction with the team, they were encouraged to support the FMI by overseeing medication adherence and ensure the FMI continued scheduled outpatient care. The religious leaders in the nearby mosque were also approached for providing local support, engaging the FMI in religious activities and assisting them in developing social networks with other community members.

2.1.7. Empowering the family to seek help and their rights: The father's caregiving burden was attenuated by providing structured goal directed supportive interventions. This included instilling hope to the caregiver and obtaining an understanding of his role strain and burden. The same allowed for formulating graded and domain specific interventions that included assigning some of the core responsibilities to extended family members. The team also empowered him to approach his paternal family members, to obtain his entitled share of inherited property and house designated for his family. The team ensured continued support for the FMI through regular follow-up and periodic review of the goals for rehabilitation.

2.1.8 Outcomes:

In spite of multiple psychosocial problems faced by the family in the context of mental illness, the 'Family Rehabilitation' approach not only ensured all three family members recovered from mental illness but the FMI jointly lead a dignified life. Instead of preparing an individually tailored rehabilitation plan, a plan prepared considering the whole family as a unit, as in this case, made significant difference to the successful outcome of the rehabilitation of the family. The FMI was able to maintain their mental health recovery through medication adherence and regular follow-up by the PRS team, which in turn helped improve their standard and quality of

life. At home, all family members started sharing the household responsibilities such as cooking, cleaning, buying necessary items. Both sons were employed and were earning an income to support the family. The vocational placement made a significant difference on the life style of the family: their neighbours and relatives developed a respect for them, they were able to procure groceries with their own money providing a sense of autonomy and their community status was not a marginalised one but rather an integrated one. Increased social support from other family members, mosque, neighbours and NGO helped in building a protective environment for the family. Social welfare and security measures such as disability pension, bus concession and food and civil supply card helped in taking care of the family's daily basic and health care needs. Future shelter was secured with paternal family members agreeing to prepare an agreement and hand over the land and house to the family on a collateral. Domain specific and systematic scaling up of supportive interventions permitted the above to occur successfully despite the overwhelming number of family members affected by mental illness.

2.3. Family 2

A family of 3 inclusive of the father, mother and patient, from middle socio status of rural Karnataka was referred to Psychiatric Rehabilitation Services in February 2018. Both parents were elderly (aged above 70 years) having multiple medical conditions with associated complex health care needs. Whilst the mother suffered from ischemic heart disease, left ventricular dysfunction, diabetes mellitus and uterine prolapse, the father had a retroviral positive status, suffered vertigo (cause unknown) and prior pulmonary tuberculosis. Their son, Mr GR, 35 years old gentleman, unmarried, having completed industrial training in electricals had schizophrenia for the past 20 years. He was brought to NIMHANS for exacerbation of positive symptoms and persistent negative symptoms.

The psychosocial challenges faced by the family were (1) Long duration of mental illness, (2) Stigma and lack of help-seeking behaviour, (3) lack of opportunities in the locality (4) unemployment due to mental illness, (5) Caregivers health issues (6) lack of awareness about mental illness and burden and (7) Not availing government social security benefits.

2.3.1. Interventions provided:

2.3.2. Improving family's health: In the family, both the caregivers were aged and having health issues. The team liaised with different departments within the institute and with other medical institutes to improve caregiver health. Mother's health was regularly monitored by the team and appropriate liaison was done within and outside the institute for dietary modification and cardiac evaluation. Liaison with the neurology department and geriatric clinic was done for evaluation of his father's cognitive functions and for managing age-related medical issues. He was on regular antiretroviral therapy treatment. The son, Mr GR was admitted in our tertiary care hospital, NIMHANS for seven months for management of negative symptoms and vocational rehabilitation. A combination of pharmacological (Fluoxetine 40mg with Clozapine 400mg) and psychosocial interventions (activity scheduling, motivating to attend day care centre and training in prevocational skills) was provided during the inpatient care.

2.3.3. Assistance in housing: The family was unable to find suitable employment for their son in their rural area. Further as the parents were aged, they were not working and relying on the pension of the father for their daily needs. In hope of better opportunities the family migrated to urban Bangalore 3 years ago. Over the time their son was being treated, the team admitted the family in the in-patient ward and subsequently, as a transient arrangement, accommodation was provided at low cost in the hospital's dedicated brief stay home established for patients and family members. The rehabilitation team once successful with procuring an employment opportunity for the son, helped the family in the identifying a suitable rented accommodation

near the workplace by enrolling them in online rental portals and checking with personal contacts/ brokers for affordable housing in the area.

2.3.4. Improving the financial status of the family: Given that both parents were aged and not in a position to work and to improve the financial status of the family in the long term, the rehabilitation team during the course of in-patient admission provided pre-vocational training to the son in the day-care centre (computer, printing and photocopying sections) to help improve his work related behaviour skills. Once regular and able to perform basic tasks, whilst he remained an inpatient, he was referred to a vocational skills training centre outside NIMHANS. There he received training in data entry, life skills, social skills, and interview skills over a period of three months. The PRS team along with the training centre helped him secure a job in regular competitive employment and negotiated with his supervisors to provide for reasonable accommodation for him at the workplace (Ministry of Law and Justice, 2016) as well as organising unpaid leave, a single supervisor for supervising the work, flexibility in work timing and easy tasks. He was initially placed in garments section of the supermarket, subsequently shifted to the electronic section and finally to the counter of the supermarket at the entrance based on his work performance and social skills.

The father's pension was the only source of income for the family. The family was not ready to seek any other social support due to stigma attached to the mental illness. The rehabilitation team conducted the disability assessment(Mohan et al., 2005) based on which the son was able to apply for government job vacancies. Further transfer of government pension of the father after the parents demise to the son (Ref. No 1/27/2011-P&PW(E) was initiated to ensure future financial security of Mr. GR.

2.3.5. Improving family dynamics: The family had a minimal understanding of mental illness and had high expressed emotions such as over-involvement and criticality especially towards the son. Family psychoeducation sessions were conducted regularly where the family was

educated about the nature of the illness, course, prognosis and also expressed emotions in the family was addressed. The sessions also helped improve the family dynamics especially decision making in the parental subsystem. Caregivers burden was addressed through management of the expressed emotions and reducing face to face contact with son by him spending most of working hours at the day-care centre and subsequently the vocational training centre.

2.3.6. Helping family plan for 'What after Parents': Considering their old age and multiple health conditions, the parents considered marriage of the son as a solution to their 'What after Parents' dilemma. However they were not willing to divulge the status of son's mental health due to the stigma. Employment was considered as a step towards finding a successful alliance for the son. It was also the reason for the family to migrate to an urban area from their native village. The PRS team discussed with the parents on their, 'What after Parents' dilemma in the context of legalities of marriage, guardianship, making a will/trust and improving social and community support. However the parents were resistant to any of the suggestions provided by the PRS team due to stigma faced in labelling their son as a person with mental illness.

2.3.7. Outcome:

Family rehabilitation helped in improving the health condition of all family members as they started regular health monitoring. Family that had poor help seeking behaviour due to stigma, however, after engaging with the team, improved with respect to the same, the negative expressed emotions improved and they started coming for weekly follow up to tertiary care centre and contacted the team during crisis. The financial burden of the family members was reduced by the client gaining employment and securing his future through the pension transfer process. The family rehabilitation process helped in finding a shelter to stay near to the son's work place. His own work helped in improving the financial condition of the family, caregivers

health was improved optimally by regular monitoring, and family was able to stay together in a family

3. Discussion

The above case studies encapsulate the concept of Family Centric Rehabilitation proposed by us(Figure number 1). It is defined as "a process that facilitates families, dysfunctional due to PMI, to reach their optimal level of independent functioning by harnessing resources available within the community". Family centric rehabilitation focuses on enhancing the global functioning of the "family unit", in essence all members, rather than just the PMI. Strategies deployed include concurrently addressing and minimizing anticipated challenges across domains including medical, psychosocial, vocational as well as economic, thereby aiding in recovery of the family unit as a whole. Through the above figure we depict the model of "family centric rehabilitation". The model includes domain specific processes and interactions with multidimensional impact leading to an overall global positive outcome. This model, derived from the above case studies, demonstrates the various components including symptomatic recovery from both psychiatric illness/ physical illnesses of multiple family members (health and well-being), addressing unemployment (financial), enhancement of family level social support (social), reducing family's burden and expressed emotions (emotional), networking with various stakeholders for facilitation of social welfare benefits and other basic needs for the family (resource mobilization to support health, emotional, social and financial needs). The above mentioned interventions are synergistic and complementary i.e. symptom recovery improves likelihood of family members to be gainfully employed, leading to alleviation of social stigma with consequent formulation/consolidation of social support systems and community reintegration as well as development of emotional wellbeing. Community reintegration and emotional wellbeing in turn secure health gains by enhanced illness awareness/ understanding to prevent relapse and continued employment with consequent

health as well as financial security. The overall result is a significant and sustainable reduction in family burden and greater empowerment for all. Creating awareness and facilitating access to social welfare benefits for family members also help reduce family burden, given it provides enhanced security and autonomy to the family.

Both cases illustrated above belonged to different socio- cultural backgrounds. Studies report that the factors such as social, cultural and religious beliefs of the family play a major role in understanding mental illnesses, help seeking and management. Explanatory models of mental illnesses in different cultures and help seeking behaviour can be interconnected especially in Indian communities (Padmavati et al., 2005). This aspect contributes to the protracted nature of mental illness related disability encountered in the Indian setting, as is evident in the first family presented in this paper, spiralling into financial burden, extreme poverty and deprivation. Studies have shown that there is a positive correlation between mental illness and poverty creating a self-perpetuating cycle (Patel and Kleinman, 2003), wherein an increased risk of mental illness has been noted among people living in the lower socio-economic countries and persons with mental disability are often unproductive leading to poverty. This cycle of mental illness and poverty also acts as one of the factors hindering access to mental health care services (Murali and Oyebode, 2004; Patel et al., 2011; Saunders, 2003).

Facilitating employment was integral to family rehabilitation in both the cases depicted above. Employment and an earning member contributed to improving the social status of the family. Employment in both the above cases, brought about changes for the entire family across various domains such as reduced financial burden, improvement of quality of life, enhanced standard of living, alleviation of stigma in the community and reduced emotional burden with greater family autonomy (Cook and Razzano, 2000). Research has shown that employment is associated with better functioning across a range of skills including cognitive abilities, social

skills apart from symptom recovery, community integration (Mueser et al., 1997; Srinivasan and Tirupati, 2005; Srinivasan and Thara, 1997; Suresh et al., 2012).

Family Centric Rehabilitation involves active periodic after care that is regular, either face to face or through telephone. In this case series, both the families were followed for almost four years; initially for once in two weeks, and later for once in a month by the PRS team to address their needs. The multimorbidity in the family also necessitated the need for long term-follow-up. Liaison with various stakeholders such as NGO's, various Government services, employers and other service providers was essential for successful family rehabilitation. Studies have reported the role of networking to improve various aspects of the families of a person with mental illness(Becker and Drake, 1994; Hubinette et al., 2017). Constant availability and active after care including telephonic availability and liaison with agencies for all family members was the key to successful family rehabilitation in both cases.

The model of "Family Centric Rehabilitation" is different from the concept of family-based interventions; the former emphasizes on rehabilitating the entire family by focusing mainly on multi-domain needs to alleviate family burden. Interventions designed for the family (family based interventions) on the other hand focus on improving family communication, educational sessions to reduce expressed emotions, medication compliance, expressed emotion and dynamics ignoring the psychosocial and financial challenges faced by the family (Addington et al., 2010; Falloon et al., 1999; Sin et al., 2015).

Community Based Rehabilitation (CBR) model has been successful in making a paradigm shift in psychiatric care from hospital to community-settings (Chatterjee et al., 2009) (WHO, 2010). The CBR matrix has five domains including health, education, livelihood, empowerment and social. Studies on efficacy of CBR in India, have assessed outcomes such as medication adherence, level of disability, participation in self-help groups, involving in social activities, family based psycho educational programme and assessing the community

resources (Chatterjee et al., 2009, 2003). However these domains discuss mainly individual centric approaches through collaboration with various resources in the community rather than focusing on the family.

Even in tertiary care centres, the focus is more on immediate or acute care and family interventions are confined to family psychoeducation and managing expressed emotions and immediate psychosocial issues (Addington et al., 2010; Lehman et al., 2003). Recovery oriented services in collectivistic societies can be adapted to include family centric rehabilitation. Mental health care and rehabilitation are state assumed responsibilities, delivered by mental health services for the PMI and the role of family involvement is minimal. No specific benefits are available for delivery to families of PMI (Thirthalli et al., 2020)

In the family centric rehabilitation approach the team has worked with different systems in the micro and macro levels. Facilitation of identity cards ensures right for political participation (right to vote). It is considered to be the gate way for getting welfare benefits, and for opening the bank accounts for persons disability due to mental illness (Sivakumar and James, 2019). The PRS team has been actively collaborating with NGOs, governmental departments and various stakeholders in the system for facilitating welfare benefits, social security schemes, skill training and job placement plays a major role in rehabilitation and recovery of a person disabled due to mental illness(Harish et al., 2020; Roy et al., 2019). The team was also involved in the implementation of reservations in employment of persons with disability due to mental illness.

The major strength of the concept of family centric rehabilitation is its focus on the entire family rather than being individual-centric. It involves interwoven nature of interventions for the process of family upliftment. Whilst family rehabilitation also encompasses individual rehabilitation goals which help in improving functionality of individuals within the family system, the overall goal is to develop a self-sustaining system

that ensures family well-being and autonomy. Limitations of this model include the number of professionals needed to deliver the same in the initial stages, which may not be feasible in a resource-scarce country like India. However, as demonstrated, following the initial intensive phase, the family unit was integral to its own recovery and warranted minimal support. A significant proportion of the interventions delivered under this model included domains that create awareness among families of PMI, community and general health workers and with coordination, "proactive liaison" between various existing services/ministries/departments. This can be delivered at regional and grassroot levels with minimal involvement of expert mental health resources who may primarily play a role in creating awareness among various community members/stakeholders and front line general health and auxiliary workers such as An accredited social health activist (ASHA) or the rehabilitation workers(Village rehabilitation workers and multipurpose rehabilitation workers) to implement the family centric rehabilitation model.

Whilst a comprehensive team is required to formulate and implement family centric rehabilitation processes, the integration and graded autonomy of the family may allow for mobilizing other resource persons in care provision, like general physicians, lay counsellors, social welfare department front line workers.

4. Conclusion

Family centric rehabilitation is a process that facilitates families, dysfunctional due to PMI, to reach their optimal level of independent functioning by harnessing resources available within the community. Family rehabilitation aims to provide the optimal level of functioning of all family members by minimizing challenges thereby aiding global recovery of the family. By concurrently addressing the medical, psychosocial, vocational and economic domains

impacted by mental illness, family rehabilitation contributes to the family achieving self-sustenance, a sense of autonomy and empowerment.

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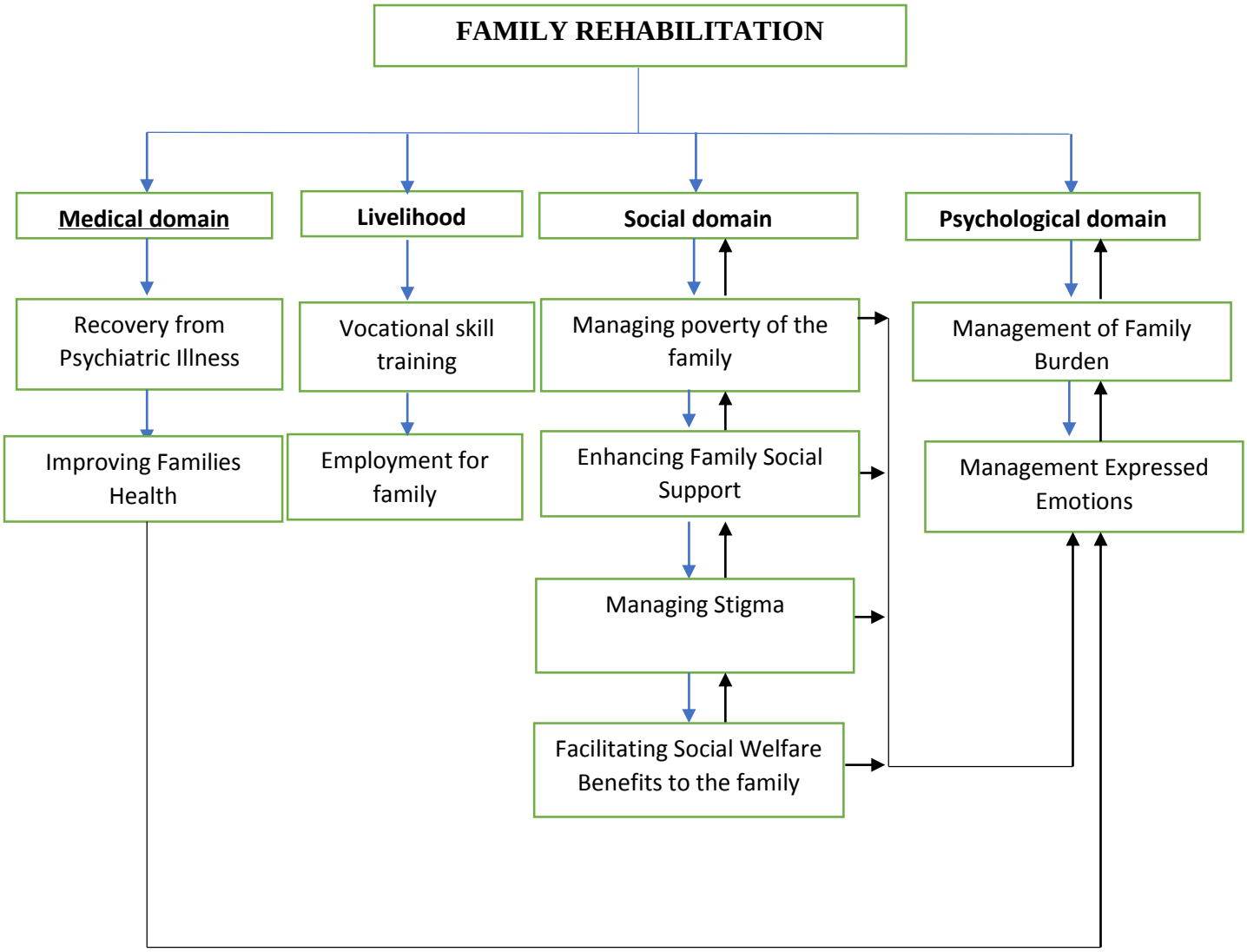
Figure

Figure 1



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