

Family engagement as part of managing patients with mental illness in primary care

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ABSTRACT The family unit plays a crucial role in patients with mental illness. Mental health problems have been associated with an assortment of dysfunctional social and psychological processes in one's family of origin, yet families are now expected to be responsible for the care of the patient with mental illness. There are many short- and long-term benefits of engaging the families in the care of patients with mental illness. However, the implementation of family engagement in patients with mental illness is fraught with challenges. The primary care provider possesses several distinctive characteristics that lend an advantage to successfully engaging the families of patients with mental illness, such as better accessibility, better rapport, and being associated with less stigma. Primary care providers could engage the family in various ways, ranging from basic functions such as psychoeducation and supporting the family's needs, to more specialised interventions such as family assessment and family therapy.

Keywords: carer engagement, family engagement, family interventions, primary care, primary mental healthcare

INTRODUCTION – FAMILY AND MENTAL HEALTH

We are influenced tremendously by our family of origin. From the time we are born, we begin to form early attachments to our primary carers. This need for connection and attachment to others continues throughout our lifespan. Our families shape us – they influence our development, and we model their behaviours and habits. We look to our families for shelter, support and provision of resources. We instinctively expect our families to be available for us in our time of need.

For patients with mental illness, the family unit plays an even more crucial role. Mental health problems have been associated with an assortment of social and psychological processes in one's family of origin. These include parental conflict and affection,⁽¹⁻⁵⁾ emotional detachment from parents,^(6,7) parenting style,^(8,9) time spent with family,⁽¹⁰⁾ family cohesion⁽¹¹⁾ and perceived family support.⁽¹²⁻¹⁵⁾ Low socioeconomic status of the family and exposure to social stress have also been found to be correlated with poorer mental health.⁽¹⁶⁾ With the deinstitutionalisation of mental health services over the past few decades, families are now expected to be the primary carers of patients with mental illness. As a result, families have often felt blamed for mental health problems and laden with the responsibility of providing support.⁽¹⁷⁾

FAMILY AS CARERS FOR PATIENTS WITH MENTAL ILLNESS

Over the last four to five decades, psychiatric care has evolved from the former asylum system of care to that of 'care in the community'. This has resulted in a trend towards engaging patients and their families and carers in the management of their mental illness. Family engagement has been defined as *"the*

process of identifying, enrolling and retaining families in treatment services".⁽¹⁸⁾ The terms 'carer' and 'caregiver' usually refer to the *"substantial, yet 'non-professional' role that individuals in a close relationship have in supporting a person receiving mental health treatment"*.⁽¹⁹⁾ In Singapore, the carer of a patient is usually a family member.^(20,21) It is now widely accepted that it is necessary to acknowledge the personal experiences of patients and their families during the planning and organising of psychiatric care. The World Psychiatric Association (WPA), in its Task Force on Best Practice in Working with Service Users and Carers,⁽²²⁾ has recommended that clinical psychiatric care of any person in acute or rehabilitation situations should be done in collaboration among the user, the family or carer, and the clinicians. The World Health Organization's Mental Health Action Plan (2013–2020) also called for greater collaboration with families in the delivery of mental health services.⁽²³⁾ The Royal College of Psychiatrists (RCPsych) has made it a priority to strengthen the involvement of service users and carers in the planning of services and in research initiatives.⁽²⁴⁾ As a result, the RCPsych regularly involves local carers' groups in their audits of mental health services. Closer to home, the Singapore 3rd Enabling Masterplan 2017–2021⁽²⁵⁾ recognises the importance of family members and carers of people with mental disabilities such as autism by including 'Supporting caregivers' as a key thrust. This included recommendations to improve carers' well-being and enhance their carer capabilities, and to support carers in future care planning.

BENEFITS OF FAMILY ENGAGEMENT IN PATIENTS WITH MENTAL ILLNESS

This movement towards engaging families and carers of people with mental illness has been driven by research, which demonstrated both short- and long-term benefits of this approach. Family

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engagement in patients with mental illness could lead to better patient outcomes, such as fewer relapses,⁽²⁶⁻³¹⁾ longer duration between relapses,⁽³⁰⁾ reduced hospital admissions,^(26,32-34) shorter inpatient stays,^(35,36) and improved compliance to medication and treatment plans.^(32,37) For patients with schizophrenia, family engagement has also been shown to lessen residual psychotic and deficit symptoms,^(28,33) as well as helping with earlier detection of warning signs of relapse.⁽³⁸⁾ For patients with depression, early intervention involving the family when symptoms first emerge may help to reduce the severity of the episodes.⁽³⁹⁾ Family engagement is associated with better self-reported quality of life by patients^(40,41) and reduced general social impairment.^(32,33,42) There is evidence that these benefits endure over time if family engagement is actively maintained.^(29,43-45) Families could also help patients gain access to mental health services during times of crisis.^(46,47) Family engagement does not merely benefit the patients, but extends to the family and carers as well. Studies have shown that family engagement helps to ease family burden and carer stress,^(31,48-50) as well as reducing expressed emotions in family members and carers.⁽³⁴⁾

CHALLENGES OF FAMILY ENGAGEMENT

Despite the well-documented potential benefits of family engagement in the care of patients with mental illness, there have been many reports of difficulties with the implementation of family engagement in routine psychiatric care. A systematic review by Eassom et al indicated that the challenges in implementing family engagement in the treatment of patients with mental illness extended beyond those generally associated with translating research into practice.⁽¹⁹⁾

Patients with mental illness may have reservations towards engaging their families in their treatment for several reasons. Patients may prefer to keep the extent and details of their illness from their family. This preference may be borne out of not wanting to burden the family members,^(51,52) or the fear of making the situation worse.⁽⁵²⁾ These concerns may be valid, especially if the family members are hostile and critical, which could be a source of stress and a trigger for relapse. The patients could also have concerns about privacy and confidentiality.⁽⁵²⁾ Patients could feel exposed and vulnerable when their problems are laid open to their family.⁽⁵³⁾ They may also worry that the service providers may inadvertently reveal sensitive personal information to their family members during the process of family engagement. In addition, some patients may have fears about placing their family members in a position of power,^(52,54) resulting in an imbalanced relationship in which the family members 'know better'. This, again, could be a valid concern if the family members are the source of stress.

Families of patients with mental illness may have their own concerns about being engaged. Family members could have concerns over their own privacy,⁽⁵²⁾ especially in cases where family factors are significant contributors to the patient's mental illness. The family may prefer to keep the extent of their family issues from mental health services, to avoid being criticised or blamed for the patient's problems.⁽⁵⁵⁾ Some families may want to avoid being burdened by carer stress, perceiving that it would

require a lot of time⁽⁵²⁾ and effort on their part should they be intricately involved. This could be exacerbated if the family members have psychosocial or mental health issues of their own. Other possible barriers to successfully engaging the family in treatment are the lack of understanding of mental illness and the family's role in recovery,⁽⁵²⁾ as well as the stigma associated with mental illness.^(54,56) For some families, their unwillingness to engage could be related to prior negative experiences when working with service providers. Poor rapport with service providers, including feeling patronised and not understood, has also been stated as a reason for their lack of motivation for further engagement.⁽⁵⁷⁾

From the perspective of the service providers, barriers to family engagement include fears of burdening the family,⁽¹⁹⁾ increasing professional burden,⁽⁵²⁾ perceived lack of time and resources,^(51,52,56-59) perceived lack of supervision and training,^(51,58,59) and self-doubt about one's capabilities in engaging the family.^(52,57,58) Some service providers have also cited inadequate whole team commitment and collaboration, resulting in lack of continuity and issues of 'ownership' of the patient and family.⁽¹⁹⁾ In some instances, prevailing negative attitudes towards families as the cause of the mental illness were reasons for service providers' hesitancy to involve the family members.^(19,60)

In summary, issues of confidentiality, vulnerability, stigma and poor rapport are commonly faced by patients and families during family engagement. For the service providers, apart from the stigma towards families of patients with mental illness, barriers to family engagement include concerns about the lack of time, resources and training to engage the family.

PRIMARY CARE AND ITS ADVANTAGES IN MENTAL HEALTHCARE

Primary care, or primary healthcare, refers to the provision of universally accessible healthcare to individuals and families in the community, and as close as possible to where people live and work.⁽⁶¹⁻⁶³⁾ Primary care includes disease treatment, disease prevention, health promotion, rehabilitation and palliative care.^(62,63) It encompasses physical, mental, and social health and well-being.^(62,63) In Singapore, the term 'primary care providers' usually refers to general practitioners or family physicians in government polyclinics and private medical clinics, as well as allied healthcare professionals such as nurses, psychologists, counsellors and social workers in the primary care setting. Given the multitude of challenges and concerns reported by patients with mental illness, their families and service providers, the proposal of family engagement as part of managing patients with mental illness in primary care may seem like a tall task. However, the primary care provider and the primary care setting possess several unique characteristics that lend an advantage to successfully engaging patients and their families.

Accessibility

With the increase in lifetime prevalence of mental illness in Singapore,⁽⁶⁴⁾ primary care providers have come to play a significant role in the provision of mental healthcare in the

community. Over the years, Singapore has built up a network of mental healthcare services in the primary care setting in order to improve access to mental health services.⁽⁶⁵⁾ The Mental Health General Practitioner (GP) Partnership Programme (MHGPP) has made it possible for GPs to collaborate with tertiary mental health services in the provision of mental health treatment in the community.^(65,66) Several polyclinics run mental health clinics manned by primary care physicians who receive guidance and training from psychiatrists. Some polyclinics also have psychologists, counsellors or social workers providing psychological support and counselling for patients with mental illness and their families. In addition, these clinics work together with Community Intervention Teams (COMITs) and Family Service Centres (FSCs) embedded in the community to provide holistic services for patients with mental illness and their families.⁽⁶⁵⁾ The accessibility of this network of interdependent mental health services in the community means that service providers could lean on one another for expertise and resources in the provision of holistic psychiatric care to the patient and their families. This ensures that no single primary care provider bears the costs, time and training required for family engagement alone.

This vast network of mental health services in primary care is further boosted by the fact that polyclinics and GP clinics are usually located in the neighbourhoods, which confers greater accessibility and convenience for the patients and their families. This allows the patients and their families to save on transport costs and travel time.⁽⁶⁷⁾ Most GP clinics are open on weekday evenings and weekends, which allows for greater flexibility when arranging for a doctor's visit. The proximity and ease of access to the doctor will encourage patients and their families to maintain regular follow-up visits for the management of the patient's mental illness.⁽⁶⁷⁾ This would create more opportunities for family engagement. Similarly, the FSCs and COMITs, which are located in neighbourhoods around Singapore, allow allied health professionals to work closely with patients and their families.

Better rapport

Primary care physicians are multi-skilled and often manage a patient's care needs from 'cradle to grave'. The primary care physician often acts as a stable point of contact for patients and their families for various acute and chronic medical conditions.^(67,68) It is not uncommon for a primary care physician to look after the healthcare needs of different generations within the same family. The ease of access and increased opportunities for repeated patient-doctor interactions make it more conducive for rapport-building between patient and doctor. With greater trust in and familiarity with the primary care physician, patients with mental illness may be more willing to share their struggles and seek help for their mental health difficulties. A postal survey⁽⁵⁶⁾ conducted among a random sample of GP clinics in Singapore revealed that over 90% of the GPs who were managing patients with mental illness felt that these patients were more comfortable receiving treatment from them than from a psychiatrist because of their confidence in and familiarity

with the GPs. Similarly, family members of patients with mental illness may find asking for help from a primary care physician to be less intimidating than from a psychiatrist. With better rapport among patient, family and doctor, concerns about confidentiality and vulnerability during family engagement may be assuaged. This would make it easier for patients and families to confide in the doctor, increasing the likelihood of successful family engagement.

Less stigma

In the same postal survey,⁽⁵⁶⁾ it was found that the perception of stigma associated with visiting a psychiatrist was one of the leading reasons that patients preferred seeing the GP for issues related to their mental illness. Other reports in the literature⁽⁶⁹⁻⁷³⁾ have also cited stigma as a major factor preventing patients with mental illness from seeking help. Despite efforts to destigmatise mental illness, mental illness is still associated with significant stigma in Singapore.^(74,75) This makes the engagement of patients with mental illness and their families more challenging. The prospect of visiting a mental health service provider, be it a psychiatrist, psychologist, social worker or counsellor in a mental health institution or acute hospital, may deter people with mental illness and their families from seeking appropriate treatment and help. Seeking help for mental health issues from a primary care provider in the community may be a more palatable option, as it is not automatically associated with mental illness. With the issue of stigma attenuated, patients with mental illness and their families would be more likely to confide in the primary care provider. This would significantly increase the likelihood of successful family engagement.

WHAT PRIMARY CARE PROVIDERS COULD DO TO ENGAGE THE FAMILY

Family engagement in mental health services could take several forms, ranging from more basic functions such as providing information, to more specialised interventions such as family therapy.⁽¹⁹⁾ The forms of family engagement that the primary care provider decides to use would depend on the unique characteristics and needs of each patient-family unit, and their motivation and willingness to be engaged.

Psychoeducation

The primary care provider could take on the role of an educator. Family and patient psychoeducation has been shown to significantly reduce relapse and rehospitalisation rates in patients with mental illness, and reduce the burden and stress level of carers.⁽⁷⁶⁻⁷⁸⁾ Providing information to family members about the nature of the mental illness suffered by their loved ones could help the family members better understand the difficulties experienced by their loved ones. Psychoeducation could help dispel myths and misconceptions about mental illness. This could help family members better empathise with the patient and avoid blaming the patient for his or her symptoms. Family members could also learn about recognising relapse warning signs and act accordingly to support the patient. This ranges from providing emotional

support to arranging for an early consultation with the primary care provider or psychiatrist. The primary care provider could also provide guidance to the family on problem-solving skills and crisis management. Psychoeducation could help dissipate some of the stigma surrounding mental illness. As family members become more knowledgeable about mental illness and how they can support their loved ones, they could become stronger pillars of support for the person with mental illness.

Supporting the family's needs

Caregiving is a rewarding but demanding role. Caring for a family member with mental illness can have negative effects on one's physical health.⁽⁷⁹⁻⁸³⁾ For patients with dementia, family members may need to help the patient with physical tasks, such as dressing, washing, feeding and ambulating. In the process of caring for a mentally ill patient, the family members may neglect their own physical health needs, such as the need for sleep, exercise, dietary nutrition, or tending to their own medical conditions. The primary care provider would be well-placed to routinely enquire about these aspects of physical health during his or her interactions with the carers of patients with mental illness, and provide intervention options and medical support upon understanding their needs.

Caring for a loved one with mental illness can be very stressful due to the chronic nature of many mental illnesses.^(84,85) It can be emotionally and mentally draining when one is a carer for a patient with mental illness.^(79,81,83) Family members often experience first-hand the challenging behaviours manifested in certain mental illnesses, such as bizarre actions, lack of self-care, self-harming behaviour or suicidality. Family members may even become the targets of aggression or hostility from persons whom they care deeply about. Some family members have difficulty grappling with the loss of their loved ones to mental illness and may harbour unrealistic expectations of how their loved ones should feel or behave. The burden of care, which refers to the impact of a family member's mental illness on the carers' physical health, emotional health and quality of life, has been increasingly recognised and documented over the years.⁽⁸⁶⁻⁹²⁾ Carer burnout can adversely affect the ability of the carer to care for the patient with mental illness.

Primary care providers could help to alleviate carer burnout by providing practical help. For example, the nurse in the polyclinic could engage the family for certain tasks, such as helping to monitor medication compliance, arranging of medical appointments and reminders to attend scheduled medical appointments. Social workers could engage families proactively through frequent contact to check in on their needs, such as through telephone calls or home visits. This could facilitate early identification and resolution of practical problems. With regard to the psychological aspect, enquiring about the emotional state of family members of patients with mental illness could help to screen for family members who are at risk of emotional burnout. The primary care provider could provide simple mental health first aid to the family members, such as supportive counselling to help ease their stress and improve their problem-solving skills and coping mechanisms. Promotion of self-care and instillation

of hope are also useful engagement strategies to support family members in the care of their loved ones with mental illness. These tasks could be done via the social workers, psychologists or counsellors in primary care. In some cases, family members may also develop mental illness as a result of the significant stress associated with caring for their loved ones with mental illness. If the primary care provider detects this during his or her interaction with the family member, he or she could initiate a referral to the psychiatrist to help with evaluation and treatment.

People with mental illness and their families are known to face significant social problems such as poverty, unemployment, low educational level and social exclusion.⁽⁹³⁻⁹⁷⁾ These factors could act as predisposing, precipitating and perpetuating factors to the mental illness, and also contribute to the carer stress faced by the family members. The primary care provider, by virtue of his or her intimate knowledge of the family set-up and circumstances, as well as better rapport with the patient and family, would be well positioned to assess the patient and family holistically to identify these problems and render assistance accordingly, such as providing financial assistance or linking them to vocational training and employment opportunities.

Addressing the practical, psychological and social needs of families could help reduce carer burnout and enable families to be better carers for the vulnerable patients with mental illness. In addition, studies have shown that patient and family engagement with mental health services improves when providers adequately tackle these hurdles.⁽⁹⁸⁾

Family assessment and therapy

In order to establish the needs of the patient and family, some form of family assessment is required. Assessing the family helps to determine the types of services that are needed for the family system and the need for monitoring and support, so that the appropriate options and recommendations are explored and offered. This would involve evaluating the family's understanding of the mental illness and how specific areas of family life may be affected by the mental illness.⁽⁹⁹⁾ It also involves assessing the family's protective factors, strengths and resources. This is especially helpful in families with complex family dynamics. Family assessment could be done by the social worker in polyclinics or FSCs.

There may also be a role for family therapy in some family systems. Family therapy may be targeted at dysfunctional systemic issues and maladaptive interaction patterns between the family members and the patient,⁽⁹⁹⁾ both of which could be perpetuating factors for the patient's mental illness. Family therapy could possibly be offered by skilled psychologists, counsellors or social workers in the polyclinics, FSCs or COMITs.

LOCAL CHALLENGES AND POSSIBLE SOLUTIONS

Family engagement in primary care is not without its difficulties. Despite the network of mental health services in primary care, some GPs still have reservations about managing patients with mental illness. The postal survey by Vaingankar et al,⁽⁵⁶⁾ conducted

in random GP clinics in Singapore, showed that 65% of GPs expressed a need for more knowledge on managing patients with mental illness, particularly schizophrenia and addiction disorders. The need for longer consultation times (72% of GPs) and perceived lack of support services (60% of GPs) to manage patients with mental illness are other cited difficulties, which may pose a challenge to successful family engagement by the GPs. Specialist-led right-siting of patients with mental illness, such that only patients with milder severity or stable course of mental illness or those in remission are managed in primary care, would help to ensure that primary care providers are not stretched in their capability to provide mental healthcare. Education and training in mental healthcare for GPs, including the Graduate Diploma in Mental Health (GDMH)⁽¹⁰⁰⁾ and continuing medical education activities, could help to increase their capability and confidence in providing mental healthcare in the primary care setting. The Ministry of Health's plan to establish mental health or dementia clinics in 50% of polyclinics by 2021 and the expansion of the MHGPP to involve more GP clinics⁽⁶⁵⁾ would help to enhance the infrastructural resources and capability to treat patients with mental illness and engage their families in primary care.

CONCLUSION

Family engagement is an important aspect of the holistic management of patients with mental illness. Despite its challenges, family engagement for patients with mental illness has demonstrated benefits in several patient outcomes. The primary care provider possesses several distinctive characteristics that offer an advantage to successfully engaging the family, such as accessibility, better rapport and less associated stigma. Primary care providers in the community could engage the family in various ways, such as providing psychoeducation, supporting the family's physical, emotional and social needs, and conducting family assessments or family therapy. The provision of education and training in mental healthcare for primary care providers and the enhancement of infrastructural capabilities to provide mental healthcare in the community are steps in the right direction.

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