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CASE 7

What Do We Do About the Families?

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BACKGROUND

The Centre for Addiction and Mental Health (CAMH) is a hospital and academic health sciences research centre. CAMH provides client-centred care driven by a philosophy that in addition to medical needs, each client's social, physical, emotional, spiritual, and psychological needs should be addressed (CAMH, 2015a). The CAMH vision is "transforming lives" based upon values of courage, respect, and excellence (CAMH, 2015a). CAMH prides itself upon working with its staff, clients, and families to "continuously improve" quality of care (CAMH, 2015a). The main campus of CAMH is located in Toronto, Ontario and there are 19 satellite locations throughout Ontario.

Dhilan Mohan stood in the cafeteria line at CAMH in downtown Toronto. "Oh, I'll take a BLT sandwich," Dhilan responded to the cafeteria employee. His question had snapped him out of a bout of intense thinking. The employee was a former CAMH client. In fact, all of the cafeteria employees and managers were former and current clients. Employing clients is one example of how CAMH works in collaboration with them to provide solutions that are rewarding to the entire CAMH community (Porter, 2013).

As Director of Client and Community Relations at CAMH, Dhilan's portfolio included fielding client and community concerns/suggestions and increasing client and community engagement. His role required him to respond to concerns expressed by patients and family members about the CAMH services. In fulfilling this role, Dhilan often considered 'community engagement' as a criteria for good quality care.

Dhilan brought his BLT sandwich back to his office. His busy schedule meant that he rarely ate in the cafeteria. Dhilan scratched absently at his moustache as he sat at his desk. What was he going to do about the families? There were more and more concerns brought to him about families who wanted to be more involved in the care of their loved ones at the hospital. Many patients were vocal in their agreement with their family members. Does family involvement improve patient care? Does family involvement alter the determinants of health? Could family involvement result in unintended adverse effects? What kinds of supports would families require in order to improve patient health? The Board of Trustees had asked for a set of

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recommendations on what to do about family engagement. Dhilan would need to consider these complex issues in making his recommendations to the Board.

Families frequently play an important role in patient care. They often provide care before and after patients are admitted to hospital. Families are a source of financial, emotional, and social support. The role of families in supporting individuals with mental illness is even more important due to the diminished capacity to accomplish daily activities as a result of disease symptoms. Families often play a crucial role in meeting the needs of patients with mental illness.

Families are knowledgeable about their loved one's needs and preferences, and also have information on the patient's personal and medical history. For clinicians treating these patients, the information can be extremely useful and sometimes significantly alter treatment plans. Examples include history of medications, prior and concurrent diagnoses, allergies, important personal/social history, and details from previous hospital stays. Families also have insight into preferred treatments, indicating what treatments have been more effective in the past, and what treatments should be avoided. Families understand the personal beliefs of their loved ones and how these may influence their choices. These insights are ones that would not only aid the clinical team, but might also lead to a more effective recovery for the patient.

Insights from family members are especially relevant for patients with mental illnesses because the symptoms often prevent the patient from being able to share this information with the clinical care team. Just last month, Dhilan saw a patient with schizophrenia experiencing an acute psychotic episode. The young man was experiencing disorganized thought and speech patterns that are characteristic of the disorder. When he was admitted to the hospital he was not coherent. The young man's recollection and account of his medical history was not consistent with reality. Patients may also experience hallucinations or delusions that make collecting a useful history very difficult.

Dhilan was also faced with a new problem: some of the families involved with the patients at CAMH provided so much support to their loved ones that they were clearly experiencing 'caregiver burden'. Did CAMH have a responsibility to provide support in alleviating this caregiver burden?

CAREGIVER BURDEN

Caregiver burden can be defined as both the tasks and functions associated with caregiving and the way in which the person performing these tasks/functions experiences and appraises the performance of these tasks (Hoenig & Hamilton, 1966). Depending on the particular needs of the patient, the caregiving duties will be different, and these needs often change over time.

Mental illnesses are varied in their scope and symptomatology, and so are the corresponding needs of the individuals who experience them. Some families may not experience the amount of caregiver burden that others do. Some families deal with this responsibility with greater ease depending on the time and resources they can put towards care.

Caregiving can sometimes result in families providing many resources to their loved ones including financial support, housing, transportation, assisting with daily living tasks, etc.

Caregiver burden is not a problem unique to mental health. Approximately 28% or more than eight million Canadians aged 15 or older have provided care for a family member or friend with a serious illness (Turcotte, 2013).

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Dhilar sighed loudly. 'The family problem' was more complicated than it first appeared. CAMH as an organization clearly has a responsibility to aid in the recovery of their patients. As an organization dedicated to health promotion in the community, it has a social responsibility to aid in alleviating any potential caregiver burden that families might have in providing support to patients. CAMH has a responsibility to do even more: it should attempt to prevent the potential factors resulting in caregiver burden if at all possible. But Dhilar's new problem now was how?

Families are valuable resources to patients and often are valuable resources within the clinical care setting. Is it possible that the impact of families on the health of their loved ones could be enhanced through increased knowledge of the problems that their loved ones face? Many families already provide support that increases a patient's resilience and responsiveness to therapy.

Strategies to increase knowledge could include information on access to resources to help families address caregiver burden. These might include information on financial and social supports available for caregivers; strategies on how to deal with specific symptoms their loved ones face; and recovery programs to provide caregivers with respite and support.

Maybe these benefits could be increased through strategies focused on increasing family members' health literacy?

HEALTH LITERACY

Health literacy includes being able to comprehend, access, evaluate, and communicate the information necessary to improve, maintain, and promote health across a lifespan (Public Health Agency of Canada [PHAC], 2014). Researchers have proposed various measures of health literacy including the International Adult Literacy and Skills Survey (IALSS), Test of Functional Health Literacy in Adults (TOFHLA), and the Rapid Estimate of Adult Literacy in Medicine (REALM) as well as other health literacy scales (Collins, Currie, Bakken, Vawdrey, & Stone, 2012). The IALSS contains four domains (prose literacy, document literacy, numeracy, and problem solving), consisting of 15 blocks and a varying number of questions (Rootman & Gordon-Ei-Bihbety, 2008). The TOFHLA contains 17 numeracy items and three prose passages using health and medical related information including pill bottles and appointment slips (Collins et al., 2012). The REALM does not test understanding, but does provide a reading level estimate (Collins et al., 2012). According to PHAC, as many as 60% of adults and 88% of seniors in Canada may not be health literate based on the PHAC definition (PHAC, 2014). The PHAC study surveyed adults and seniors about literacy using the IALSS. Another study revealed that increased IALSS scores were correlated with excellent health. Low health literacy was also related to negative health outcomes (PHAC, 2014).

Are literacy levels and health literacy related? One argument is that health literacy is merely an extension of literacy. Another might be that they are related but separate concepts. Undoubtedly a low literacy level would suggest a low health literacy level because of the decrease in ability to access, evaluate, and comprehend health information that might be useful to one's own health.

MENTAL HEALTH LITERACY

Jorm et al. (1997) introduced the term mental health literacy, and it is related to health literacy in the same manner as the latter is related to the term 'literacy'. Jorm et al. defined the term as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (Jorm et al., 1997). Both health literacy and mental health literacy incorporate the capacity for comprehension, access, evaluation, and communication of health related knowledge and skills. Both share a common model, but mental health literacy is specific to

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knowledge and skills surrounding mental illness/mental health. These skills and knowledge are unique and require different strategies to increase capacity within mental health literacy. Mental health literacy includes seven attributes grouped into three key areas: “recognition, knowledge of factors relating to mental health, and attitudes and beliefs about mental disorders” (O’Connor, Casey, & Clough, 2014). A framework for mental health literacy including all seven attributes is included in Exhibit 1.

Existing mental health literacy tools include a “Vignette Interview” designed by Jorm et al. (Jorm et al., 1997), which provides a vignette of a person experiencing mental health symptoms and difficulties. The person is then asked a series of questions to evaluate their understanding of key attributes. Mental health literacy tools measure beliefs about psychosis, including negative beliefs and stigma. Another goal of measurement is to gauge the ability to identify specific mental illnesses (Canadian Alliance on Mental Illness and Mental Health, 2007). The tools available for evaluating mental health literacy are still evolving and there is no widely accepted standard tool. Often new research on mental health literacy will be assessed using a survey or tool developed specifically for the research being described.

The potential benefits of improving health literacy amongst family members can be illustrated through Dhilan’s experience with a patient named Steve. Steve’s family was supportive, but the family might have benefitted from strategies aimed at increasing knowledge of mental health prevention, management, and recognition.

Steve was a 21 year old who was brought to CAMH by ambulance after he was found unresponsive in his apartment by his parents. After he arrived he was stabilized (for a combination of alcohol and acetaminophen toxicity) and assessed. Steve was having trouble getting good grades in his engineering program. He was also having trouble paying his rent and tuition on time. When asked how all this made him feel he said: “Feel? I dunno man, this is all just...it’s too much... it’s too hard. It’s not supposed to be so hard. I just want it all to stop. I’m going to make it stop”. When asked more questions he just repeated variations of the same sentiments. He fit a diagnosis of depression and the psychiatric resident felt that he posed a danger to himself and should remain in the hospital.

The resident spoke to Steve’s parents to get more of Steve’s history. His parents were very concerned. They had seen their son go from being very optimistic about his future career to being very concerned about his future. He was also always upset by his finances. His parents wanted to help him more financially but Steve wanted to ‘do it on his own’. They had noticed Steve had lost weight in the last few months. He was also very irritable and slept more when he came for visits. When asked if Steve had ever “tried something like this” his parents had very different responses.

His mother said, “Tried what? So what he had a couple of Tylenol and a drink or two and took a nap ... he’s kind of a heavy sleeper so he didn’t wake up when we tried to wake him. I think his father was over-reacting by calling for an ambulance.” When the resident asked if she thought he had any reason to kill himself her response was, “Kill himself? He wouldn’t do that. He’s going through a rough patch right now, but he’s not weak! He would never do something like that!”

His father’s response was more solemn. “I know Steve is having a hard time at school. We tried to help him out with rent – but he thought this was something he needed to do himself. He lets us give him some grocery money but not much more. At Christmastime, I noticed he was drinking a lot ... and when he stayed over on Christmas Eve there was something like what

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happened tonight. I found him lying on the sofa, and there was a glass of vodka next to him and a bottle of Tylenol. I shook him awake and he was fine. He was a little groggy, but I just thought he had a headache or something. He said he just had one drink and must have nodded off. I can't believe I didn't see all this coming. I'm a terrible father. I don't know how I let it get to this. I want to help him, but I don't know what to do."

After four days Steve went home with his parents. On discharge he was given a prescription for an anti-depressant and a follow up appointment in two weeks with the psychiatrist who had been treating him. His parents had been asked to fill in a feedback form at the hospital. On it they indicated several concerns. What could they do to help Steve? What should they do if Steve didn't want their help? Should they try to get Steve to stay with them instead of going back to his full time studies? What is the course of recovery for depression? How could they help prevent another suicide attempt? Since Steve was a student how was he supposed to pay for his medication? Who should they get to answer their questions? Is there a website or something? What did other parents who were involved in this kind of thing do?

Dhilan was asked many questions about how a patient's recovery could be enhanced by increasing family members' understanding of mental health and their loved one's particular needs. The practical nature of how to do this led to many possibilities, but also to many questions: what is the best way to increase the 'mental health literacy' of families?

While it was something that might result in better patient recovery, it also begged the question: should the hospital be doing this? Families are not the direct client of hospitals – the patient is. The hospital is responsible for helping to empower the patient towards their own recovery, but does that include doing so by increasing the capacity of a third party that the hospital has no formal relationship with?

Dhilan thought back to some of the successful strategies for providing patients with support. There were many positive results from peer support programs where patients provided each other with support and helped disseminate information and knowledge amongst their peer group. Dhilan began drafting a proposal for a new peer support program aimed at families and caregivers for patients with mental illnesses. This would simultaneously provide support and aim at increasing mental health literacy in families who chose to participate.

PEER SUPPORT

Peer support is a model based upon supportive relationships between people who have a lived experience in common (Mental Health Commission of Canada [MHCC], 2015). The programs that use this model focus on building support, encouragement, and hope amongst participants (MHCC, 2015). Support of this kind facilitates recovery (McLellan et al., 1998). Participants often share an illness or common event in the past. The experiences that peers have are unique but the pathology or common event is shared (Davison, Pennebaker, & Dickerson, 2000). The model itself is simple enough to be used in various settings, and for various shared backgrounds. The definition of 'peer support' is wide and also inclusive of 'self-help'.

While the peer support model is considered to be evolving, for this case it should be perceived as inclusive of the ideas of social support and social networks working towards positive changes and/or coping with present conditions (MHCC, 2015).

This support has been provided both within and outside of formal healthcare structures; it has also occurred within formalized programs and independently. It includes one-to-one relationships as well as groups of varying sizes. Often the shared experience between peers is

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their common experience of the healthcare system, and may be related to their common experience within a particular healthcare setting (such as within a psychiatric unit) (Hardiman, Theriot, & Hodges, 2005). This can often be the 'consumer experience' (Mead & MacNeil, 2006) they share as consumers of healthcare services. It may also include the 'illness experience' of a shared pathology. One caveat might be that these experiences are often negative and moving forward in recovery and coping with present situations might be difficult while focusing on negative experiences. A contrasting argument might be that common negative experiences also bind individuals together into groups who move forward and draw strength from a shared sense of social justice.

Within the discussion at hand, examples involving health related issues are most relevant. Peer support has been used successfully in providing support to people experiencing mental health concerns, and a large amount of literature has focused on peer support in mental health. Within mental health, peer support has varied in form from grassroots self-help groups to formalized peer support programs with 'peer support workers' who have further training and a shared background of 'lived experience'. Peer support workers are paid employees/consultants who work in varied roles within organizations. Their roles range from providing one-on-one support to participating in community treatment teams performing formal assessments and providing treatment.

While peer support and peer support workers are used widely in mental health they are also used in providing support to people experiencing other health pathologies including diabetes (Balagopal, Kamalamma, Patel, & Misra, 2012), stroke (Goldfinger et al., 2012), and cancer (Hoey, Ieropoli, White, & Jefford, 2008). The current healthcare model would certainly benefit from including the support and resources inherent in sharing lived experiences.

Peer support and peer support workers are methods of supporting people directly experiencing health related pathology, but they are also used in supporting people around them. Family and caregivers often have experiences related to the problems their loved ones face. These experiences sometimes result in stress, hardships, and related health concerns.

CAMH offers a number of peer support and self-help oriented groups/workshops and sessions for family members of patients to seek support and knowledge about their loved one's care. Many of these groups are well attended and appreciated by the family members. But was this sort of support enough? Could more be done to help support family members of patients?

Dhylan bit into his BLT. The sandwich was really good. Dhylan thought about how this sandwich was made by clients and CAMH working together. This collaboration gave Dhylan ideas about how the families should be more involved with the care of their loved ones at CAMH.

Families needed more than just information on their loved one's care, or to be able to share vital information concerning their family member's history with the clinical team. They also needed more than just support to alleviate any 'caregiver burden'. They needed to be involved more with the community of CAMH. Families held the information about what they needed, how they could best serve patients' needs, and how they could have their own needs supported. They needed to actually be part of the decision-making process and to be able to advocate for themselves.

THE EMPOWERMENT COUNCIL

CAMH has an 'Empowerment Council' that aims to act as an advocate for current and ex-patients within CAMH. The Council is an independent organization, which aims to collectively

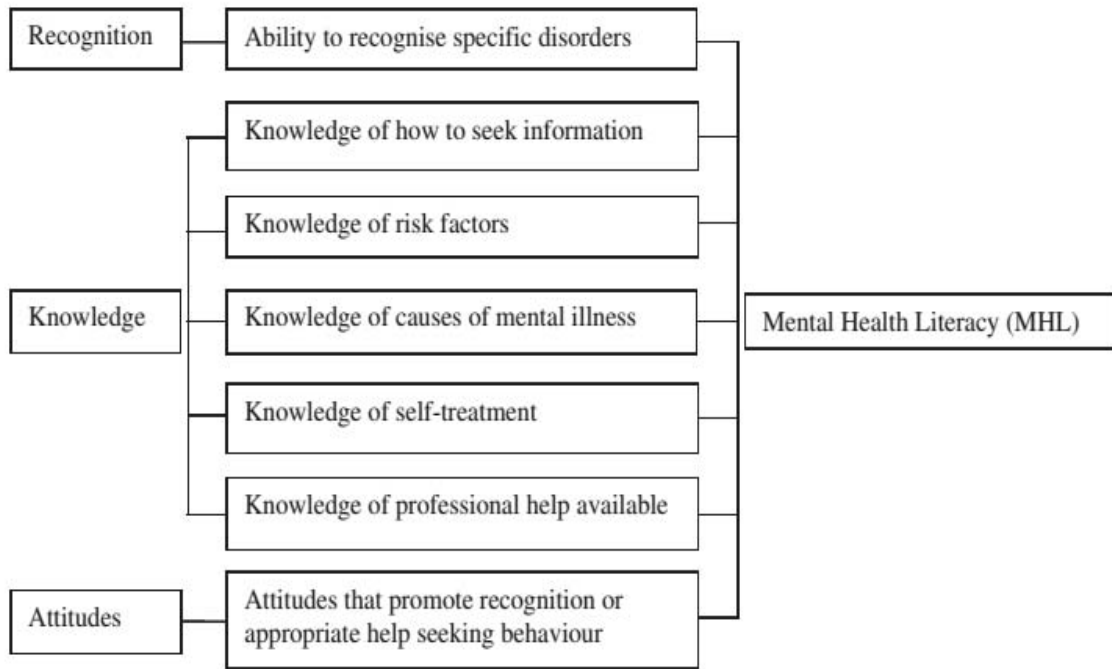
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involve the patient 'voice' via participation in committees, work groups, and other decision-making structures at CAMH and via government (Empowerment Council, 2009). Its Board and membership are comprised of clients and ex-clients of CAMH and other addiction and mental health services (Empowerment Council, 2009). It does not handle individual patient advocacy, which is overseen by a Patient Advocate Officer at CAMH.

The Council also shares information with patients concerning rights, self-advocacy, and empowerment. Similar sharing/training is done with health care providers and staff at CAMH and on a systemic level. The Empowerment Council is also dedicated to outreach and community development with CAMH patients. In collaboration with CAMH there is now a CAMH Bill of Client Rights (see Exhibit 2).

Dhilan wondered if it would be possible to develop an Empowerment Council for families. Families might benefit from having a 'voice' advocate for their needs both at CAMH and in the greater community. Dhilan had many ideas to consider now about how families could be involved more at CAMH. The Empowerment Council was an example of how collaboration with patients worked well. It was clear 'the family problem' was complex. It required CAMH to consider more collaboration with families. It also required that CAMH consider helping families become better advocates for themselves and their loved ones.

EXHIBIT 1
Mental Health Literacy Framework



Source: O'Connor et al., 2014, p. 198 (by permission of Taylor & Francis Ltd.).

EXHIBIT 2 **CAMH Bill of Client Rights**

Right #1: Right to be Treated with Respect

Right #2: Right to Freedom from Harm

Right #3: Right to Dignity and Independence

Right #4: Right to Quality Services that Comply with Standards

Right #5: Right to Effective Communication

Right #6: Right to be Fully Informed

Right #7: Right to Make an Informed Choice, and Give Informed Consent to Treatment

Right #8: The Right to Support

Right #9: Rights in Respect of Research or Teaching

Right #10: Right to Complain

A detailed description of each right can be accessed at:

http://www.camh.ca/en/hospital/visiting_camh/rights_and_policies/Pages/bill_of_client_rights.aspx

Source: CAMH, 2015b.

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INSTRUCTOR GUIDANCE

What Do We Do About the Families?

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BACKGROUND

Families are involved in the support of many people with mental health conditions. Support ranges from financial, housing, help with ADL (activities of daily living) etc. Families can also be useful sources of clinical information/history during inpatient treatment. Families generally want to be more involved in the care of their loved ones while they are in hospital.

Mental health literacy includes knowledge and information on access and evaluation related to mental health pathology/issues. This includes being able to assess and identify mental health pathology and symptoms. Increasing mental health literacy (and health literacy) among family members can lead to improved health outcomes in patients. It can also lead to better health among family members.

Families who support loved ones with mental health conditions can face caregiver burden. This can be related to the amount of physical and emotional resources required to deal with their loved ones. CAMH tries to address issues involving caregiver burden via peer support initiatives and training/workshops.

Peer support is a model that includes building relationships based on shared experiences. The peer support model includes 'self-help' initiatives and peer support groups.

The above issues faced by families should be brought together in a way that facilitates the families advocating for changes that involve them and their loved ones. Families need to be consulted to gather information on how to best address their needs, but their role should also be more participatory in nature.

OBJECTIVES

1. Review and define the terms Health Literacy and Mental Health Literacy and how they apply to individuals and groups seeking to increase their health.
2. Review the Peer Support model and Peer Support workers and discuss their role within healthcare.
3. Review and discuss the role of families of mental health care patients/clients in providing support.

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4. Review and discuss the idea of 'continuity of care' and how families are involved in supporting patients over the long term.
5. Review and discuss caregiver burden.
6. Review and discuss the idea of families and patients being involved in healthcare in a decision-making capacity.

DISCUSSION QUESTIONS

1. How can families contribute to the care of individuals within the healthcare setting and within the community? What problems might this pose?
2. Why is peer support of value? Attempt to research (online) a few examples of peer support. These do not have to be limited to mental health. Can you find examples of peer support workers?
3. Is there any potential conflict that peer support workers might face in healthcare settings? (Consider how their roles might overlap with the responsibilities of other staff in healthcare settings.)
4. How does health literacy and mental health literacy change the health of individuals? How would increasing the health literacy or mental health literacy of families affect the outcome of their loved ones? Discuss examples in your learning teams.
5. Does CAMH have a responsibility to provide support for families to alleviate caregiver burden?

KEYWORDS

Health literacy; mental health literacy; peer support; peer support worker; self-care; caregiver burden; mental health; community engagement.