EXEMPLIFYING LEADERSHIP IN THE PREVENTION OF CAREGIVER BURDEN WITHIN THE MENTAL HEALTH SYSTEM:
How occupational therapists can support caregivers and optimize client care

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The deinstitutionalization of psychiatric services in the late 1960s and 1970s resulted in mental health patients moving out of hospitals and into the community. Regrettably, the funding for community-based services and social programs did not coincide with the reduction of in-patient care. This meant that family and friends were forced to assume the role of primary caregivers (Sealy & Whitehead, 2004). Family and friends of persons with mental illness now provide the bulk of informal care, as well as emotional, financial, and social support. However, they receive little support from mental health services and frequently report caregiver burden, isolation, financial strain, and losses of meaningful occupation (Chaffey & Fossey, 2004).

My review of recent mental health literature reveals that little focus is being placed on caregivers’ needs or on the benefits of collaborating with caregivers to improve client care. Consequently, this paper will examine how occupational therapists are ideally suited to take on a leadership role in supporting caregivers and preventing burden of care. I will also explore how the caregiver role benefits those they care for and contributes to the mental health system. In addition, I will examine the impact of caregiving on carers’ well-being, including its influences on interpersonal relationships, financial security, occupational repertoires, and overall health. These findings will help to unveil the current lack of support, services, and information available for caregivers.

In this paper, I will also discuss the occupational therapists leadership role in providing caregiver support. Topics will cover educating about mental illness, advocating for supports and services, collaborating with caregivers as partners in care, and encouraging occupational balance. In addition, I have provided a set of guiding principles that occupational therapists’ can utilize when working with carers to improve communication and optimize client care. Finally, a theoretical discussion on the importance of occupational engagement highlights how occupational therapists’ expertise in enabling occupation can be affective in improving caregivers’ overall health and well-being.
The Importance of Caregivers

Family members typically assume the caregiver role. However, a caregiver can be defined as any person that “invests time and effort in giving care (Ikiugu, 2007, p. 354)”. Thus, caregivers may be husbands, wives, partners, siblings, parents, children, cousins, or close friends. The incidence of providing informal care for persons with mental illness is approximately 2% of adult Canadians, or 500,000 individuals (Health Canada, 2004). While these numbers may not seem high, limited resources for community care means informal caregivers are increasingly required to shoulder more of the responsibilities of care (Ikiugu, 2007). These responsibilities can be wide spread as chronic mental illness can interfere with functional capacities in self-care, interpersonal relationships, and occupations (Biegel, Sales, & Schulz, 1991). Caregiver responsibilities are vast and can include direct supervision, crisis intervention, emotional support, assistance with system navigation, encouragement and support of treatment, the provision of food and shelter, encouragement of medication adherence, advocating for appropriate help and support, and the timely report of client information and decompensation behaviours to health professionals (Family Mental Health Alliance, 2006; Chaffey & Fossey, 2004).

Caregiver involvement has shown to have powerful influences on the health and well-being of those with psychosocial illness, including decreased risk of illness relapse, decreased rates of hospital admissions, improved treatment adherence and recovery rates, and fewer encounters with the criminal justice system (Riebschleger, et al., 2008; Family Mental Health Alliance, 2006). While the specific components that contribute to improvements in health have not been studied explicitly, it has been suggested that the intimate knowledge that caregivers have of those they care for is an important factor (Chaffey & Fossey, 2004). For instance, caregivers` familiarity of a clients` personality traits and behaviours can act as a baseline for assessments. Caregivers can also be key informants in reporting symptoms and decompensation behaviours, which can help tailor treatment...
plans and improve intervention response time. Health benefits may also be seen when caregivers monitor client’s medication adherence, which can help decrease the risk of illness relapse (Townsend, 2009). Furthermore, caregivers commonly provide financial support because the unemployment rate for individuals with a serious mental illness is between 70% and 90%, (Family Mental Health Alliance, 2006). Financial support helps to ensure the client’s primary needs are met and aid in reducing environmental stresses. Emotional support provided by caregivers is also considered to be important, and is typically the primary context in which the client receives care, affection, guidance, and a sense of stability (Ikiugu, 2007; Chaffey & Fossey, 2004). Finally, caregivers often advocate on the clients behalf to ensure their needs are met through supports and services (Family Mental Health Alliance, 2006).

The benefits of caregivers’ involvement do not stop with the client. The health care system also benefits from their contributions. Fewer hospital admissions, increased recovery rates, and reduced strain on the justice system all work to save the government time and money. Furthermore, the government does not compensate caregivers for their care giving services, which means the health care system saves on homecare and in-patient hospitalization costs (Family Mental Health Alliance, 2006).

The Impact on Caregivers

The mental health literature consistently reports a correlation between caregivers’ emotional status and the client’s well-being and quality of life (Ikiugu, 2007, p. 353; Family Mental Health Alliance, 2006). Unfortunately, caregivers consistently report negative emotional states, including psychological distress and caregiver burden. Care giving for a person with a chronic mental illness has been described as “a 24-hour day job, being ongoing and pervading daily [life]” (Chaffey & Fossey, 2004, p. 204). To further investigate this impact, caregiver burden has been categorized into
two categories: objective burdens and subjective burdens. Objective burden refers to the tangible consequences of caring for someone, such as interactions with the health care system, illness symptoms, and economic costs. Subjective burden, on the other hand, refers to perceived emotional costs associated with caring for someone, such as feelings of powerlessness and loss (Chaffey & Fossey, 2004).

An underlying theme of time stress was found throughout the research on objective burden. Caregivers reported large amounts of time spent learning about the illness, arranging appointments, advocating for supports and services, and helping the client with instrumental activities of daily living (Dore & Romans, 2001). Chaffey & Fossey (2004) found that mothers caring for sons with schizophrenia would rearrange their own lives to meet the needs of their sons. This involved monitoring their son’s behaviours, protecting them from negative public encounters, encouraging the maintenance of routines, providing transportation, and completing daily errands such as shopping, banking, and picking up prescriptions. Not surprisingly, caregivers’ describe difficulties in balancing personal and family needs. Social and leisure activities are limited, and quality time with family and friends is minimal (Chaffey & Fossey, 2004). As one woman caring for a husband with bipolar affective disorder explains, “We’ve lost several friendships as we’ve had no time to nourish them” (Dore & Romans, 2001, p. 154).

Financial strain is another common objective burden for caregivers because disproportionate amounts of family resources are often devoted to professional services, transportation costs, and medication costs. According to a report produced by the Family Mental Health Alliance in 2006, 58% of informal caregivers in Canada pay out of pocket expenses for care and services. Time off work can further exacerbate financial difficulties, as highlighted in a study by Dore and Romans (2001), where 76% of caregivers of persons with bipolar affective disorder were found to have taken time off work or reduced work hours in order to provide care.
Caregivers also experience subjective burdens when caring for a person with a mental illness. Common feelings include grief and sadness over personality changes and illness related symptoms and frustration over a lack of support. Feelings of anger, guilt, anxiety, and self blame, are also commonly reported (Chaffey, 2004; Dore & Romans, 2001). Of those caring for a person with bipolar affective disorder, 44% report having experienced violence and/or fearing the occurrence of violence (Dore, 2001).

Overall stress is high for caregivers, with reports ranging anywhere from 34% to 71% (Health Canada, 2004; Dore & Romans, 2001) The mental health literature shows that these burdens have detrimental affects on caregivers’ health and well-being, including increased risk of emotional distress and anxiety related disorders. As one caregiver explains, “It isn’t just that you’re dealing with someone who’s ill. The nature of this illness means that you’re constantly traumatized. We suffer from all the symptoms of Post-Traumatic Stress Disorder (Family Mental Health Alliance, 2006, p. 3)”. This emotional distress is compounded by social attitudes and stigmatization. Caregivers describe social contact as embarrassing or difficult, and report a lack of support from friends and family (Chaffey & Fossey, 2004). Furthermore, research suggests that caregivers may resist seeking help for themselves or their loved one because of the stigma attached to mental illness (Riebschleger, et al., 2008).

It is important to note that care giving can also be beneficial. Rewarding factors associated with caring for a person with mental illness include learning how to endure hardships, developing a greater tolerance of others’ differences, discovering personal strengths, and becoming knowledgeable about the illness and the mental health system (Chaffey & Fossey, 2004). Moreover, some caregivers feel that they had a closer relationship with their loved one as a result of the illness (Dore & Romans, 2001).
Lack of Support for Caregivers

The mental health literature suggests that caregivers provide the bulk of care with little support from the health care system. For occupational therapists to take on a leadership role in providing support, we must understand where the current system falls short. Four themes emerge from the literature: gaps in communication, limited availability of psychoeducation, a shortage of supports and services, and a lack of appreciation for caregivers as partners in care.

Caregivers described a number of communication concerns. First, there were reports of communication gaps between various service providers. This resulted in caregivers trying to supply multiple health professionals with information in an attempt to keep everyone abreast of changes (Jones, et al., 2009). There were also communication gaps between caregivers and service providers. These gaps appear to stem in part from ambiguous confidentiality policies that exclude caregivers from assessment and treatment processes. Consequently, important client information and illness symptoms are not taken into account during treatment planning. The lack of clarity around confidentiality also hinders communication in regards to discharge planning, medication options, and legal issues (McAuliffe, et al., 2009).

In addition to confidentiality road blocks, caregivers report a lack of psychoeducation. Psychoeducation should cover topics on mental illness, treatment options, recovery skills, legal issues, available services, and information on how to navigate the system. Without this knowledge, caregivers are left feeling frustrated, confused, and ill-equipped to handle the challenges of caregiving (McAuliffe, et al., 2009). During a fieldwork placement at a medical rehabilitation unit at a local hospital, I became aware of the frustration and confusion that caregivers experience. I worked with an older man who was being discharged from the hospital to return home with his wife. In the days leading up to discharge his wife became nervous and expressed concerns about caring for her husband at home. When I asked her why she was feeling nervous, she informed me that she had
received little information about his medical condition, was not aware of available supports, and did not know who to contact in case of a problem. While my experience did not take place in a mental health setting, this woman’s stress and anxiety stemming from a lack of information bares striking resemblance to that of caregivers discussed in this paper.

The mental health literature reported insufficient services for both caregivers and clients. For caregivers, peer support groups and respite services are lacking. Thus, caregivers are not benefiting from the therapeutic sharing and learning associated with peer support groups and may not be afforded much needed breaks from care giving. As one caregiver explains, “There are two sides to the role of the family – we can be so much help in our relative’s recovery, but we need help ourselves (Family Mental Health Alliance, 2006, p. 8)”. As for the client, services tend to focus on crisis intervention and not preventative care. This is problematic because clients will often relapse before they receive help from the system (Jones, et al., 2009). Clearly, early treatment intervention to counter illness symptoms and decomposition behaviours would be favourable over illness relapse.

Finally, caregivers are often excluded from the rehabilitation process. Caregivers report that service providers often discount their opinions, leave them out of the decision making process, or behave as if they are to blame for the illness (Family Mental Health Alliance, 2006). This is concerning because caregivers’ often have a wealth of experiential knowledge about the client that can be used to tailor treatment plans.

**Occupational Therapy’s Leadership Role in Supporting Caregivers**

Research supports the involvement of caregivers with mental health services. It also encourages open communication with health professionals, and acknowledges that caregiver burden can be reduced through psychoeducation and support services (McAuliffe, et al., 2009; Lakeman, 2008). Thus, it is important that changes are made within the mental health system that will encourage partnership in care. The Canadian Model of Client-Centered Enablement (CMCE) will be
used to highlight how occupational therapists are ideally suited to take on a leadership role in supporting caregivers and creating change within the mental health system.

**Psychoeducation: using CMCE educate, advocate, and design/build skills**

Currently there is a lack of psychoeducation from mental health services. Psychoeducation can improve client care and caregiver coping skills (Chaffney & Fossey, 2004). Therefore, occupational therapist should take on a leadership role in ensuring caregivers receive information and education on caring for a person with mental illness. Educational sessions could cover mental illness, understanding symptoms, treatment options, the recovery process, availability of services, and how to best advocate for support. Occupational therapists can also design handouts containing information about mental illness and available supports. Providing information in written format can be helpful because caregivers may have difficulty processing large amounts of information in times of stress (McAuliffe, et al., 2009). One way to provide this information could be through a caregiver binder. I have developed a caregiver binder that contains important information about mental illness, treatment options, supports/services, and hospital contact information. For an outline of my caregiver binder please see appendix A.

**Services & Supports: using CMCE advocacy and design/build skills**

It was apparent from my review of the mental health literature that there were insufficient supports for caregivers and limited services for consumers. Occupational therapists can play a leadership role in advocating for increased funding and improved access to preventative care. Advocating for preventative care will help to decrease the risk of illness relapse and ensure caregivers are receiving continuous, coherent support. Organizations to contact include The Ministry of Health and Long-Term Care, the Local Health Integration Networks (LHINs), and the Addiction and Mental Health Service Providers. On a meso level, occupational therapists can advocate for services
within their community mental health organizations, and help develop day programs and peer support groups. Developing peer support groups that are community-based can help provide an important bridge between the caregiver and the outside world (McAuliffe, et al., 2009).

**Caregivers as Partners in Care: Using CMCE consult, collaborate, and educate skills**

Despite research indicating that caregivers have important knowledge that could be used to improve client care, mental health professionals were found to rarely include caregivers' as partners in care (Chaffey & Fossey, 2004). Occupational therapists could work to educate service providers about the importance and benefits of working with caregivers. This can be achieved by modeling client-centered, collaborative care. For example, occupational therapists should encourage the sharing of ideas and show caregivers mutual respect and genuine interest. When consent has been provided by the client, caregivers should be included in diagnostic and treatment processes, and should be consulted about discharge plans and symptom monitoring. Furthermore, occupational therapists can encourage open lines of discussion and the sharing of ideas by organizing family meetings with the mental health team. For a list of practice standards that can be implemented to improve caregiver participation see appendix B.

**Reduce Stigma: using CMCE coach and engage skills**

Societal stigma associated mental illness is common and can work to alienate clients and caregivers from much needed supports and services (McAuliffe, et al., 2009). Consequently, occupational therapists can play a leadership role in helping caregivers cope with the stigma associated with mental illness. This role can be accomplished through two avenues: coaching caregivers to speak out against stigmatization and helping them to cope with social marginalization by accessing peer support groups. Helping caregivers speak out against discrimination may be an important first step in reducing stigmatization. As one caregiver describes, “We have to start coming
out of the closet. I think we’ll have a much stronger position when everybody can finally relate to the reality of mental illness (O’Grady, 2004, p. 205)”. Caregivers could be coached to help educate the public about the prevalence of mental illness, raise awareness about the need for services, and disentangle mental illness myths from reality. In addition, forming a collective identity through peer support groups has been shown to empower caregivers and give a renewed sense of self (O’Grady, 2004). Therefore, encouraging caregivers to access peer support groups may help to mitigate the ill effects of discrimination and social marginalization.

**Overcoming communication barriers: Using CMCE adapt, advocate, and coordinate skills**

Communication barriers between health professionals and caregivers can result in poor and fragmented mental health care. Confidentiality restrictions have been cited as a main cause for these communication barriers (McAuliffe, et al., 2009). Many mental health services exclude caregivers from client care and disregard their opinions. However, clients often want their caregivers to be involved in the rehabilitation process and benefit from their taking part (Chaffey & Fossey, 2004). It is therefore in the best interest of the mental health system to review and modify current confidentiality policies so that open communication with caregivers is possible. For example, modified policies could allow clients to consent to caregiver disclosures. Occupational therapists can play a leadership role in this process by encouraging mental health services to review confidentiality policies. A review of policies will likely require consultation with team members, organization decision makers, and the College of Occupational Therapist of Ontario (COTO).

Occupational therapists can also play a leadership role in improving communication between service providers. This may involve coordinating with management to improve file transfer or documentation procedures. Finally, organizing family meetings can be a useful way of encouraging communication between caregivers and the team.
How understanding occupation can help to prevent caregiver burden

Caregivers experience a number of occupational changes as a result of care giving. These changes tend to include ceasing personal occupations to have more time for care, rearranging schedules to meet the clients’ needs, and taking on new occupations related to care, such as illness education or facilitation of the clients’ involvement in services or activities (Chaffey & Fossey, 2004). There are two problems that can arise as a result of these occupational changes. First, caregivers can become over-involved in the clients care, which has been shown to cause psychological distress in clients (Ikiugu, 2007). Second, caregivers can experience a loss of meaningful occupations, which can result in occupational imbalance.

Occupational balance is when an individual has an optimal mix of various occupations that allows for work, rest, and play (Townsend & Polatajko, 2007). Caregivers are at risk of loosing occupational balance as a result of the large number of responsibilities and tasks involved in providing care. Caregivers frequently report having little time to relax, participate in social or leisure activities, visit family or friends, or take care of personal responsibilities and errands (Chaffey & Fossey, 2004). When caregivers experience occupational imbalance, they are at increased risk for depressed mood, burnout, poor physical health, and medical problems (Townsend & Polatajko, 2007).

Occupational science and occupational therapy have consistently shown that participating in meaningful occupations improves coping skills (Chaffey & Fossey, 2004). Thus, occupational therapists could educate caregivers on the importance of occupation and coach them on ways to take care of their own occupational needs. This will involve working with caregivers to develop a plan that balances care giving responsibilities with occupational goals. Collaborating with the caregiver to identify how care giving is affecting their occupational functioning can be beneficial when developing occupational goals (Ikiugu, 2007). The Occupational Performance History Interview – Version 2
(OPHI-II) is an ideal assessment tool to help facilitate this information gathering. It will provide information about the caregivers’ occupational roles, daily routines, and life events that influence occupations (Chaffey & Fossey, 2004). In addition, it can be used as an outcome measure to determine if your therapeutic interventions have been successful at improving occupational balance within a caregivers’ life. For more information on helping caregivers achieve occupational balance see appendix C.

When working with caregivers to enable occupation, it is important to remember that the caregivers’ occupational issues are interconnected with those of the client. Therefore, it may be beneficial to help the client establish his/her own set of regularly performed activities (Chaffey & Fossey, 2004). This will help to ensure that the caregiver has time away from care giving duties so that they can undertake their own occupations. Other means of enabling occupation include advocating for increased support services, directing caregivers to available supports such as respite care, and encouraging participation with community support groups (Townsend & Polatajko, 2007). Finally, occupational therapists can educate caregivers on the importance of asking for help when they become overwhelmed.

**A final note to the reader**

Occupational therapists are experts in enabling occupation. We are ideally suited to working with caregivers to help them find occupational balance and prevent caregiver burden. I hope that this paper has helped you to see how occupations are inexplicably tied to the client and caregivers’ health and well-being. Furthermore, I hope that you have gained an appreciation for the lack of support and services currently available for caregivers of persons with mental illness. Occupational therapists can play an important leadership role in improving caregiver support by advocating for
improved services, providing psychoeducation, encouraging open discussions between caregivers and health professionals, and most importantly, including caregivers as partners in care.
References


Appendix A

Caregiver Binder

What is a caregiver binder?

A caregiver binder is an information package provided to caregivers after a client has been admitted to the hospital for a mental health issue. It contains important information about mental illness, treatment options, supports/services, and hospital contact information.

Why is it important?

A caregiver binder is an effective way to provide information to caregivers who receive large amounts of information from many different sources. Remembering all this information can be difficult, especially when dealing with coinciding health issues and life transitions. Uncertainty surrounding the navigation of the mental health system and a lack of information can create anxiety and stress for clients and their families (Jones & Lester, 1994). Effective communication and the transfer of information, has been associated with a reduction in caregiver anxiety and burden (McAuliffe, et al. 2009).

What are the benefits of a caregiver binder?

- Means of transferring information to caregivers
- Information is kept in one easy to find location
- Can be used by the caregiver as a reference guide for support and recommendations
- Can help to reduce stress and anxiety about caregiving
What is included a caregiver binder?

What is included in the binder will vary depending on the client’s mental health issue, required services, and treatment plan. Potential Information that may be included in the binder includes:

- Hospital and therapist contact information
- Treatment information/plan
- Follow-up appointment information
- Referral/service information (such as CCAC services and contact information)
- Supports or services (respite/day programs, community programs, community support groups, etc)
- Therapist recommendations
- Nursing information
- Plastic sleeve for pamphlets or business cards

References


Appendix B

Practice Standards Relating to Caregiver Participation

The following practice standards have been modified from those introduced in an adult mental health service.

Caregivers right in sharing information:

- To aid in assessment, and understanding of the caregivers relationship to the client
- To receive information about the diagnosis
- To receive information about strategies to help the client and improve care
- To participate in the development of treatment plans

Underlying principles:

- Caregiver and client participation depends on open communication and processes
- Caregivers and clients have the rights to supports and services
- Clients and caregivers have the right for information not to be shared
- Caregivers should be involved in discharge planning whenever possible

Quality assurance standards:

- Caregiver involvement should occur early on after client admission
- Regular feedback and reviews should be provided

Please note that client consent must be obtained before confidential information can be disclosed to caregivers. If you are unclear on confidentiality policies speak to your organizations management
and/or contact the Canadian Occupational Therapists of Ontario (COTO) prior to implementing the above principles. COTO can be contacted at 416-214-1177 or via email at info@coto.org

References

Appendix C

Helping Caregivers Achieve Occupational Balance

Occupational balance between caregiving, rest, work, and personally meaningful activities is important for caregivers' health and well-being. Finding occupational balance can be challenging for caregivers because they have many responsibilities and often little support (Chaffey & Fossey, 2004). Occupational therapists have an important role in helping caregivers achieve occupational balance.

As discussed in this paper, the Occupational Performance History Interview – Version 2 (OPHI-II) is an ideal assessment tool to help gather information about a caregivers’ occupational roles, daily routines, and life events that influence their occupations (Chaffey & Fossey, 2004). If you suspect a caregiver is experiencing occupational imbalance based on this assessment, it may be beneficial to have them fill out a time diary. A time diary is a record of each activity an individual engages in and the context in which it was carried out (Harvey & Pentland, 2004). Having caregivers keep a running tab of all their activities over the course of a few days can help them to develop insight into their own level of occupational balance. In addition, it can provide you with valuable information about the caregivers’ occupational roles, daily routines, and life events. This information can be used to develop an intervention plan that will help the caregiver achieve occupational balance.

Analysing your own occupational repertoires is a beneficial way to improve your ability to identify occupational imbalance in your clients. Attached is a prototype of a time diary taken from Harvey & Pentland (2004). Fill out the time diary over a 2-3 day period. Then, analyse your time diary, looking for a balance of activities that allow for rest, work, and play.
**Time Diary**

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