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Caregiver Burden in Diabetes Care and Psychosocial Interventions: A Review

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Abstract

Diabetes is a chronic disease that effects both the individual and their family members. Management of diabetes is a continuous and lifelong concern and one's family is an informal source of support throughout the process. The present paper is an attempt to understand the varied challenges that diabetes caregivers face daily, summarised few effective psychological interventions and attempted to propose some suggestions to manage or ease their burden. Google Scholar, PubMed, and other search engines were used for the literature review. The paper reviewed various intervention studies or programs that have been administered so far in helping caregivers of people with diabetes. The paper also sheds light on how the novel coronavirus—COVID-19 brought about a humongous challenge to both the formal (health care units) as well as the informal (family) diabetes caregivers. The paper focuses on the many difficulties and burdens faced by diabetes caregivers that were presented with various containment measures by governments all over the world—total lockdown of public places, social distancing, home isolations, etc., and with little to no knowledge about the new caregiving pattern.

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INTRODUCTION

Diabetes is one of the significant non-communicable diseases (NCDs) responsible for mortality and morbidity rates in developed and developing countries. It involves inappropriately elevated blood glucose levels (Sapra & Bhandari, 2024). Diabetes, according to the World Health Organization (WHO, n.d.), "is a chronic, metabolic disease characterized by elevated levels of blood glucose (or blood sugar), which leads, over some time to serious damage to the heart, blood vessels, eyes, kidneys and nerves." It is frequently referred to as a silent epidemic that claimed 6.7 million lives in the year 2021 (IDF, 2021; WHO, 2020). As per the International Diabetes Federation (IDF, 2021) report, three diabetes cases are detected in every four person especially in low and middle-income countries, including India. In fact, India is regarded as the diabetes capital of the world with 17% of the total diabetes record worldwide (Times of India, 2022; Mishra, Gaikwad & Bapat, 2021).

Diabetes effects people of all ages and restricts their daily activities. Though some individuals lead almost everyday life without much dependency, the role of caregiver is conspicuous, especially for the younger and the elderly, who are generally dependent, owing to their age. Type 1 and 2 are the two most common types of diabetes, where Type 1 is insulin-dependent and Type 2, non-insulin-dependent. Type 1 was earlier called “juvenile-onset diabetes” while Type 2, “adult-onset diabetes”; however today, both occur across age-group with no such age demarcation (Gatta & Taylor, 2024). The only difference could be in terms of the kind of care required as per their age specific requirements and dependency. However, considering its chronicity and complications, the role of caregiving is a life-long commitment, which makes it even more burdensome. Above and beyond, all the caregivers are informal, family members who take on the role out of their familial relations without any formal or proper training. This is the fundamental cause of the caregiver burden which makes the process highly tasking. The scope of this paper is to explore various forms of caregiving in some common types of diabetes, summarised few effective psychological interventions and finally suggests some steps to manage or ease the caregiver burden. It also investigates how COVID-19 effected caregiver experiences.

Caregiver burden refers to composite stress (economic, psychological & physical) ‘perceived’ by people providing care to others with illness/disability or in need of care. Other terms used interchangeably comprise caregiver strain, distress, or stress (Ayres, 2008). According to research, caregivers are more prone to depression, loss of control and autonomy (Schulz, Martire & Klinger, 2005), anxiety and guilt (Schulz, Martire & Klinger, 2005; Cooper, Balamurali, & Livingston, 2007), poor quality of life (del Río Lozano, 2017) and more health problems (Do et al., 2015). Family is generally considered a conventional social institution for care of any patient, more so the elderly, especially when it concerns health. In fact, in certain cultures, it is considered a social norm for the children to care for their parents or elderly in the family, often reflected as filial peity—tending their parents or elders not just out of duty but as a matter of reciprocity of their love and with a feeling of gratitude (Alsaedi et al., 2022; Aung et al., 2021). As stated earlier, caregiving burden is dependent on the individual’s perception and this component of filial peity also acts as a psychological buffer in some cases (Alsaedi et al., 2022; Li & Yu, 2018). However, it can become overwhelming when the disease is chronic and advanced—demanding higher level of care, especially when the caring starts to interfere in their daily lives.

Type 1 diabetes (T1D) affects 15 out of every 10,000 (Mobasseri et al., 2020) people worldwide (Mobasseri et al., 2020; Titoria et al., 2022), and due to the disease’s early onset, family members, especially parents, are responsible for their care. Along with transportation (hospital consultation), insulin administration and overall illness management cause significant disruption in the lives of the parents, everyday family functioning (Rubin, Young-Hyman, & Peyrot, 1989; Bobrow, AvRuskin, & Siller, 1985; Hanson et al, 1989; Schafer, McCaul, & Glasgow, 1986; Wysocki et al., 2005; Malerbi et al., 2012). Parents also tend to experience a sense of shame, grief, guilt, (Frank, 2005) distress, (Hatton et al., 1995; Hilliard et al., 2011) anxiety, and depression, (Malerbi et al., 2012, Aloulou et al., 2012; Grey, 2009; Hansen et al., 2012; Jaser et al., 2008) as well as poor quality of life (Malerbi et al., 2012, Aloulou et al., 2012, Jaser et al., 2008, Farnik et al., 2010). According to a previous study (Bhadada et al., 2011), approximately two-thirds of the parents (64 percent of their study population) of patients with Type-1 diabetes displayed psychological morbidity, while diagnoses of a psychiatric condition were made for one-third of the population. A qualitative study by Hatton et al. (1995) reported the experiences of parents of type 1 Diabetes mellitus, where a mother was recorded saying— “Diabetes consumes our lives. It seems as if it’s not our child we are caring for but this monster called diabetes.” Another study (Keklik et al., 2020) also found that mothers of children with type 1 diabetes mellitus (T1DM) had a moderate care burden. Thus, one can see that diabetes impacts all spheres of life.

In Type 2 diabetes (T2D), accounting for its age of onset - 45 years (Huizen, 2023) and above, the majority of patients are married and their spouses and children automatically become their caregivers.

Diabetes-specific informal care includes activities such as—helping with glucose monitoring, foot care, and adherence to a diabetic diet, taking them to a medical practitioner (Silliman et al. 1996), etc. However, in advanced stages, i.e. those with diabetes-related complications, a higher amount of care is necessitated. Adherence to the treatment regime is a prime factor for its control, which further demands lifestyle modification for the patients, including their caregivers. Subsequently, the time spent by caregivers in providing care to the patients also increases, affecting their self-care and well-being. Research has indicated an inverse relationship between caregiver burden and their quality of life—a decline in their quality of life with an increase in caregiving burden (MirHosseini et al., 2020) and distress (Ogunmodede et al., 2019).

Diabetes care becomes even more tasking when the patients are elderly. The caregivers now have to take care of both the age-related physical and psychosocial requirements as well as that of diabetes. Considering the amount of care mentioned earlier, diabetes care is time consuming; in fact, a full-time job, contributing good amount of hours from their lives. Langa and colleagues (2002) reported that elders without diabetes received 6.1 hours of caregiving, those with diabetes who were not taking any medication received 10.5 hours, individuals taking oral medications received 10.1 hours, and individuals taking insulin received 14.4 hours of caregiving weekly. Similarly, another study on elderly care (Aung et al., 2021) also observed that, of the five dimensions of the Caregiver Burden Inventory (CBI) measuring "time-dependence, physical, emotional, social, and developmental burdens"; time-dependence burden dimension ranked the highest. Thus, it becomes obvious that the physical and mental toll of caregiving can culminate into fatigue and even hopelessness and burnout, which can further impact the caring process negatively—both for the patient and the caregiver (Aung et al., 2021). It can also impact the social life of a person when they have someone to take care for such long hours. Psychological distress was significantly associated with caregiving among Nigerian caregivers of Type 2 diabetes (Ogunmodede et al., 2019); similar results were found in other studies studying the distress level of caregivers (Trief et al., 2004). The burden becomes even more distinct, when the caregivers are the sole source of income in the family and they have to avail high number of leaves from their job owing to diabetes care of their family members (Aung et al., 2021).

Diabetes disease burden is mostly caused by comorbidities such as heart disease, visual impairment, and stroke. These comorbidities are major predictors of disability and account for approximately one-third of the rise in informal caregiving (Langa et al., 2002). Research also indicates that preventable consequences such as heart disease, stroke, vision loss, and lower extremity amputations contribute significantly to diabetes-related caregiving (Vijan et al., 1997, American Diabetes Association [ADA], 1998; Vijan et al., 2000; Langa et al., 2002). Thus, one can understand the onerous responsibility that a caregiver of diabetes undertakes especially in cases with comorbidities.

The process of caregiving becomes even more burdensome when the caregivers themselves have certain illnesses and are in requirement of adequate self-care (Aung et al., 2021) putting both parties in need of care. A study (King et al., 2021) found that 20% of the unpaid/informal caregivers in the US have diabetes. Their study included 795 caregivers with diabetes in which 59% of the participants were women and 146 caregivers (18.4%) reported significant strain; high caregiver strain was linked with less physical activity, poor medication adherence, and poor self-care. Another study (Lebrec et al., 2016) also stated that caregivers with diabetes had higher odds of outpatient visits for their health than non-diabetic caregivers. However, research is scarce about the relationship between caregiver stress and self-care practices used by caregivers with diabetes to maintain their health. More studies are required to explore and understand the experiences of caregivers with diabetes to eventually help them.

Addressing Diabetes Caregiver Burden

Caregiving involves sacrifices and adjustments such as lost time that could be spent on other things like paid work, fulfilling other family responsibilities, social life, and leisure time (Heitmueller & Inglis, 2007). Some of the common sources of stress for caregivers include (Cousino & Hazen, 2013; Cherkes et al; 2023)

- Worrying about the person's health and well-being
- Managing complex medical regimens and monitoring blood sugar levels
- Feeling responsible for the person's diabetes management
- Difficulty in balancing caregiving responsibilities with other aspects of life
- Difficulty in understanding the emotional needs of the person with diabetes and providing them with emotional support.

The identification of risk factors—psychosocial factors, plays a crucial role in reducing the caregiving burden. Research shows varied elements can pose as risk factors for the caregiver's burden—health and dependency level of the individual being cared for (Lethin et al., 2020; Oliva-Moreno et al., 2018), being a caregiver for an extended period (Swinkels et al., 2019), financial difficulties, limited access to social and health care services (del-Pino-Casado, 2018; Pinquart & Sörensen, 2007); complications and presence of a chronic comorbid medical conditions, etc. Moreover, the deteriorating functional status of the patients can further aggravate the burden. Financial burden is also found to be significant contributor to caregiving burden, especially in chronic illness like diabetes which entails incurring of long-term expenses for the treatments.

Psychological Interventions for Diabetes Caregivers

Diabetes management is a continuous process and since most caregivers assume the responsibilities without proper training, it often results in a higher burden level. Thus, it is advocated that caregivers consult a diabetes educator or healthcare provider for better guidance and support. Seeking support, for instance, from a diabetes caregiver support group or a counsellor is deemed helpful. Given the strenuous care involved, it is important for the caregivers to also make time for self-care activities such as exercise, hobbies, and socializing with friends; setting realistic expectations for themselves and communicating effectively with their patients. Numerous researches have effectively contributed in alleviating the caregiver burden in diabetes care. A study (Farahmandnia et al., 2017) demonstrated the possibility of developing successful programs aiding parents in caring for children with T1DM by identifying the number of factors influencing the amount of caregiving burden. Family psychoeducation can lessen the caregiving burden among caregivers of adolescents with T1DM. Improved caregiver and patient education (Brown, 1988; Li et al., 2019), disease management programs (Aubert et al. 1998; MirHosseini et al., 2020), and improved communication systems (e.g., through telemedicine) (Po 2000; Tsang et al. 2001) can all play a role in reducing the caregiver burden in diabetes. To support caregivers in these demanding roles, various interventions have been developed. These interventions include:

Education and training

Caregivers should be knowledgeable about the individual's specific needs, medical conditions, and any treatments or medications, which can optimize their quality of care. Since most caregivers are not properly aware of the disease and its management (Lee et al., 2017), providing them with the necessary education and training can increase their confidence and make them competent in their caregiving role (Siswoaribowo et al., 2018; *Psychiatric Mental Health Nursing: Concepts of Care in Evidence-Based Practice*, 2017; MirHosseini et al., 2020). Family psychoeducation can lessen the caregiving burden among caregivers of adolescents with T1DM (Farahmandnia et al., 2017). In an intervention study conducted by Zupa et al. (2022) on 239 patient–caregiver dyads focused on social skills and training, bi-weekly coaching sessions were conducted for 12 months. Their results showed that, the treatment group was more involved in several areas of self-management assistance. Thus, despite increased involvement in care recipients' diabetes management, caregivers did not display diabetes distress or caregiving strain.

Respite care

It is a form of support service that gives caregivers with short reprieve when caring for a loved one suffering from an illness, disability, or aging-related concerns. The goal of respite care is to give caregivers a break from their responsibilities and help prevent burnout and stress. It can take a variety of forms, based on the needs of the caregiver and the person they are caring for. It can be provided in different types of settings, such as in-home care, adult day-care centres, or residential care facilities (Lotfalinezhad et al. 2022; Mitchell et al., 2016). Other studies (Aung et al., 2021; Lotfalinezhad et al., 2022) have also talked about the need for national policies and interventions to help families, such as respite care services, care capacity building, paid and unpaid caregiving leave, and so on, which may minimize the burden on families struggling with informal care tasks.

Counselling and support groups

Support groups and counselling offer a safe and supportive atmosphere for individuals to share their experiences and receive emotional support from peers who understand their condition (Goldberg & Ritalkckler, 2011). Caregivers consider support groups as their lifelines, which makes them feel less lonely (Bruening et al., 2020). A systematic review by McBroom and Enriquez (2009) explains the effect of different family-centered interventions like Behavioral family systems therapy (BFST), multisystemic therapy, family therapy, etc. to increase the health outcomes of children with Type 1 diabetes, which showed improved metabolic control and decreased family conflicts.

Financial and practical assistance

Ndjaboue and colleagues (2020) in their qualitative study indicated the need for external support—finance and logistics for people with diabetes, which can be further applied in the context of the caregivers of diabetics. Financial aid can be provided by multiple sources like the government, private organizations (Banks or credit unions), and NGOs. Help can also be in forms of leaves in their jobs. In India, organizations like Microsoft (Stories, 2017), Accenture (Singh et al., 2021), and Zeta (Sarkar, 2022) offer caregiver leaves to support employees and their family's health.

The Government of India under its National Health Mission (NHM) provides free necessary medicines like insulin to the poor and needy and also provides good quality medicines at affordable prices to all under its 'Pradhan Mantri Bhartiya Jan aushadhi Pariyojana (PMBJP); in-patient treatment is also free in all the government hospitals (Ministry of Health and Family Welfare, 2022).

Health and wellness programs

Caregivers also need to prioritize their own health and well-being such that better care can be provided. Programs promoting healthy lifestyle changes like exercise, healthy diet, and stress management can enhance both physical and mental health (Aubert et al. 1998; Goldberg & Rickler, 2011). This wellbeing of the caregivers can have a positive percolating impact on the caring process.

Technology and assistive devices

Telehealth, a virtual platform has been found effective in diabetes management and involves using technology, like telephone calls, text messages, various applications (Apps), websites and portals, and videoconferencing bringing the medical facilities closer to the patient's doorstep by reducing the geographical barriers with the healthcare experts with real-time interactions (Duke et al., 2018). It involves a multidisciplinary team of physicians, dieticians, nurses, psychologists, etc. (Tuckson et al., 2017) providing education, monitoring health and care (Rachmiel et al., 2021; Tuckson et al., 2017) as one-point access for enhancing diabetes care management and further lessening the caregiver burden. Though direct consultations cannot be equated with telehealth care, given the recent unfortunate scenario like COVID-19 where physical movements were highly restricted, adopting such measures could accommodate the needs of both the patients and their caregivers (Jones et al., 2020). A recent study on diabetes (Rachmiel et al., 2021) also showed that 65% of their participants showed satisfaction with telehealth services, with 50 – 70% showing interest in combining telehealth with in-clinic visits. A systematic review on Internet-based interventions for caregivers on older adults (Guay et al., 2017) inferred that interventions which included professional and social support, as well as instructions for changing behaviour and problem-solving in an interactive manner, appeared to have a positive impact on caregivers. Additionally, self-help guidance can be provided to caregivers to aid their caregiving. Covid-19 has established the strength of media on the healthcare system. Although exposure to partial and unscientific media reports can result in fear; accessing scientifically supported information can be of help. Likewise, media can also enhance the reachability of healthcare, catering to the needs of both the patients and their caregivers with multi-dimensional, one-point access. However, owing to the variability of caregivers' needs, such solutions should best customized. Most effective interventions could be multidimensional, focusing on skills training, counseling and providing caregivers with tangible resources.

COVID-19 and Diabetes Caregiving

In 2019, the world witnessed an outbreak of a novel coronavirus called COVID-19. Governments all across different countries imposed various COVID-19 containment measures like—total lockdown of public places, social distancing, home isolations, etc. The spread of COVID-19 was unprecedented, posing humungous challenges to the healthcare units. Caregiving in such a time, with no proper tangible and intangible resources was even more challenging and exhausting. As caregivers themselves were already stressed, the possibility of misinterpreting emotions, symptoms, or behaviors of their wards was high, resulting in miscommunication. Thus, with little to no knowledge about the new caregiving pattern, the caregivers were faced with an enormous amount of caregiving burden.

A study indicated that many informal caregivers experienced an increase in caregiving intensity (CI) and caregiver burden (CB) during the initial months of COVID-19 (Cohen et al., 2021). Individuals with Type 1 diabetes are medically required to have follow-up visits with their healthcare professional every 3 – 4 months (American Diabetes Association [ADA], 2020; Pihoker et al., 2018), especially for their care plan reviews (Rachmiel et al., 2021). Alessi and colleagues (2021) found that caregivers of children and adolescents with Type 1 diabetes reported higher levels of concern and burden during social distancing compared to those without diabetes.

CONCLUSION

Diabetes is a concern for all age groups in the world, often requiring formal and informal care. Considering the disease chronicity, complication and the chances of comorbidity, effective diabetes management is indicative of a continuous, challenging and multifaceted care process. The significance of psychosocial wellbeing of both the patients and their caregivers along the disease trajectory is established for many chronic disease, including diabetes. The current paper has attempted to review the diabetes caregiver burden, varying in terms of types, age and comorbidity. It has also remotely touched upon the impact of caregivers' own physical and psychological health on the caregiving dynamics. Further, this review paper also reported the effectiveness of a few existing psychological interventions for easing diabetes caregiver burden— Education and training, Respite care, Health and wellness programs, Counselling and support groups, Technology and assistive devices, and Financial and Practical assistance.

Literature advocates employing an integrative and a holistic approach involving all the stakeholders, i.e. patients, health professionals and the caregivers. Caregiver burden in diabetes care encompasses physical, psychosocial and even financial strain. Since most caregivers assume the responsibilities out of filial duty, without having any formal training, it often puts the caregivers vulnerable to psychological strain and burden. This particular aspect of informal care can make the care giving process overwhelming, resulting in a higher burden. Research abounds with the report of stress, distress, anxiety, depression, burnouts and lowered quality of life among diabetes caregivers, indicating the importance of the caregivers' mental health. Thus, intervention like psychoeducation can benefit the caregivers for better care. This education can encompass required knowledge about the disease and its care, also of likely complication that may arise. It is also important to include the knowledge of psychological concomitants of the caregiving process, such that they are empowered to cope and also seek required assistance in time. The intervention could be tailored into the healthcare requirements and functional dependence of the patients, which would also cater the psychological needs of caregivers such that they don't compromise their own well-being in the process of caregiving. Psychological interventions not only ease the caregiver burden but also enhances the quality of care, resulting in cost-effective treatment—avoiding preventable complications and reducing/ delaying hospitalization.

As mentioned earlier, India is ranked as the diabetes capital of the world, which directly indicates two things in the diabetes care—the number of patients and their caregivers and also the likely caregiving burden. However, review of existing literature indicates that psychological studies in diabetes caregiver burden among Indian population are sparse. Thus, the authors would also like to suggest some measures in terms of research and policy implementations. Since caregiver burden is multifactorial, in-depth studies are suggested so as to arrive at a precise profiling of diabetes caregivers and their requirements. This will also help in designing suitable psychological interventions, tailored into the cultural specifics. Family behaviour therapy at every tier of the diabetes care can also be implemented, beginning from psychological screening, assessment to developing and implementing psychosocial interventions. A checklist can also be formulated to identify those caregivers who are at higher risk of developing or succumbing to caregiver burden, such that timely and proper interventions can be provided. Evidence-based research towards comprehensive psychological intervention is also indicated.

Speaking of customising interventions, India has a diverse demographics with varied socio-cultural communities. It constitutes a large number of population with primary to no formal education. There also exists huge economic disparity in the country. Hence, not all patients can afford high-end medical care and diet regime at equal footing. Also, while considering the complication involved in diabetes care, disease specific education is pertinent, irrespective of the educational level or economic status of the people. Thus, both clinical and demographic history of the patients and their caregivers need to be accounted while planning any psychological interventions in diabetes care in such a diverse country like India. Likewise, health-care professionals can conduct awareness programs at the community/local level to aware and sensitise both the patients and their caregivers. Diabetes care regime should also focus on socio-cultural practices of each community while developing care plan, especially in the rural area. Given that diabetes is a lifestyle disease, these programs can also target certain modifiable health risk behaviours that can aggravate the disease complications. These kind of initiatives can also act as a support system for both the patients and their caregivers. Additionally, lifestyle modification can also be promoted in such programs for the non-diabetic population as a preventive measure. More care facilities also needs to be instituted in order to cater the number of diabetes population in India. Government can also implement short-term respite care services and programs to ease the caregiver burden, both at the local and national levels. The recent COVID pandemic has also proved the effectiveness of Tele-health care, which can be considered for wider reach and spread of programs. To conclude, the present paper focuses on various challenges that diabetes caregivers face and presents a summary of few effective psychological interventions to manage or ease their burden.

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