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Best practice in caring for dementia patients, in an institutional setting, with a family therapy approach

1. The topic and its relevance

The authors Orsolya and Attila head a retirement home in Hungary and wish to report on the work done in caring for clients living with dementia or Alzheimer's disease (who therefore are in a unique life situation and require special care) and in upholding their living conditions and quality of life.

The institution in question is the Szent Lőrinc Gondozóotthon (St. Lawrence Retirement Home) maintained by the Diocese of Pécs. The institution houses 71 seniors, most of whom live in small apartments consisting of a private bedroom and bathroom. I wish to begin my account by highlighting two important characteristics of retirement homes in Hungary.

The first characteristic has to do with the establishment of our institutions. Retirement- and nursing homes in Hungary were born of an effort to provide for those members of society who for various reasons (family circumstances, lack of supportive relationships, socio-economic situation) were unable to provide for themselves. The system of retirement homes in Hungary was in place before 1990, that is, before the fall of the Socialist regime. The development of Hungarian institutions mirrors that of similar institutions in post-Communist countries, but differs significantly from Western models. The roots of the difference may be found in the fact that while post-Communist countries establish and manage their retirement homes and similar institutions under the aegis of social services, in Western Europe, the management of such institutions is considered a healthcare issue.

The other difference is that in ageing societies – such as our society in Hungary – professional emphases within care for the elderly have changed and shifted significantly. This change has come about because those living in retirement and nursing homes are on average older and in greater need of nursing/medical attention. It is for this reason that a social institution such as a residential home is forced to provide services that are increasingly medical in nature. Medical workers are becoming the majority among retirement home staff, and more often than not, the institutions themselves are run by health professionals (e.g. individuals holding a nursing degree).

The authors of the present article are both social service professionals; Orsolya is a social worker and in charge of the mental hygiene team, while Attila, a social policy specialist, heads the institution. This is of importance because the trend in care for the elderly towards increased presence of healthcare workers (as described above) may be compensated by dedicated efforts in the fields of social work and mental hygiene to maintain and improve the quality of life for clients suffering from dementia.

It is of highest importance for our ever growing number of patients living with dementia to be given not only qualified medical attention but holistic care, including psychological and social therapy. In our experience – as this present paper seeks to show in its presentation of "best practices" – quality of life for dementia patients is determined not so much by the nature of medical care they receive (though medical care is of great importance), but by personal attention and care provided by those with a social service mindset.

2. Dementia in Hungary

While the percentage of the elderly suffering from various mental disorders in Hungary is very high (Kovács, 2013, 199), the understanding and treatment of mental disorders is insufficient both at the preventive and the chronic level. This is true across Europe regardless of the level of development typical of a member nation's social- or healthcare system. The reason for this is that in the case of elderly patients, focus tends to shift to physical and other chronic diseases to the detriment of mental disorders. Neglected mental disorders serve to make a bad situation worse. The leading mental disorder affecting the elderly is depression (Kovács, Osváth, Szabó 1997, 58). Ten percent of seniors over 65 suffer from depression, and the ratio can reach as high as 40–50% in those already living with a chronic physical illness (Kovács, 2013, 199).

The other mental disorder that affects a great number of the elderly is dementia. The growing number of patients with dementia is characteristic of the age in which we live. The reasons for this tendency can be found in what is termed "double ageing". Double ageing means that while the number of children born annually is on the decline, the existing population tends to live longer. In other words, life expectancy is on the rise. As a result, dementia is becoming even more widespread. Dementia is more than a mood disorder, although mood changes are a symptom of the illness. Dementia is a psychosomatic disease typical of old age. The extent of the problem can be seen when we consider predictions that the number of patients with dementia (both in Hungary and throughout Europe) will double by 2030, and triple by 2050 (Tariska, 2002, 28). This is a gloomy prospect as the current consensus is that patients with dementia are best cared for in an institutional setting. Caring for such patients is a medical, social, and mental task that is virtually impossible to achieve at home. The number of patients suffering from dementia is on the rise, and dementia currently affects 10% of those 65 or older (Kovács, 2013, 201).

Dementia patients may be grouped into four categories. Approximately 60% of cases may be attributed to Alzheimer's disease. The next largest group (15–30%) comprises those suffering from vascular dementia. The final two groups include patients with frontotemporal dementia and Lewy body dementia, although the latter two are often not properly recognized and therefore rarely figure in the diagnoses.

It is beyond the scope of this paper to give an exhaustive account of the symptoms of the above mentioned four groups, but I wish to describe in brief the stages of dementia. I find this to be of vital importance because families of patients suffering from the disorder often have difficulty both in identifying and accepting the disorder in their loved ones, mostly because cases of dementia were relatively rare in the past. Furthermore, family therapy-oriented approaches are difficult to put into practice, because families have no inherited norms upon which to base their behavior. This poses a challenge that is best met when an institution combines social work, best practices, and family therapy to help patients' families (Szücs, 2013, 139).

There are three major phases of dementia. In the "mild" phase, a patient may experience memory loss, inability to understand and learn new things, difficulty finding words and trouble with personal care and hygiene. "Moderate" dementia is characterized by increased memory problems, difficulty recognizing familiar persons, and increased problems with personal care and hygiene. Patients with "severe" dementia are unable to recognize their closest family members and to orient themselves in space and in time, and require round-the-clock care (with meals, personal hygiene, etc.).

In light of the above, it is easy to see that caring for persons with dementia and maintaining their quality of life and their dignity entail a great and complex challenge for families and institutions alike.

In order to adopt best practices, we had to look holistically at the situation of dementia patients and create a complex system of care giving that serves both our clients and their families. In what follows, we hope to present the role of family therapy in adopting best practices at our institution.

3. Placement in an institution, "best practice" in correctly assigning clients to institutions

In Hungary, it is markedly difficult to qualify for a place in a live-in retirement home. Individuals under the age of 70 must be examined to determine whether they are in need of care, furthermore, they must meet at least one of the important criteria that make them eligible for this form of social service.

One of the central criteria is the presence of at least "moderate" dementia. In Hungary, the tendency is for families and relatives of would-be clients to seek out live-in institutions only when a patient's condition has deteriorated to such an extent that it makes living with that person virtually impossible and places the entire family at risk. We mostly meet families who have made the decision to seek help after a drawn-out crisis period and extended family discussions. As a part of the admission process, we and our colleagues always offer families an opportunity for a personal meeting, which allows the family to discuss their present situation, tour the institution, and gain insight into what an average day looks like.

We feel it is very important for this initial meeting to take place in a calm, unhurried context which allows the families of moderate to severe dementia patients to share with us the difficulties they experience in as much detail as they desire. It is of vital importance to listen to families tell us about their struggles, because dementia leaves an indelible mark on the lives of patients and loved ones alike. Loved ones who live with a dementia patient and are dedicated to caring for him or her find themselves in an extremely difficult situation (which may or may not be exacerbated by societal pressure) that affects them in all their roles (as a family member, child, wife or husband, employee, etc.).

During our meeting with family members, we discuss not only practical matters but provide a space in which family members can freely give vent to thoughts and emotions they have had only few and superficial opportunities to express. As professionals meeting family members of a dementia patient, it is our duty to make sure they understand that dementia is an issue that affects the immediate and extended family of the sufferer. We try to take stock of the coping strategies and psychological and emotional reserves of the family members and to help them face their problems by presenting a realistic view of the situation. We attempt to take a step in the right direction either by initiating the admission process or by offering the family membership in our support group.

The motto of the Saint Lawrence Retirement Home is “Faith. Security. Home.” Our motto, beyond sounding good, also presents serious expectations and guidelines for live-in patients and their families alike. We do everything in our power to get our mission statement across during the sign-up process. Our institution provides clients with a chance to live their faith, and round-the-clock care by our workers gives them a sense of security. For our retirement home to truly feel like a home, however, we need the help and partnership of families as well. At our institution, clients and their families are free to furnish and decorate their living environment in whatever way suits them. Furthermore, visiting hours last all day, facilitating spontaneous visits from family, friends, and acquaintances in much the same way that a grandchild would drop by anytime to visit his or her grandparent at home.

We offer our clients and their families a chance to keep in touch during the registration process, and in the case of a prolonged process, we make sure our future clients have an opportunity to get to know our institution. Prospective clients may spend the morning with us, taking part in the activities planned for that day and attending mass and physical therapy with their future neighbors.

We have a waiting list of people expecting to be admitted, and a team consisting of the institution leader, caregivers in charge of easing the moving-in process, and the head nurse decide together who can be accepted. They are the best qualified to make this decision as they have a good understanding of a prospective client’s life, health condition, circumstances, and current situation.

Structure and predictability are very important for dementia patients moving into our home. It is vital for them to be successfully integrated into their new community and environment. The elderly person will find himself or herself in an entirely new environment surrounded by unfamiliar people in what will become his or her home from that day forward. In the case of dementia patients, we must reckon with not only impaired cognition but with lower motivation levels and often drastically altered social behaviors.

Our clients must also accept an increased number of people who are now a part of their daily life – nurses, social workers, physical therapists, the heads of the institution, and fellow clients will have an effect on their lives every day thereafter. Dementia sufferers typically experience a loss of a sense of self and identity, and deteriorating human relationships. It is in such a condition that our client will meet his or her roommates, and get to know – with the help of our psychologists – the daily schedule of the institution and the activities we offer. This time of transition is critical, as the new client will find himself surrounded by a much greater number of people even as his sense of security, already eroded by dementia, is shaken. It is very important for our clients to be in regular contact with their loved ones during the adjustment phase. In some cases, however, daily contact with loved ones actually prevents a client from adjusting to her new life situation. It is vital for social workers to pay special attention to these patients and to keep track of their state before and after visits from family.

We try to give our clients a sense of stability with the help of an unchanging daily schedule complemented with a rich array of activities. A regular daily schedule gives dementia patients a sense of security which is both comforting to them and of great help to our nurses and psychologists as they go about their work. At our institution, we strive to organize events and activities that are of therapeutic importance to our dementia patients while giving them a chance to spend time and interact with other clients as well.

4. Therapeutic approach

Our retirement home offers weekly sessions of dog therapy, art therapy, and dance therapy. These therapies are geared towards stimulating the emotional life of our clients. They are effective at motivating dementia patients and promoting their social interactions with others. Such activities allow dementia sufferers to express and to experience emotions that are not readily put into words. Some dementia patients find that they are best able to share their difficulties, joys and sorrows with a dog companion rather than a human carer. Therapy provides our clients with a chance to understand their emotions (or at least attempt to do so), and for this reason, our clients have a very positive attitude towards therapy sessions and express their desire to participate again.

Besides participation in group therapy, dementia patients also have a need for one-on-one interaction with our social workers who offer them personalized care and support. This often takes the form of singing or reading together. Our specialists seek to get to know all our clients on an individual basis so that they may reach back together to pleasant, emotionally positive events of the past and help the client recall life events and thoughts that are a source of comfort and joy.

The current state of dementia research shows that the disorder is irreversible and incurable, so rather than using therapies for improving or enhancing memory, we find it is more important to give our patients the sense of love and security they need to live a peaceful old age despite their illness. The forms of therapy practiced at our institution have been specially chosen to allow all of our patients to participate according to their own emotional, mental, and physical capabilities. We would like to avoid burdening our patients with unrealistic expectations or tasks too difficult for them. The therapies listed above are successful at stimulating emotions and moods, and are not meant to improve cognitive function. They are a great help at reducing unwanted and inadequate behaviors such as aggression or wandering off.

5. Social work with loved ones, support group for loved ones

Besides providing for the wellbeing of our clients, our institution is deeply committed to cultivating personal relationships with loved ones. The pressure family members experience while caring for a loved one with dementia may change in kind but not in magnitude as their loved one begins life at our institution. From that moment on, family members are no longer the ones responsible for organizing and structuring their time with the patient. This responsibility now lies with our institution, yet loved ones have an altered but vital role to play in the life of the patient. This may often lead to conflicts and misunderstandings, which must be addressed as they come up.

During the nursing process, loved ones will encounter a variety of specialists (nurses, carers, physical therapists, doctors, etc.) but often find it difficult to talk about their own problems and difficulties.

The support group for loved ones was established for this very reason. The group – led by a psychiatrist and a mental health professional who also work at our home – seeks to educate loved ones about dementia. Family and other loved ones of our current clients and those undergoing the admission process are free to attend the monthly meetings.

At these meetings, our specialists discuss the different types of dementia as well as the various stages of the disorder. It is very important for these occasions to address the concepts of deterioration and loss, and to provide loved ones with a space in which to share their thoughts and emotions. The monthly sessions are also effective at tackling the sense of guilt which arises in loved ones caring for dementia patients and is often the most difficult obstacle to overcome. Members of the support group grow in their knowledge of dementia even as they acquire new strategies for successful treatment, communication, and coping.

Participants also realize that they are not alone with their difficulties, anger and sense of insecurity, and can share their own best practices with the rest of the group. Through these monthly sessions, a support system is built up that allows for the sharing of information and lessens participants' sense of isolation.

Besides taking part in the support group meetings, loved ones also have the opportunity to seek private appointments and consult with our social workers, head nurse, or institution leader.

6. Education and support of our workers

As discussed above, it is vital for all those affected by dementia – patients and their loved ones and caretakers – to receive adequate and comprehensive help, but it is of equal importance for professionals working with and caring for clients and their families to receive the support they need to cope with their own difficulties and to share with each other the care strategies they find useful. The risk of burnout is especially high in fields where there is a low success rate, and work with the elderly and with dementia patients mostly ends in loss. Thus carers themselves must receive care and support as they go about their daily work.

At our institution, regular debriefing sessions and personal and group supervision offer our workers support on a professional and personal level. Our colleagues receive mental support and a chance to gain further education and training to facilitate better understanding of the processes of dementia and the condition of their patients.

As our dementia patients often do not join our community until their condition is moderate to severe, carers dedicated to serving our elderly clients must face new challenges on a daily basis.

Conclusion

Care for dementia patients in an institutional setting has become a complex and challenging task. While presenting our best practices in this present paper, we have argued that caring for the elderly is a group effort involving the institution, social workers, healthcare professionals, and families. We have also attempted to show that best practices in care for the elderly must have a family therapy focus and offer a support system for loved ones. In our experience, adherence to the practices detailed above contributes to the wellbeing, quality of life, and activity level of the elderly persons in our retirement home.

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