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A case for a narrative approach to research into social work perspectives on dementia

Social work with people with dementia is an important complement to the knowledge of the treatment of people with dementia developed by other sciences, especially medicine, psychology and sociology. For more effective and adequate help for people with dementia we need more research in social work with people with dementia. In this paper we present concrete use of a narrative approach in Slovenia for a better visibility and understanding of the living world of people with dementia. The narrativity is demonstrated in several meanings: as an example of taking action from the perspective of relatives, enabling people with dementia and their relatives to let go of their marginalised roles, and as a potential method of social work with relatives of people with dementia. The stories are analysed by the use of a qualitative method and the results present the knowledge relatives have about understanding dementia and the changes dementia reflects in interpersonal relations, changes in everyday routine and formation of additional help. Verbalising experiences of people with dementia enables relatives to recognise ways to take action, which empower them in the helping process.

Key words: narrativity, old age, informal care, long-term care, Slovenia.

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Primer narativnega pristopa k raziskovanju socialnodelavne perspektive demence

Socialno delo z ljudmi z demenco je pomembno dopolnilo k znanju o ravnanju z ljudmi z demenco, ki so jih razvile druge znanosti, zlasti medicina, psihologija in sociologija. Za učinkovitejšo in ustrezno pomoč ljudem z demenco potrebujemo več raziskav v socialnem delu z ljudmi z demenco. V tem prispevku predstavimo konkretno uporabo narativnega pristopa v Sloveniji za boljšo vidljivost in razumevanje življenjskega sveta ljudi z demenco. Narativnost prikažemo z več vidikov: kot primer ravnanja iz perspektive sorodnikov, ki ljudem z demenco in njihovim sorodnikom omogoča, da izstopijo iz marginaliziranih vlog, in kot potencialno metodo socialnega dela s sorodniki ljudi z demenco. Zgodbe analiziramo s kvalitativno metodo. Rezultati predstavljajo znanje sorodnikov za razumevanje demence in spremembe, ki se kaže v medosebnih odnosih, spremembah vsakodnevne rutine in oblikovanju dodatne pomoči. Ubeseđenje izkušenj ljudi z demenco omogoča sorodnikom, da prepoznajo načine za ukrepanje, ki jih spodbujajo v procesu pomoči.

Ključne besede: narativnost, starost, socialno delo, neformalni oskrbovalci, dolgotrajna oskrba, Slovenija.

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Introduction

In the last decade, the phenomenon of dementia has been the subject of numerous discussions, research, development of new approaches and ways of working with people with dementia in the area of various sciences and professions (Whitehouse & George, 2008). Each science has developed its own perspective on dementia. There are the biomedical, the psychological and the sociological perspectives of understanding dementia. Cantley (2001) adds the philosophically spiritual perspective, whereas Mali, Mešl and Rihter (2011) also add the

social work model of understanding dementia. Since we aim to contribute new findings in understanding social work with people with dementia in this paper, we shall present the particularities of the social work model. Nevertheless, we would like to avoid a likely false impression of the social work model as being the most relevant of all models in understanding dementia.

In order to undergo changes in the area of understanding dementia and treating people with dementia, partial knowledge, as well as scientific and professional experience are simply not sufficient. The abovementioned perspectives and models of dementia contain an extremely precise and focused knowledge of each individual discipline on what dementia is. When it comes to justifying their knowledge, they often turn to critical reviews of the preliminary findings of other models and ways of understanding dementia. Thus, the biomedical model, which may be classified as the oldest on the list of the presented models (Mckeith & Fairbairn, 2001; Innes, 2009; Cahill & Dooley, 2005), is most frequently the target of criticism and strong opposition on the part of the psychological and sociological models. In order to provide a more effective and adequate treatment for people with dementia, professionals need to take into account the findings of all the abovementioned models, i.e. a balanced attitude and, above all, recognition of the equality of knowledge gained within particular models.

The threshold of our discussion is based on the conviction that we need to collect the findings of all of the aforementioned models in order to provide more effective and adequate help for people with dementia; therefore, we are striving to demonstrate specific themes researched in the area of dementia and social work. Social work places a human being into the core of their professional activity, rather than the disease – dementia (Lynch, 2014; Moore & Jones, 2012; Ray, Bernard & Phillips, 2009; McDonald, 2010). Such presupposition enables social workers not only to become acquainted with the living world of an individual with dementia, but also to understand the attitude of the closer and broader social environment towards a person with dementia. On the one hand, we encounter personal distress, disappointment and the problems faced by people with dementia and on the other hand, the distress of the relatives who provide care for an individual with dementia. The assistance provided by social work is directed towards finding a way to overcome the distress caused by dementia. By doing so, we help people with dementia and their relatives to gain self-respect, recognise the value of their own experience and show others that they are worthy of respect in spite of the disease (Mali, Mešl & Rihter, 2011). We create a new relationship with people involved in dementia care that is more like a partnership (Marshall & Tibbs, 2006).

The narrative approach in social work for people with dementia shall be demonstrated as an example of taking action from the perspective of power, enabling people with dementia and their relatives to let go of their marginalised roles. We shall present it as a potential method of working with relatives of people with dementia in social work, which not only provides concrete assistance to relatives, but also places people with dementia, whose stories are

described in this paper, into the position of subjects, at the very core of social work action. The stories provided by the relatives of people with dementia will be used to demonstrate how it is possible to get acquainted with the living world of people with dementia, so that in the process of providing assistance, we can make use of the real life situation of an individual with dementia. The approach taken is based on the definition of the narrative approach in social work (Urek, 2005, 2006; Baldwin, 2013) and the specific particularities of social work with people with dementia (Marshall & Tibbs, 2006; Ray, Bernard & Phillips, 2009; Mali, Mešl & Rihter, 2011; Moore & Jones, 2012).

Dementia is a phenomenon in modern society and a challenge for different professionals to work with. It is estimated that 46.8 million people worldwide were living with dementia in 2015. This number will almost double every 20 years, reaching 74.7 million in 2030 (Alzheimer Europe, 2015) and 131.5 million in 2050. The most recent estimates of diagnosed and undiagnosed rates find that the prevalence of late onset dementia is 7.1 per cent among people of 65 or over, resulting in an overall figure of 850,000 people in the UK in 2015 (Ray & Davidson, 2014, p. 15).

In Slovenia, evidence is not kept of people with dementia. There are only estimates, which rely on foreign research data, assuming that in Slovenia there are no significant differences in the prevalence of dementia than comparable developed areas of Europe. In 2010, the estimated number of people with dementia in Slovenia, was 30,000 (Strategy for coping with dementia in Slovenia in 2020, 2016). Their treatment is discordant; there is insufficient staff in the area of health, as well as in the social sphere.

Providing help for people with dementia and their relatives in the community is underdeveloped and not adapted to users' needs. The provision of institutional care, which is implemented in the closed wards of homes for older people, prevails (Mali, 2013). The role of people with dementia and their relatives as respectful people and co-creators of help is overlooked, although the trends in the national policies of EU countries (Alzheimer Europe, 2015) are clearly defined as creating physical and social environments that enable people with dementia to be part of their communities and to feel respected and valued.

Social work with people with dementia and their family caregivers contributes the social perspective in solving the multidimensional problems of people with dementia and their caregivers. Social work plays an important role in the search for new potentialities which would allow people with dementia to live within the community for as long as possible. Though the care of such persons is extremely demanding and stressful for the relatives it also offers positive experiences for them. The well-being of people with dementia and their relatives should be considered as a mutual responsibility of all the professions involved in the care of people with dementia. Care for people with dementia involves various registers of existence, and a combination of various resources (formal and informal, welfare state and relatives, medical, psychological, social and also technical interventions). Effective dementia care involves connecting different links and providing answers not only to the users but also to their environment. Through a more intensive engagement of

social workers in programs of treatment for people with dementia and with the support of their family caregivers, it can be expected that social work will develop new professional roles in this challenging new field of practise in the future. Our aim is to present one of the possible new approaches in social work – the presentation of stories of relatives caring for people with dementia in order to give an example for developing new knowledge for social work with people with dementia and their relatives.

The social work perspectives of understanding dementia

Dementia issues a challenge for social work, as it involves a lot of direct contact with people with dementia and with their supporting networks, which play a key role in care-providing for people with dementia. In relation to other professions, social work perceives life with dementia in a fairly specific way. It pursues the concepts used in the practice of social work that complement the overall understanding of dementia, especially the following: partnership, the perspective of power, empowerment, advocacy, anti-discriminatory practice, mobilisation of the user's social network (Burack-Weiss & Brennan, 1991; Nathanson & Tirrito, 1998; McDonald, 2010; Mali, 2010; 2011). The common characteristic of paradigm shifts in social work, perceived from the 1970's and 80's onwards, consists of seeing users as partners in the helping process and consistently takes into account their right to choose the form of help (including the ability to reject it).

Social workers differ from medically-oriented professionals. They are aware of the urgency of respecting social justice, implementing human rights, participation and equality (Moore & Jones, 2012; Parsons, 2005). A special emphasis of social work consists of revealing the needs of people with dementia, so that the forms of help for people with dementia and their relatives meets their needs, desires and goals (Moore & Jones, 2012). Due to the widespread attitude of the rejection of dementia and negligence of people with dementia, a relevant emphasis of social work with people with dementia is also embedded in the concept of empowerment, which Thompson and Thompson (2001) see as an opportunity to overcome the prevailing care-and-protection pattern of help intended for older people. Although "empowerment" means different things to different people, there is a degree of consensus about its use in the broadest sense as the dynamic process whereby individuals and groups gain or increase choice and control over key aspects of their lives in order to maximise their quality of life (Larkin & Milne, 2014, p. 31). It is also of vital importance to empower the relatives who provide care for people with dementia, because they are themselves often confronted by the rejection of their environment and furthermore, exclusion from everyday life (Hill, 2015; Page, Keady & Clarke, 2007).

The model of social work with people with dementia in Slovenia

The model of social work with people with dementia in Slovenia could be described in the four levels of life of people with dementia (implementing, interpersonal relations, economic, ethical level). Mali, Mešl & Rihter (2011)

present experiences of living with dementia in the four levels and reveal the possibilities for developing partnerships with relatives in the helping process.

The first, implementing level, is represented by the everyday life of people with dementia, the problems they are faced with due to their dementia and the characteristics of help they receive. It is important to provide perpetual care, the presence of familiar people and a regular rhythm of care, all of which are also highlighted by Bryden (2005). The second level, the level of interpersonal relations, refers to relations with people, their social distress and social networks. People with dementia have a strong need to establish and maintain contacts with other people (Kitwood, 2005, pp. 81–85), but they stumble upon many problems. On the one hand, attachment is favourable, as it strengthens mutual trust and helps to make sense of living with dementia, but on the other, it is difficult for both the individuals with dementia and their care providers, because it is characterised by stress, conflicts and exhaustion (Innes, 2009; Challis, Sutcliffe, Hughes, von Abendorff, Brown & Chesterman, 2009). The third, economic level, draws attention to financial capabilities, means of subsistence and costs linked with care-provision for an individual with dementia. Proportionally to the progression of the disease, the costs of care-provision also increase as they impose the use of additional medical accessories, adjustment of accommodation, and, above all, the organisation of additional, often formal, care (institutional and community) (Mali, Mešl & Rihter, 2011, p. 70; Hlebec, Mali & Filipovič Hrast, 2014, p. 16). The fourth, ethical level, emphasises the rights of people with dementia, the maintenance of respect and the presence of stigma. Practice underpinned by ethics of care would go a long way to progressing ethical care for people with dementia, as it has the potential to strengthen opportunities for enhanced citizenship through the facilitation of participation in care (Brannelly, 2006).

Recognising the experiences of people with dementia is of utmost relevance for social work, since it provides us with an insight into their needs and the adequacy of the existing forms of help in terms of responses to their needs. Through this approach, people working in social work strive to find new forms of help to enable people with dementia to live independently within their communities. It is necessary to find ways of including people with dementia as the active co-creators of help in the helping process. This demands that professionals and family caregivers give up the enduring role of care-providers, a role which involves a patronising attitude towards people with dementia; it is overprotective and proprietary.

Narrativity and dementia

Story-telling has a special place in working with people; thus, the same is true of social work. In social work, story-telling is closely related to the core skill or competence of social work – talking. Without conversation in social work, we cannot perform any action or deeds that might improve the living situation of people and induce changes in their lives (Lynch, 2014; McDonald, 2010). The users of social work tell stories, which is a fundamental need of any in-

dividual, as it defines us as people and separates us from other living beings. This is precisely the reason why anthropologists named us *homo narrans* or *homo fabulans*, i.e. male and female human species of story-tellers and interpreters of stories (Urek, 2005, p. 12).

In the area of social work skills, communication with users occupies an important place, as it is one of the most relevant techniques that enables the methods and principles of social work to be put into practice. Telling stories is one of the communication types that initiate us into understanding, for example, the user's world, situation and distress, and thus, puts a social worker into the role of a researcher who learns, becomes acquainted with and discovers the user's life situation right from the beginning. An individual is placed at the centre and the social worker follows him/her by using communication techniques in order to co-create solutions and the desired outcomes together. Crawford and Walker (2009, p. 93) prescribe that social workers have to ensure that the ways in which we communicate are sensitive to the needs of the older person and that we are flexible and responsive as we work with them. Notwithstanding, communication most directly initiates us into a relationship with a user, which cannot be established without the consensual agreement on mutual cooperation and moreover, cannot be nurtured. The relationship between a social worker and a user is consensual. It is therefore an agreement on mutual interaction, competences, tasks and responsibilities. It enables an interpersonal dialogue of both parties participating in the helping process in order to work together and co-create solutions (Mali, Mešl & Rihter, 2011, p. 54).

Story-telling also demands particular skills, abilities and competences that enable quality communication between a user and their social worker. Successful communication in social work demands knowledge on methods and forms of conversation. We need knowledge and skills for verbal communication. We also need observational skills. Behaviour, or non-verbal reactions, on the part of the users are often more telling than their words. Communication patterns are not universal; they are subject to culture, gender, age, status and are determined by the various dimensions of users' worlds (Thompson, 2005, p. 88). For this reason, social workers need knowledge on the social construction of reality in communication with users. Understanding a user's distress goes hand in hand with interpersonal communication, which displays the multi-levelled involvement of a social worker in the user's world.

In social work practice, we often encounter people with limited skills in story-telling. When it comes down to people with dementia, their verbal communication is hindered due to the disease, which is why stories of people with dementia are often related to the stories of their relatives. This represents the co-authorship of stories, because relatives complement the stories of people with dementia or reconstruct narrations that have been expressed in an unrelated or unclear way by an individual with dementia. This may take the form of the co-construction of narratives, whereby the final narrative is very deliberately and consciously a negotiated product between those living with dementia and others (Baldwin, 2013, p. 37). Nevertheless, even this type of story-telling needs to be encouraged, since it is through common stories

that the meaning of experiences of people with dementia are highlighted. Family members may also benefit if we involve them in the life story process, as well. Gibson (2005, pp. 178–179) wrote:

They may find an intriguing way of actually spending time with their ageing, deteriorating relative; discover that dementia is less frightening or threatening and they may begin to accept their own inescapable ageing and mortality.

Bartlett and O'Connor (2010, p. 88) suggest on the Baldwin literature that the practitioners look toward joint authorship where the narrative processes are shared or co-constructed and a final narrative is a deliberate and consciously negotiated product between those people living with dementia and others, or a piecing together of the fragmented narratives of the person living with dementia with those who support them. We believe that this is the starting point for different treatment for people with dementia, especially treatment that will enable people with dementia to lead proper lives, adapted to their own needs and desires.

Methodology

The aim of this paper is to present the findings based on the analysis of the stories from relatives of people with dementia that are important for the creation of social work practice in this field¹. In the narration from relatives of people with dementia, we may find sources, key points and experiences of people with dementia as a starting point to provide them with help from the perspective of partnership with relatives and people with dementia.

We see relatives as important co-workers in the process of providing help to people with dementia, because they are very familiar with the individual. However, they are also very burdened by their care-providing. There are some other negative effects of dementia upon family carers according to Gibson (2005, p. 178): “Grief for changing or lost relationships, increasing social isolation, a feeling of subjective burden, stress and exhaustion.” By telling us the story of their relative with dementia, they release their burden, on one hand, and, on the other, recognise the advantages and disadvantages of living with dementia, thereby discovering sources, key points and bases for good quality help for people with dementia.

Our contribution is based on qualitative research in which the empirical material is presented by the stories of relatives caring for people with dementia. In the academic years 2014/2015 and 2015/2016, 25 students of Masters study Social work with older people at the Faculty of Social Work, University of Ljubljana, collected stories of people with dementia during the social work study course: *Holistic care for people with dementia*. They collected 25 narrative interviews. Before having conducted the interviews, the students were

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involved in forming the questions on the basis of lectures, practical classes, workshops and literature studies on dementia, with special attention paid to the social dimensions of the disease, formal and informal care, the relevance of integrated care and various forms of help in social work. Preparatory classes consisted of conversation and case studies of stories from abroad (i.e. Whitman & Trollope, 2010). In cooperation with the students, the author of the paper designed instructions on how to document stories in the structure and form of records, further on, she also provided comments on the collected records. It was essential to put a human with the experience of dementia (i.e. the narrator of the story) at the very core of the written story and not their relatives. The records of the stories were then forwarded by the students to their interviewees who verified the correct annotation.

Field work, i.e. concrete conversations with relatives of people with dementia, was executed independently by the students with no intervention on the part of their teacher, although they were offered assistance in case they needed it. The interviewees were selected from the students' own social network or students were helped by their mentors in learning centres where they received practical training in social work. During the time of the collection of stories, the teacher was available to them for consultations.

After having collected the interviews and written down stories, we carried out a group presentation with the relatives of people with dementia as guests. The meeting was attended by only one relative. The reasons for poor attendance are to be found in the stigma, experienced by family carers, which has already been drawn attention to by Mali, Mešl & Rihter (2011). Nevertheless, all the relatives were enthusiastic about the records of stories. Some even suggested their publication, so that other relatives could get valuable information on the care of people with dementia.

It is precisely due to the active role of relatives that the students gained relevant experience in concrete practical work with the relatives of people with dementia and thus, came closer to the living world of people with dementia. During the evaluation of the subject matter they clearly stated that such form of learning was much more effective than classical learning taking place in lecture halls. Above all, they learned a lot regarding the communication with users, which is a key social work skill.

The interviews were conducted with 6 men and 19 women. Their roles in relation to each individual with dementia were different. The research involved family members and acquaintances. In seven cases, the narrator was the wife of a man with dementia; in fourteen cases, children (in four cases sons and in ten cases daughters); in three cases grand-children (in one case a grandson, in two cases a granddaughter) and in one case a female friend of a woman with dementia. The stories also differ in terms of whether the persons with dementia lived in their home environment or in an institution at the time the narration was recorded. In eleven cases, people with dementia lived in their community, in their home environment and their stories were told by their care providers; in fourteen cases, they lived in homes for older people. Such frequency of the institutionalisation of people with dementia is not surprising, because it is

characteristic for Slovenia to provide extremely institutionalised care for older people (Mali, 2011; 2010). In Slovenia we do not keep the evidence of carers, just an estimation assuming the same degree as the European average. Larkin and Milne (2014, p. 26) highlight that over a quarter (26 per cent) of all carers care for a spouse or a partner, and more than half (52 per cent) care for their parents or parents-in-law.

The content of the stories is divided into three thematic headings in which the following categories of data were formed:

1. Recognising the disease in a relative: beginning of the disease; diagnosis; initial changes in life of an individual with dementia.
2. Knowledge about dementia: general information and knowledge on dementia.
3. Changes within a family: changes in interpersonal relations; changes in everyday routine; organising formal help.

In the following chapter, we present the key findings from each of the thematic headings in relation to the role of the relatives in the empowerment of people with dementia.

Stories were analysed by using the qualitative method according to Mesec (1998), which is an established method of analysing empirical material in the area of social work in Slovenia. Mesec (1998, p. 102) summarised this method as a research process in which we form concepts and, from concepts, categories are formed and linked to prepositions (judgements) that are further organised into a fairly systematic and coherent theory that reads as a narrative on the phenomenon that was the subject of the research.

By using the above-described research approach, we strive to show that the inclusion of relatives of people with dementia in dementia research is possible and is vital for encouraging the active role of users in tailoring further strategies of help. In Slovenia, there is no tradition of research on dementia that involves the people with dementia, as presented by Innes (2009), who demonstrates the inclusion of people with dementia in research in terms of the third stage of research development, whereas the first stage is presented by research on the effects of care on family care providers and the second by research on the characteristics of care provided by formal care providers. Mali (2007) shows that research on the social perspectives of dementia in Slovenia begins with the involvement of relatives and formal care providers, whereas people with dementia are only involved indirectly, through observation; interviews with them are also scarce. However, we show how through the involvement of relatives we may include people with dementia in our research and thus, open space for more active inclusion for people with dementia in the future.

Research results

Recognising a disease in a relative

We deliberately did not start to talk with the relatives in terms of the diagnosis of dementia, because the label dementia has a very stigmatised connotation and, in this way, does not play an encouraging role. As Milne (2010, p. 228) described:

The combined impact of the dementing illness itself – cognitive decline and memory loss – and the negative responses to diagnosis and symptoms, profoundly undermine the psychosocial wellbeing and quality of life.

Our focus was on the description of changes they recognised as the starting point of dementia. The relatives state that they began to notice the behaviour and actions of their family member with dementia when they pointed to memory problems. At first, they attributed memory gaps to changes brought about by age and therefore did not pay greater attention to it. But when they witnessed an unusual event, they assumed that the memory problems were the result of unusual aging. Unusual events may be various and are dependent on the organisation and functioning of the family. For example, the fall of a grandmother who lived alone, far away from her relatives, had large consequences on her independence. After having fallen, she was hospitalised and was completely confused during her treatment at the hospital. The physicians and health staff informed her relatives that she was showing the signs and symptoms of dementia, so she did not go back to her home environment after treatment, but was released directly to a home for older people. The voice of the grandmother, her wishes and needs, were completely ignored.

After unusual events, memory loss is the second most frequent reason why relatives suspect dementia. When relatives notice strange behaviour in their family member, they quite accurately describe the areas in which they notice their family member's memory loss. This is an important piece of information for professionals (i.e. doctors and health care professionals), as relatives' observations should be taken into account during the helping process.

Relatives also reported changes in behaviour, habits and convictions. They describe them as personality changes. For example, a father who was never quarrelsome, suddenly began to get caught in quarrels often; a mother who was always a meticulous housewife and wife changed overnight and left household chores to others; a father who was always cheerful and enjoyed company suddenly became sad, apathetic and antisocial. Nevertheless, mood and habits may swing, but it is difficult to discern the behavioural pattern that leads to further confusion and lack of understanding by relatives. The content of this information could be useful in social work practice since relatives often understand dementia as a condition of normal ageing and not an illness.

The process of diagnosis is experienced and described through various emotions, e.g. as shock, fear and sadness. Shock is the most frequent emotion reported by relatives as a response to the diagnosis. In some cases, shock is the result of the quick deterioration of health and the diagnosis merely confirms the suspicion that dementia is the cause. In others, shock appears to be a reaction to the long-term hiding of the disease, which concerns both individuals with dementia and the people who live with them. The fear appears in those who have not heard of dementia or cannot imagine the consequences it may cause in their lives. It is a reaction to the unknown, to the feeling of insecurity and ignorance regarding the changes that await them. Those who are familiar with the disease are usually overwhelmed by feelings of sadness, especially when they are well acquainted with the disease and are afraid of getting it themselves. Marshall

and Tibbs (2006, pp. 190–191) suggest counselling for carers, because relatives experience a lot of issues that cannot be shared within families. Social workers could be the counsellors to relatives with regard to listening and offering what is called “unconditional positive regard”.

Contrary to relatives who tend to experience strong emotional reactions when they find out about the diagnosis, some people with dementia see it as obvious and give in to fate:

Stane had no emotional reaction to the disease, he accepted it indifferently and even when asked what he thought about it, he said if it was meant to be, let it be. (Z 12)

In some families, the relatives assume a caring and protective attitude and do not mention the diagnosis to their family member. We cannot state with certainty that people with dementia are not aware of their disease, so they should believe their family member when they say they were not aware of the disease:

After the diagnosis, my mum’s life didn’t change much, because she was already in her own world. Even when we talked to her about her disease, she didn’t understand the conversation. She claimed that she didn’t have dementia and that she didn’t see herself forgetting things. But she forgot that she had forgotten. (Z1)

Such conviction is probably the consequence of the social stigma around the disease, since dementia is still a mark, a label and therefore something bad (Cantley, 2001; Innes, 2009; Mali, 2009; Milne, 2010).

Knowledge about dementia

Relatives use various resources to learn about dementia. The use of these resources shows that information about the disease is still not general knowledge, so the choice of approach to finding information is dependent on the individual. The strategy of gaining information is also dependent on situations and events on the basis of which people are acquainted with the diagnosis. The patients and their families receive their first information on the disease through the physician. Information on the disease is also gained from various physicians, not only from the specialist who gave the diagnosis, but also from general practitioners, family practitioners and psychiatrists. The families did not see the information gained from physicians as sufficient, so they sought additional information from various sources, but social workers were not mentioned. This finding from our research is important because our help could be developed in this context of help and support for relatives. Instead of gaining the help of social workers, the younger and middle generations of relatives often read material about the disease published on the Internet.

Often, they combined information received from professionals and acquaintances who already had experience with providing care for people with dementia with information from literature (books, magazines, articles, etc.). We also recorded the process of the person with dementia and a family member learning about the disease together:

Soon I realised that no matter how much you read, your situation is always new and unique. Every symptom will manifest in your family member and in your environment in a new way for which you are not prepared. But this is also an experience that makes you grow as a person ... (Z 20)

Learning along with people with dementia is exactly the sort of learning we all need, including family care-providers and professionals, in order to have a better understanding of the disease itself, and, above all, the problems it may cause:

My mum was in many ways my greatest teacher, the master of all of us. She took our life with dementia to a new level and she managed to bring us closer; she showed us what really matters in life. Of course, there comes a time when things get intense, but our relationship has improved and now we are more permissive and accommodating to each other. We are stronger. (Z 20)

Not only does such an approach to getting to know dementia have advantages in the practical implications of learning, but it also makes people with dementia assume a new role. Thus, people with dementia are becoming our teachers, allowing a shift from the role of a service user into a new position that empowers them in the support process. Such a position enables them to co-create solutions for the problems and distress that they need to cope with on a daily basis, living with a family member's dementia. It gives the opportunity to develop the model of citizenship (Marshall & Tibbs, 2006, p. 18) which involves civil, political and social rights and participation in the sort of activities most of us take for granted such as work, leisure, political debate and religious observance. Even though this model for Slovenia is new and has not been mentioned in the Strategy for coping with dementia in Slovenia in 2020 (2016), we have to consider it. The role of social work in promoting the citizenship model is inevitable.

Changes in the family

On the basis of the data research findings (Mali, 2008; Mali, Mešl & Rihter, 2011), we know that intensive care is taken on by one family member, usually a woman, who is most closely related to the individual with dementia – e.g. wife, daughter-in-law, granddaughter (Gillard, 2001, p. 88). Other relatives may also get involved, though less intensely, in the support process, through performing various tasks and chores. In most cases, we observed cooperation among relatives. Female partners are assisted by brothers, daughters and granddaughters and their partners. In several cases, we observed increased feelings of belonging in a family, which was the result of providing care for an individual with dementia. Dementia may strengthen family ties (Toseland, Smith & McCallion, 2001).

The most extensive problem in care provision concerns communication with individuals with dementia and their family care-provider. Relatives see changes in communication in relation to the progress of the disease. They are disturbed by the fact that they cannot possibly know if their family members with dementia have eaten enough, if they are full or hungry, and what sort of help they need, because they can no longer use words to express how they can be helped. Such behaviour raises special concerns in

care-providers. They state that such events make them realise that they are losing them, so they tend to encourage and motivate them to talk for a while more. Of course, such communication demands a lot of time and patience.

For relatives, care for people with dementia has a special value because they gain special life insights through their own experience. They draw attention to the fact that we do not cherish the positive moments in life enough. Dementia highlights the tiny little things that improve our lives, to which we are usually oblivious:

Diseases such as dementia cannot be taken in a positive way, but it has enabled us to see our mother in a different light. One begins to cherish the moments when this individual is truly with you. (Z 4)

Family care-providers also get to know the value of their own lives through providing care:

Dementia is a disease that took a lot away from me. But on the other hand, I can also say that it gave me experience, knowledge and understanding. Due to my parents' dementia, I see many things differently and I am grateful for each and every day I am given. (Z 17)

This sort of knowledge cannot be gained while growing up, but only through personal ordeals brought on by living with dementia. Although we may live in a world that does not accept faults, we are still people who make mistakes. Dementia may give us an opportunity to “become human” again, and above all shows us how we are unique as people, as well as important and needed in this world (Kitwood, 2005). That is the confession of a son who lives through his mother's disease and claims:

My perspective on the world has changed throughout the disease. Once you have an experience like this, which affects all areas of your life, you change and you learn to accept each day as it comes and try to make the most of it, knowing that it won't be the same as the day before, which is a challenge in its own right. (Z 20)

Often, relatives combine various forms of help or increasingly connect with one care-provider in one period of the disease and with another in the other period of it. When a family puts forward the needs for medical assistance in providing care for a relative with dementia, other family members also begin to cooperate more intensely with practitioners and home care services. But when the need for help from the social perspectives of life are put forward, the assistance of social care-providers and social care at home is highlighted.

Relatives describe the reasons for resorting to additional help as a combination of circumstances that necessitate a change from well-planned and organised family support. External help represents a solution:

It is difficult to take care of your own family and at the same time provide care for parents. My blood-pressure rose and I experienced trauma. Now, it would be fair to say that I am relieved and find it much easier to coordinate everything, although I still cannot grasp how this happened to us. (Z 8)

When additional assistance is not enough, it is inevitable that individuals with dementia must move to an institution. Family members claim that prior

to this, they try everything they can to help their relatives stay in their home environment. They give up their annual leave, and assistance at home, but when his/her suffering becomes too overwhelming, moving to a home for older people is the only option left.

Conclusion

In social work with people with dementia, narrativity is not yet a frequent and established form of help for people with dementia and their carers. Narrativity in social work is also not yet well documented in literature, which is criticised by Baldwin (2013). He claims that social work and its working up of cases, assessments, care plans, reviews and their presentation to supervisors, panels and courts are, essentially, a narrative activity. Our contribution shows concrete use of narrativity in social work in direct relation to the provision of support for people with dementia in order to establish a better visibility of life with dementia and thus, form more adequate help for service users.

The analysis of the stories from relatives of people with dementia shows that verbalising experiences of living with dementia enables relatives to recognise ways to take action, which empower them in the helping process. Ways to take action were recognised while gaining knowledge on dementia (people with dementia transfer their knowledge on the characteristics of dementia, the development of the disease, adequacy of help), communicating (relatives seek ways of communication that maintain the existing abilities of communication of people with dementia), recognising the disease (they observe changes in their relative with dementia very well and accept them) and becoming aware that dementia is not only a disease, but an experience that makes our lives richer and complements them by revealing the essence of life.

The first step towards changing the existing practice of social work is seeing relatives of people with dementia as co-workers in the support process. Professionals need to form cooperation with relatives and believe that relatives are capable of being the co-creators of help and support. Relatives need to be encouraged to research the experiences gained in living with dementia so that they can respect people with dementia as equal members of their family.

Hiding a diagnosis from relatives with dementia, communication problems and passing the burden of responsibility for care-provision onto professionals are only some of the factors that hinder the empowerment of people with dementia. In order to eliminate these factors, various forms of help and support intended for relatives should be developed, i.e. educational and vocational training, self-help groups, counselling programmes etc.

The narrative method may be used as a method of concrete help for the family care-providers of people with dementia. It enables relatives to verbalise their experiences, their distress and their strong points and weaknesses in the helping process. We may also use it in individual work with relatives and combine it with group treatment as well as with relatives experiencing the institutionalisation of an individual with dementia.

Dementia results in a lot of negative experiences, feelings and personality changes, but can also lead to positive recognition. Over a decade ago, the conviction that there was no hope for people with dementia prevailed, that dealing with them or developing help made no sense (Innes, 2009, p. 5). Today, professionals know that this is not the case. It is our duty to convince relatives and care-providers of this fact too.

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