

Researching the social aspects of dementia from a social work perspective

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Abstract

The issues associated with dementia are challenging for social workers, who have a lot of direct contact with people with dementia, as well as their support networks. These networks play a key role in the care of people with dementia. Social workers differ from other professionals in that they are aware of the urgency of attending to social justice, as well as the implementation of human rights, participation and equality. Recognising the experiences of people with dementia is of paramount relevance to social work, as it provides insight into their needs and the aptness of existing forms of assistance in responding to their needs. Through this approach, those working in social work strive to find new forms of help to enable people with dementia to live independently in their community. It is important to find ways to involve people with dementia as active co-creators in the helping process and in exploring the social perspectives of dementia. In the present paper, we present the literature review on experience of researching dementia from a social work perspective in Slovenia and Croatia—two countries with similarities in the development of social work and its research. The inclusion of people with Alzheimer’s disease or dementia in research is very complex. Both professionals working with people with dementia (formal caregivers) and family members (mostly informal caregivers) face various difficulties and pressures. It is therefore important to consider research ethics and respect existing legal frameworks and informed consent. An individualised approach should be used to include people with dementia in research to meet their need for personal worth and dignity (despite numerous mental and functional deficits). Ultimately, all research should strive to determine the true situation of people with dementia and their needs, with the aim of using and developing their remaining abilities to improve the quality of life for both those people and those who provide care for them.

Keywords: social work, dementia, ethics, user’s perspective, needs assessment

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1. Introduction

The increase in life expectancy is associated with various risks characteristic of older people (e.g., disease, poverty, social exclusion). Among the many risks faced by older people and their social networks, which are associated with numerous changes at the micro level (the level of older people's lives), the mezzo level (the level of service organisation and services of help) and the macro level (state and society), is dementia. Although dementia is a disease, its consequences are primarily social, affecting people with dementia as well as all those close to them. The consequences of dementia have a strong impact on people's everyday lives and interpersonal relationships (Bartlett & O'Connor, 2010; Innes, 2009; Marshall & Tibbs, 2006).

It is estimated that, in Slovenia, due to the rapid ageing of the population, the number of people with dementia will increase by 60 % by 2035 (Bednaš & Kajzer, 2018); projections at the global level are similar—from 47 million in 2015 to 75 million in 2050 (World Health Organization, 2017). In Slovenia, there is no register of people with dementia, but the prevalence of dementia (i.e., calculated on the basis of epidemiological data from neighbouring countries) was estimated at 30 000 people in 2010 (Petrič et al., 2016). Today, there are probably 40 000 people living with dementia in Slovenia, 5 % of whom are in old people's homes, with the rest living in the home environment. As the disease mostly occurs in people over 65 years of age, the trend of this disease will increase in line with the increase in the proportion of people over 65, which is now 20 % of the total population in Slovenia and will reach 30 % in 2030.

According to data from 2012, 80 864 people in the Republic of Croatia suffered from dementia, which corresponds to 1.89 % of the total population (Mimica et al., 2015). Since most of them were cared for by family members, the number of caregivers was estimated at 202 164 people (an average of 2.5 people per patient). The share of people over 65 in the total population of the Republic of Croatia was 17.7 % in 2011 (Ostroški, 2013). It was estimated that it could increase to 26.2 % in 2050. Looking at the data on the prevalence of dementia in relation to age, an increase in patients is expected: 5 % of people over 65 suffer from dementia, 10 % of people over 75 and at least 40 % to 50 % of people over 85 are in the early stages of dementia (Mimica et al., 2015).

Due to the need for help from others and especially because we still do not know much about the disease, people with dementia are very stigmatised. The stigma is also felt by their relatives, who do not get enough support and help in caring for their loved ones in their home environment, so people with dementia often live in old people's homes. In Slovenia, the most common form of care for people with advanced dementia is institutional care (Mali & Kežar, 2019).

In the last decade, the phenomenon of dementia has been the subject of much discussion, research, development of new approaches and ways of working with people with dementia in various scientific disciplines and professions (Whitehouse & George, 2008). Each discipline develops its own view of dementia. The most established among the theoretical models are the biomedical model for understanding dementia and the psychological and sociological model. Cantley (2001) adds the philosophical-spiritual perspective, while Mali et al. (2011) add the social work model for understanding dementia. The latter is not often mentioned in literature, and it seems that social work does not have enough power in society against the dominant sciences in the field of research on dementia, among which medicine is assigned the leading role. Since we know that the consequences of dementia are mainly social, it is relevant to develop specific knowledge in social work to help people with dementia. Therefore, social work must have a research approach that involves people with dementia.

The purpose of this paper is to highlight the specific perspectives of research into the social aspects of dementia and the results of existing national research in Slovenia and Croatia in the field of social work with dementia. In both countries, research in the field of social aspects of dementia has been present for more than a decade and stems from a qualitative or mixed research approach, which is the predominant approach in the field of social work in both countries. Similar ethical issues and dilemmas regarding research into social aspects of dementia are prominent in both countries. Our aim is to discuss these in order to stimulate further research in this area and to inspire the research and professional community to undertake research into the social aspects of dementia. Such approach is particularly relevant to enable a contemporary development of care, which incorporates the perspective of users, i.e., people with dementia and their families. When care users are actively involved in research, they are empowered and their position in society is strengthened. Social work in practise and in the field of research has relevant experience regarding the implementation of the user perspective and can also develop this further in the field of research into the social aspects of dementia. For this reason, we will present a literature review on the social work research perspective and the ethical consideration of research on social aspects of dementia. In the second section, we present the rationale for the development of social work with people with dementia. The third section provides a historical literature review of research on the social aspects of dementia. The inclusion of people with dementia as participants in dementia research has taken place in recent decades, with Slovenia and Croatia lagging far behind. The authors illustrate the various ethical aspects of including people with dementia in research and develop a discussion of the aspects in sections four and five. In order to promote the involvement of people with dementia in research and thus enable the development of dementia care that is tailored to the needs of people with dementia, the paper concludes with a reflection on the benefits of involving people with dementia in research on the social aspects of living with dementia.

2. Dementia: A challenge for social work

A particular focus of social work is to uncover the needs of people with dementia to allow the forms of help available to people with dementia and their families to meet their needs, aspirations and goals (Moore & Jones, 2012). Due to the widespread attitude of rejection of dementia and the neglect of people with dementia, a relevant social work focus in this case is embedded in the concept of empowerment. Thompson and Thompson (2001) see the provision of empowerment as a way of overcoming the prevailing pattern of care and assistance provided to older people. Empowerment is also key for family members caring for people with dementia, as they themselves often face rejection from those around them and, moreover, exclusion from everyday life (Hill, 2015; Page et al., 2007). The focus on empowerment enables people with dementia to take responsibility for their own lives; it supports them in gaining self-esteem and awareness of the value of their experiences; it strengthens their position, enables them to take on different and valued roles and use different sources of social power to their advantage. Using the four levels of living for people with dementia (i.e., the implementation level, the interpersonal level, the economic level, and the ethical level), Mali et al. (2011) present the experiences of living with dementia and highlight the possibilities of empowerment for people with dementia.

The first level, i.e., the implementation level, is represented by everyday life for people with dementia, the problems they face due to their dementia and the characteristics of the help they receive. Continuous care, the presence of familiar people and a regular rhythm of care are essential, as is also pointed out by Bryden (2005). The second level, the interpersonal

level, refers to people's relationships, social distress and social networks. People with dementia have a strong need to establish and maintain contact with others (Kitwood, 2005), but encounter many problems in doing so. On the one hand, bonding is beneficial, as it builds mutual trust and helps to make life with dementia meaningful; on the other hand, people with dementia and their carers struggle with stress, conflict and exhaustion (Challis et al., 2009; Innes, 2009). The third, economic level, draws attention to the financial capabilities, means of livelihood and costs associated with caring for a person with dementia. The cost of care increases proportionally to the progression of the disease, as it requires the use of additional medical aids, adaptation of accommodation and, most importantly, the organisation of additional, often formal, care (institutional and community) (Hlebec et al., 2014; Mali et al., 2011). The fourth, ethical level, draws attention to the rights of people with dementia, the maintenance of respect and the presence of stigma. Practise underpinned by the ethics of care would go a long way toward advancing ethical care for people with dementia, with its potential to strengthen opportunities for expanded citizenship by facilitating participation in care (Brannelly, 2006).

Recognising the experiences of people with dementia is highly relevant to social work, as it gives us insight into their needs and the aptness of existing forms of help in responding to their needs. Through this approach, those working in social work strive to find new forms of help to enable people with dementia to live independently in their community. It is important to find ways to involve people with dementia as active co-creators of help. This requires professionals and family carers to abandon the permanent role of provider, which involves a patronising, overprotective and possessive attitude towards people with dementia (Flaker, 2012). In social work, the aim is for patients and clients with dementia to be recognised as people with important life experiences who also happen to need help tailored to their needs and who can contribute in their own way to ensuring that the help provided meets quality of life standards in the community. Care that is tailored to the person and based on their needs is also the central guiding principle of long-term care for people with dementia and is directly linked to social work theory and practise (Gardner, 2014; McDonald, 2010).

The focus and orientation toward the needs of people with dementia is based on theoretical premises of social work. These are derived from the needs of the users, in order to develop a daily routine in cooperation with them that is adapted, as much as possible, to their needs, wishes and abilities. The needs of people with dementia are often overlooked by informal carers (e.g., family members caring for a person with dementia who are unaware of their own needs due to overwork, and even less aware of the needs of the family member they are caring for) and formal carers (e.g., social care providers, as practise shows that the concept of service users' needs is not central to their work).

As we explore and recognise the needs of people with dementia, we also discover the skills and competencies of people with dementia to live independently in their community. The purpose of researching the needs of people with dementia is twofold. On the one hand, we aim to discover needs that their caregivers may overlook and draw attention to users' abilities and competencies for independent living. On the other hand, this information allows us to assess the appropriateness and success of the assistance provided.

In social work practise and in the field of research into the social aspects of dementia, approaches to exploring the needs of people with dementia are similar and based on the same premises. Social workers, although working in practise, also take on the role of researchers when providing concrete help to a person with dementia. In their professional work, they bring in the experiences of researchers of the everyday lives of people with dementia.

The methodology of researching the everyday life of people with dementia is developed theoretically and practically. One such example is the method of personal planning and implementation of services, which is a social work method developed in Slovenia based on the theoretical concepts of social work and the methodology of research in social work.

By applying the method of personal planning and implementation of services based on research conducted in the world of people with dementia, we aim to design the goals and plan the use of those services that are already available to people with dementia, as well as services that they need to acquire in order to achieve their goals. The emphasis is on the active involvement of people with dementia in the helping process, so that the method can be realised, in constant dialogue and within the working relationship with the users. Through the application of this method, the social worker directs the helping process in a way that consistently takes into account the will of people with dementia and empowers them by expanding their options and acceptable risks (Mali, 2019).

Personal planning and implementation of services is a method that is also relevant to social work, as it distinguishes the profession of social work from other helping professions. Thus, the method traces professional goals and implements their concepts while listening to the voices of users, which in social work are seen as the voices of people who experience distress, giving them a central role in the design and provision of services.

The journey to develop the method of personal planning and implementation of services in social work is based on the combination of social work theory, practice and research. The experience gained through the development of this method shows that it is possible to develop new methods of helping people with dementia, along with the combination of social work theory, practice and research on the social aspects of dementia. Based on the experience gained in developing this method, it would be necessary to adapt other social work methods to the specific needs of people with dementia.

3. Researching social perspectives of dementia

In the international literature, research on the social perspective of dementia has been present since the 1980s. We can trace the contextually and methodologically different ways in which researchers have responded to the call of current social policy and the economic and social issues promoted by existing government structures. The issues of social science and of the professions were not foregrounded, but rather the prevailing politics, which is a compelling backdrop compared to the current situation, as dementia no longer elicits sufficient attention from the prevailing political structures. The retreat of politics has allowed professional issues to enter the field of research, and now the research includes at least two areas, namely (i) the user's perspective and (ii) the research in the overlooked issues, especially the phenomenon of dementia in socially marginalised groups (i.e., migrants, older women, poorly-educated people).

Since the 1980s, we have been able to follow the social perspectives of dementia as studied in the international literature. The first research identified the characteristics of informal caregiving—more specifically, the consequences of stress and burnout, the various burdens imposed on both genders as a result of providing care, access to information and available support (Innes, 2009). The centre of research was devoted to family carers, seeing them initially from a negative perspective, but later, in the 1990s, from a positive perspective, but researchers were not very focused on examining the genuine experience of people with dementia. People with dementia were not the subject of research in any way, so we learned nothing about the quality of informal care in the first round of research.

The second wave of research also did not involve people with dementia but rather

focused on the experiences of formal carers. Researchers (Cantley, 2001; Innes, 2009; Lynch, 2014) found that care in this setting was provided by poorly qualified staff who were poorly paid for the work they did and were socially neglected due to their gender and ethnicity. Formal care was provided by representatives of marginalised social groups, and they cared for stigmatised people with dementia in facilities designed for old people (Innes, 2009). Later, researchers focused on exploring formal care within the community and looked at to the relevance of developing care beyond caring for a clean and fed body, as it became more relevant that establishing good relationships with people with dementia, as well as new methods and approaches to providing help, were key (Feil, 1992; Kitwood, 2005).

The third wave of research contributed to a complete turnaround, with the first research in the late 1990s finally looking at the concrete experiences of people with dementia (Innes, 2009). The reason for this late inclusion of people with dementia in the research was that the professional community believed that people with dementia were unable to communicate (Cantley, 2001). The inclusion of people with dementia encouraged a critique of the formal delivery of care, professional work and the development of high-quality care tailored to the needs of people with dementia. Researchers paid attention to the overlooked and lesser-known issues, such as the occurrence of dementia in people younger than 60, representatives of ethnic minorities, people living in rural areas, people with complex health issues, etc. Research into the precise new phenomena on living with dementia drew attention to finding new responses to people's needs and new perspectives on help and care.

Research on the social perspectives of dementia in Slovenia has only existed for under two decades (see Table 1). Nevertheless, we have followed the research trends from the very beginning, bringing the user perspective into the research, which is a conceptual guideline of social work. In 2003, we conducted the first round of research because we were aware of the gap in this research area, so we used contemporary research methods by bringing in our own practice of user and action research. The study entitled "Working with people with dementia—developing a model of treatment of people with dementia" (Flaker et al., 2004), conducted at the Faculty of Social Work in Ljubljana in 2003 and 2004, captured and condensed the experience of working with people with dementia in old people's homes. From 2005 to 2009, we conducted research on forms of community-based care for people with dementia (Mali, 2009). In 2014, we began narrative research on dementia by collecting stories from family members of people with dementia about the lives of their family members. Through their stories, we showed how it was possible and meaningful to learn about the world of people with dementia in order to stem from a living situation of a person with dementia in the helping process (Mali, 2018).

Over the past four years, our research on dementia has been dedicated to developing practices based on interdisciplinary collaboration. In these projects, our knowledge from social work was complemented by various technical (Mali et al., 2016), humanities (Mali et al., 2017) and social science (Mali et al., 2019) disciplines. On the one hand, this research verified and added to the knowledge and concepts of social work with people with dementia, while on the other, we maintained the user perspective with an advocacy stance and tested its application in collaboration with natural science disciplines.

Caring for people with dementia is a very demanding task and research on the subject often reports on the stress that carers are confronted with. For this reason, in our recent research in Croatia, we focused on both informal and formal carers, on the problems they face and on the benefits that caring for people with dementia brings. In our work, we used a qualitative approach to understand the perspective of (informal and formal) carers (Štambuk & Levak, 2018; Tilinger & Štambuk, 2018). The findings obtained about informal (family)

caregivers in the Zagreb area (Tilinger & Štambuk, 2018) point to numerous problems faced by informal caregivers of people with dementia. Namely, they have to acquire new skills needed for their new role as a caregiver, which requires a major adjustment and reorganisation of their previous life at all levels, including struggles with full-time care of a person with dementia, additional housework, role conflicts, difficult communication due to conversations about meaningless topics, and/or complete inability to communicate with the person with dementia. Carers also face inadequate social perceptions of their environment and often feel the public is not sufficiently educated about the condition itself. Similarly, informal carers face systemic issues including no options for institutional accommodation for the person with dementia or support and assistance from professionals as these carers are also inadequately educated. As a result of this demanding nature of care, carers report a lack of time for leisure activities, friends and family, leading to social isolation. Finally, a major problem for informal caregivers is their own impaired psychophysical functioning, reflected in burnout, sleep problems, and impaired physical health. All these problems point to a very difficult position of informal family caregivers in Croatia. Research on formal caregivers (Štambuk & Levak, 2018) shows that there are different levels of problems they face. Thus, there are problems of a personal nature that affect them (feeling helpless and exhausted), followed by those related to the organisation of work (lack of staff, difficulty of working night shifts, impossibility of an individualised approach), and finally those related to the lack of understanding of family members (poor education about the disease, rejection and difficulty in adapting to the course of the disease, unrealistic demands and distrust of professionals). A wide range of responses related to the benefits of caregiving were categorised into four themes: emotional fulfilment, increased sense of meaning and purpose in life, personal growth, and a new perspective on old people. Although the benefits of caregiving for this population are rarely addressed in the research literature, knowledge of them may point to some protective factors that can help professionals cope with the issues that caregiving brings.

Table 1. Research on social aspects of dementia in Slovenia and Croatia.

ID	Research description
1	<i>Research title:</i> Working with people suffering from dementia—preparation of treating model for people suffering from dementia in Slovenian homes for the older people (2003–2004, Slovenia) • <i>Research team:</i> V. Flaker, B. Kresal, J. Mali, V. Milošević-Arnold, L. Rihter, I. Velikonja • <i>Research topic:</i> Care for people with dementia in old people's homes • <i>Methodological approach:</i> Mixed methods (qualitative and quantitative)
2	<i>Research title:</i> Living and support forms for vulnerable groups of citizens (people with dementia, people with protracted mental disorder and mental deficiency) in the municipality of Ljubljana (2006–2008, Slovenia) • <i>Research team:</i> G. Čačinovič Vogrinčič, V. Grebenc, T. Kodele, J. Mali, V. Milošević-Arnold, L. Rihter, J. Škerjanc, M. Urek • <i>Research topic:</i> Forms of community-based care for people with dementia • <i>Methodological approach:</i> Mixed methods (qualitative and quantitative)
3	<i>Research title:</i> Narrative approaches in social work with people with dementia (2014, Slovenia) • <i>Research team:</i> J. Mali, N. Žitek • <i>Research topic:</i> Stories from family members of people with dementia • <i>Methodological approach:</i> Qualitative methods

Continued on next page

Table 1. Research on social aspects of dementia in Slovenia and Croatia. (Continued)

ID	Research description
4	<i>Research title:</i> Technological support at the care for people with dementia in community (2015, Slovenia) • <i>Research team:</i> J. Mali, A. Košir, M. Novljan, M. Mihelin, M. Smolnikar, N. Žitek, M. ten Veen, M. Kukulj, B. Penič, S. Smergut, K. Verbovšek Zabukovec, A. Debevc, Č. Letnar, D. Sirnik • <i>Research topic:</i> Interdisciplinarity in dementia research • <i>Methodological approach:</i> Qualitative methods
5	<i>Research title:</i> Dementia disclosure using artistic means of expression (2017, Slovenia) • <i>Research team:</i> J. Mali, J. Zakonjšek, T. Gubenšek, G. Stibilj, A. Tajnšek, T. Plečko, K. Ličen, L. Akif, M. Valič, N. Berger, S. Ivanov, V. Švigelj • <i>Research topic:</i> Interdisciplinarity in dementia research • <i>Methodological approach:</i> Qualitative methods
6	<i>Research title:</i> Freedom of movement in the lives of people with dementia (2019, Slovenia) • <i>Research team:</i> J. Mali, A. Kežzar, D. Zupančič, S. Šegula, M. Mlinarič, Z. Govedič, L. Fajković, E. Miklavčič, P. Frece, R. Hirsch, N. Furlan, A. M. Mičić, D. Vrenko • <i>Research topic:</i> Interdisciplinarity in dementia research • <i>Methodological approach:</i> Qualitative methods
7	<i>Research title:</i> Problems of informal (family) caregivers in the care of people with dementia—a qualitative approach (2018, Croatia) • <i>Research team:</i> A. Tilinger, A. Štambuk • <i>Research topic:</i> The perspective of informal carers • <i>Methodological approach:</i> Qualitative methods
8	<i>Research title:</i> The difficulties and benefits of working with people with dementia from the perspective of formal caregivers (2018, Croatia) • <i>Research team:</i> A. Štambuk, K. Levak • <i>Research topic:</i> The perspective of formal carers • <i>Methodological approach:</i> Qualitative methods

The content of research on the social aspects of dementia in both countries reflects the current circumstances in the lives of people with dementia and their families. In the absence of available national guidelines in this area, researchers tend to explore areas and issues relevant to the science and profession of social work. The needs of people with dementia and their relatives are brought to the fore, as this is essential to social work practise. This means that future research should also address the ethical dilemmas that arise during research in this area.

4. Ethics of research on the social perspective of people with dementia

A better quality of life for people with dementia can best be achieved by raising awareness of and resolving a number of ethical dilemmas that arise when working with people with dementia. This is often difficult. Sometimes these problems seem insurmountable, and it is difficult to decide what to do because it is not clear what is right or wrong (Alzheimer Europe, 2014). It is not always possible to give precise solutions to specific ethical dilemmas because we cannot generalise about people with dementia or their specific life situations. Therefore, the best solution to an ethical dilemma differs from individual to individual and does not always result in an ideal situation; nevertheless, we must strive to solve each ethical dilemma in a way that is best for the people involved (Alzheimer Europe, 2014). One way of analysing the level of care from the perspective of a person with dementia has been proposed by Brannelly (2006). She advocates for an ethic of care in which the impact of care decisions can be assessed using four criteria:

1. **Attentiveness:** when the needs of the person with dementia are upheld and the caregiver relinquishes control to empower and reaffirm the agency and citizenship of the person with dementia.

2. Responsibility: when practitioners identify connections between themselves and the person with dementia.
3. Competence: when the person with dementia is enabled to set the outcomes of care that would be good for them.
4. Responsiveness: when the care provider understands the viewpoint of the person with dementia and provides an opportunity to change the method of care to make it more suitable for the person.

The guidelines established by Brennelly in the field of caring for people with dementia can also be applied to the field of research on the social aspects of dementia. It is therefore important to explore how people with dementia can be involved in research in a way that best reflects their right to autonomy.

As a disease-related consequence of dementia, people with dementia are often dependent on other people, but this does not mean that their autonomy cannot be fostered in emerging circumstances. Maintaining autonomy allows people to shape their own lives according to their values and personality in a way that fits their identity (Smebye et al., 2016). Promoting autonomy does not only involve respecting the desires and values possessed in the early stages of dementia, but also means that people who become dependent on others through the development of dementia may need the support of those who care for them to continue to maintain their autonomy and feelings throughout later stages of the disease. Providing such support requires an understanding of what a person with dementia feels, wants and experiences. As people with dementia experience more severe cognitive decline over time, this becomes increasingly difficult. However, as long as people with dementia are still able to live and express their feelings and needs, it is important to enable their participation in the research (Alzheimer Europe, 2014).

Of all the professions involved in the care of people with dementia, social work is the one most committed to ethical behaviour and concern for making ethical decisions regarding the lives of people with dementia. Social workers need to be vigilant in putting the rights of people with dementia into practice and exposing any violations or discriminatory practices. Similarly, such an approach must also prevail in the field of research on the social aspects of dementia, so we will present the ethical perspectives of including people with dementia in the research in more detail.

5. Informed consent and other legal principles relevant for researchers

When considering the ethics of exploring the social perspective of dementia through the involvement of people with dementia, the greatest area of ethical uncertainty relates to the process of obtaining informed consent. For informed consent to be valid, it is important that people with dementia be informed about the relevant aspects of the research and that they give their consent freely (Sherratt et al., 2007). Free and informed consent requires that the whole process consists of dialogue, information sharing and decision-making regarding participation in the research (Slaughter et al., 2007). Informed consent involves, among other things, the researcher ensuring that the research participants will not be harmed in any way and that their participation in the research will not harm them (Wilkinson, 2002). Therefore, for individuals to be competent in giving informed consent, they must be able to understand the information presented to them and evaluate the possible consequences of the decision made. A person's ability to give informed consent also varies according to the level of complexity of the research subject, so there appears to be greater compatibility between the abilities of a person with dementia and less complex research processes (Sherratt et al., 2007). Keyserlingk et al. (1995) emphasise that respect for people with dementia requires

that every effort is made to help them understand the research subject as well as possible. However, it is sometimes very difficult for even the most experienced researchers to assess the extent to which this understanding has been achieved, particularly when a person is in the later stages of dementia (Sherratt et al., 2007).

It has often been argued that reduced cognitive capacity is not a sufficient reason to exclude people with dementia from research, thus denying them their right to participate in the research around issues of greatest concern to them (Sherratt et al., 2007). Swain et al. (1998) suggest that in addition to the right to privacy, people with dementia also have the right to be “seen and heard”. Furthermore, equality is the fundamental principle of inclusive methodology, based on the premise that people with dementia should be “valued and respected as embodied, self-creating social actors” (Sherratt et al., 2007). If we are to promote the empowerment of people with dementia, it is necessary to work on more inclusive research strategies that incorporate the experiences and visions of those affected (Wilkinson, 2002). Also, in response to the question of why people with dementia should be included in research, it can be argued that an understanding of the experience of living with dementia is necessary and such an understanding cannot be developed solely through participation by representatives of people with dementia (Wilkinson, 2002).

Berghmans and Meulen (1995) emphasise the relevance of the ethical principle of well-being and the absence of adverse effects for people with dementia arising from their participation in research. They accept that participation in research rarely brings individual benefits to that person, nonetheless the main aim of the research is to contribute to greater awareness and better care in the future. However, by subjecting to these studies people with dementia who are unable to make an independent decision about consenting to participate, the principle of ensuring well-being and the absence of adverse effects of participation is violated. Berghmans and Meulen (1995) contend that this problem can be overcome by making a distinction between therapeutic and non-therapeutic research: while therapeutic research benefits the participants themselves, non-therapeutic research has no direct benefit. They conclude that involving people with dementia in studies where they have no direct benefit should be illegal and is unethical.

Researchers play a vital role in the process of obtaining informed consent. In order to include people with dementia in research delicately, it is important to explain the intention of their participation in the research in a meaningful way. The moral character of the researcher provides the most important protection for people with dementia (Span et al., 2017). To ensure full protection for people with dementia, researchers should use an individualised approach and seek to assess the person’s remaining cognitive abilities and understand the extent to which consent can be given (Sherratt et al., 2007). If a researcher determines that a person is unable to give informed consent, there is an obligation for researchers to obtain both that person’s consent, as well as informed consent from that person’s legal guardian.

Dewing (2007) states that consent involves a reflective process on the part of the researcher, who must do the following:

1. Make background preparations to gain access.
2. Establish the basis for consent: e.g., when and how to ask and on what basis to decide on the ability to consent.
3. Obtain initial consent through verbal, written or visual information.
4. Monitor ongoing consent; this will ensure that visual or verbal signs from participants expressing discomfort or stress when participating in the research are taken into account and that the initial consent does not mean that an individual is ready to participate at all times.

5. Provide feedback and support to caregivers as needed regarding the person's comfort level and take notes on the research process for later personal reflection.

Strategies to promote informed consent include recognising the need to adapt the consent form to reflect changing cognition. This could include, for example: using simpler language; supplementing words with pictures and/or creating pictorial consent forms; audio recording consent, rather than relying on written consent (Bartlett & O'Connor, 2010).

If it is deemed necessary to obtain informed consent from a proxy, it is important to ensure that there is no conflict of interest and that the proxy is acting in the best interests of the potential research participant (Span et al., 2017). Preserving a person's autonomy requires that an authorised representative, namely a legal guardian, makes decisions that respect the previously expressed values and beliefs of a person with dementia. Therefore, it is necessary that the guardian is a person who knows the person with dementia well enough to be able to assume what decision that particular person would have made in such a situation before the manifestation of dementia. The principle of the best interest of the person with dementia (Cacchione, 2011) should be applied when giving informed consent.

It is also important to support family members and carers in decision-making situations about the extent of the user's capacity to make independent decisions. The principles set out in the "Mental Capacity Act" and "Adults with Incapacity Act" (Wilson, 2017) form the basis of good practise for carers of people with dementia when they find themselves in decision-making situations. The above legal principles are also ethical principles that guide the care and support of people with dementia. It is important that a person is considered capable until proven otherwise (Alzheimer Scotland, 2012). The traditional notion that people with dementia lack the capacity to identify their own interests has been replaced by an attitude based on the principle that the existence of capacity in people with dementia must be assumed (Sherratt et al., 2007). Secondly, it must not be assumed that a person is not capable just because they once failed to make a wise decision. Thirdly, it is necessary to continually support people with dementia to make their own decisions. It is also stipulated that any decision or activity made on behalf of a person must be in that person's best interests. It is important to take into account the views of the experts as well as any past and present opinions, beliefs and wishes of the person with dementia, whilst continually encouraging the person to use their skills and develop new skills where possible (Alzheimer Scotland, 2012). Situations in which people with dementia need to be prevented from making their own decisions arise from the need to maintain their well-being and avoid the harm that people with dementia could do or face if they are not supported (Smebye et al., 2016).

A person with dementia should also be able to withdraw from research at any time without having to give reasons for withdrawal, provided that this does not pose a high potential risk to that person (Slaughter et al., 2007). It is important to note that the wishes of people with dementia may not always be respected and that the views of carers of people with dementia may not always reflect the views of the people they represent. In order to make research involving people with dementia ethical, it is important that researchers explain why the participation of people with dementia in the research is relevant, what risks they may be exposed to during the research and why the purpose of that very research cannot be achieved by excluding people with dementia completely. It is always desirable to seek the consent of a guardian, even if a person with dementia has the capacity to give consent. It is important to consult the Ethics Committee, even if not required by law, for constructive guidance. It is necessary to keep records of all processes and forms of consent and assent. It is also essential to systematically monitor and consider the frequent changes in the law in order to remain compliant (Sherratt et al., 2007).

6. Conclusion: Benefits of inclusion of people with dementia in research

The increased rate of inclusion of people with dementia in research is the result of an approach based on the principles of equality, personhood, ethical care and social justice (Slaughter et al., 2007). Furthermore, the inclusion of people with dementia in research contributes to a decrease in depression, better quality of life, lower levels of negative tension and higher levels of understanding in people with dementia (Span et al., 2017). Indirect benefits from participating in research are notable, highlighting the opportunity to meet new people, be taken out of the daily routine and develop a sense of usefulness. The most common benefits to an individual highlighted by social research are a sense of empowerment and the development of their sense of satisfaction and altruism (Sherratt et al., 2007). Such research also holds benefits for society in general, the most significant of which, and the reason why some people with dementia choose to participate in research, being to remove other people's prejudices and fears about dementia.

The aforementioned sense of usefulness, along with providing information to society, serves to maintain a better quality of life for people with dementia (Span et al., 2017). The long-term benefits of involving people with dementia in research on the social aspects of dementia can change the position that people with dementia have in society, through their own empowerment. Although "empowerment [...] means different things to different people" (Adams & Adams, 2008, p. 17), there is some consensus on its broad use as the dynamic process by which individuals and groups gain or increase choice and control over the most important aspects of their lives in order to maximise their quality of life (Larkin & Milne, 2014). Empowering family members caring for people with dementia is also of key relevance, as they themselves often face rejection from those around them and exclusion from everyday life (Hill, 2015; Page et al., 2007).

Involving people with Alzheimer's or dementia in research is a very complex area. Both professionals working with people with dementia (formal carers) and family members (mostly informal carers) face various difficulties and pressures in their work. It is therefore important to consider research ethics and respect existing legal frameworks around informed consent. An individualised approach should be used to include people with dementia in research to meet their need for personal worth and dignity (despite numerous mental and functional deficits). Ultimately, any research study should look at the implications for determining the real situation of a person with dementia and their needs, with the aim of using and developing the remaining capacities to improve the quality of life for both that person and those who provide care for them.

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