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The Legal System and Alzheimer’s Disease: Social Workers and Lawyers’ Perceptions and Experiences

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ABSTRACT

The expected increase in the number of people living with Alzheimer’s disease (AD) worldwide will be accompanied by an increase in the number of cases involving persons with AD brought up to the courts. This study examined the perceptions and experiences of social workers and lawyers regarding these cases. Three focus groups including social workers and lawyers (n = 26) were conducted. Two main themes were raised by the participants: (a) the role of social workers and lawyers in court cases regarding AD, and (b) the need for improving legal encounters involving persons with AD. Similarities and differences were found in both professionals’ interpretations of these shared themes. Results of this study emphasize the need for increasing the knowledge and interprofessional training provided to social workers and lawyers involved in legal cases dealing with issues involving persons with Alzheimer’s disease.

Introduction

Due to advances in medicine and medical technology, and improvements in social and environmental conditions, societies worldwide are now confronted with the challenges of a dramatic increase in the average lifespan of older persons (Bloom et al., 2014). This increase is accompanied by a concomitant rise in the number of persons with Alzheimer’s disease (AD) and other types of dementia (Doron, 2014; Ferri et al., 2006). Indeed, it has been estimated that approximately 46 million individuals live with dementia worldwide in 2015. This number is expected to increase to 131.5 million by 2050 (Prince et al., 2015).

In preparation for these striking changes, researchers are discussing issues associated with the economic, societal, familial, and individual impact of AD and other dementias. Surprisingly, legal questions associated with these changes have attracted only limited attention (Foster, Herring, & Doron, 2014). This is worrisome, especially because AD is characterized by a progressive and gradual loss of the capacity of making decisions in different domains (Prince et al., 2015), leading to a vital need to create a balance between respecting these individuals’
autonomy and securing their well-being (Sailors, 2001). Solving problems associated with this balance frequently requires the intervention of the legal system (Foster et al., 2014).

Indeed, determining a person with AD’s competence in a variety of areas (such as medical competence, financial competence, driving competence, and more) is one of the core legal issues related to dementia (Barbas & Wilde, 2001). Other legal issues associated with dementia might include cases involving criminal and violent behaviors—either aimed toward the person with dementia (Cooper et al., 2009; Werner & Eisikovits, 2006) or committed by the person with dementia (Kim et al., 2011).

Legal interventions involving persons with AD are associated with complex and sensitive decisions, requiring the involvement of different professional perspectives (Raivio, Maki-Petaja-Leinonen, Laakkonen, Tilvis, & Pitkala, 2008). Developing medical-legal partnerships has recently been emphasized as one of the main avenues for dealing with the legal needs of vulnerable populations, such as persons with dementia (Sandel et al., 2010). Social workers and lawyers are an integral part of these partnerships in general (Colvin, Nelson, Cronin, & Cronin, 2012) and in relation to older persons, in particular (Bassuk & Lessem, 2001).

The professional interaction and collaboration between social work/social workers and law/lawyers has been associated with positive, as well as negative, consequences (Doron, Karpel, & Or-Chen, 2010). On one hand, those stressing the positive consequences of this partnership emphasize the possibility of providing a more holistic view of the needs of older persons in general (Bassuk & Lessem, 2001; Galowitz, 1998), and of those associated with persons with AD in particular (Pierce, Gleasonwynn, & Miller, 2001), by combining the expertise and values of two different professions. On the other hand, a long-standing debate centers on the difficulties of reconciling fundamental differences and approaches between the two groups (Dickens, 2006), controversies stemming mainly from the difference in the professional socialization of each group, and their different duties and perspectives about care (Dickens, 2006; St. Joan, 2001).

Unfortunately, there is a dearth of empirical data regarding these controversies, especially within the legal context of caring for persons with dementia. This study intends to address this gap by examining social workers and lawyers’ experiences and perceptions regarding court cases involving persons with AD. Although persons with AD may appear in court in diverse legal contexts, issues around legal capacity and guardianship comprise a significant place within legal proceedings. In such cases, lawyers (representing either the person with AD, his or her family members, or the welfare authorities) and social workers (providing professional assessment by court appointment or by either side), commonly meet under the same legal setting. It was within this context that our goal was to explore social workers and lawyers’ concerns about court cases involving persons with AD, identify both conflicting and shared views, and explore potential avenues that could improve both the current situation as well as the process.
Methods

This study was part of a larger, mixed-methods research, aimed at exploring the consequences of structural stigma and AD in the legal system (Werner & Doron, 2016). We used data from focus groups comprised of lawyers and social workers involved in the legal aspects of dealing with persons with AD. This method was selected because of the exploratory and pioneering character of the study, and because focus groups create a shared space for group discussions (Krueger & Casey, 2009).

Participants

A purposive sampling technique was used. A total of 25 participants (16 social workers and 9 attorneys) participated in three multiprofessional focus groups. The inclusion criteria were: having expertise in litigation or legal interventions associated with AD and Hebrew speakers. The majority of the participants were female (88.5%), married (73.9%), and born in Israel (80.8%). Their mean age was 50 years ($SD = 12.0$; range = 34–69). Regarding their professional characteristics, the majority of the participants were government employees (76.9%) and had, on average, 25.2 years’ ($SD = 11.9$, range $=7–43$) experience in their professions.

Procedure

A list of social workers and lawyers with extensive and direct expertise in the area of the study was generated by the authors. A trained research assistant approached each one of the potential participants and described the aim and methodology of the study. All the professionals approached agreed to participate and signed an informed consent. Focus groups were held until saturation of new information was reached (Krueger & Casey, 2009). To ensure that any new information was not missed, one additional focus group session was held after theoretical saturation had been estimated. Before each focus group, all participants were asked to complete a short questionnaire, including demographic and professional information. The focus groups were established in different places throughout the country, and they ranged from 90 to 120 min. Facilitators were at least one of the researchers, and a group facilitator skilled and experienced in conducting focus groups. Group interviews were audio taped and transcribed.

Interview guide

According to recommended focus group methodology (Krueger & Casey, 2009), a semistructured interview guide containing open questions was developed by the research team; the aim of the interview guide was to cover key topics. During the focus group discussions, the moderator followed the question guide but
asked side questions as well, to obtain more in-depth information about the
topics. The moderator also made sure to show enough flexibility to allow for
open discussions between the participants.

**Data analysis**

Thematic analysis was used (Hsieh & Shannon, 2005). Data were first analyzed
through open coding, namely reading every interview line by line to discover main
themes, uncover ideas, identify possible meanings and define categories. In
a second stage, axial coding was conducted. Categories identified in the open
coding stage were discussed among the researchers; discrepancies were discussed
until consensus was achieved. Selected quotations were translated into English.
The first letter of the participant’s name was assigned to each quotation to protect
participants’ anonymity. The number of the focus group from which the quotation
was extracted is also provided for each quotation (e.g., FG1). To ensure the
reliability of data interpretations, analyses were carried out independently by two
researchers. The trustworthiness of the findings was tested through member
checking techniques and group discussion with participants in the last focus
group, which was conducted to discuss findings and recommendations with the
participants.

**Ethical considerations**

The study protocol was approved by the Ethics Committee of the Faculty of
Social Welfare and Health Sciences at the University of Haifa.

**Results**

Two shared themes evolved during data analysis across both professional groups:
Social workers and lawyers’ role in court cases involving persons with AD, and the
need and suggestions for improving legal encounters dealing with persons
with AD. Despite their commonalities, it was possible to identify marked and
distinct differences in both professional groups’ perceptions regarding these shared
themes.

**Theme 1—Social workers and lawyers’ role in court cases involving
persons with AD**

Both groups of professionals described their role as central in cases associated
with AD in the legal system. However, it was clear from the focus groups’
discussions that social workers and lawyers differed in the type and breadth of
involvement in their legal encounters with cases involving persons with AD, as
well as in the relative emphasis they attribute to the cases.
Type of cases involving persons with AD dealt with by social workers and lawyers

Social workers described themselves as being involved in the task of appointing a guardian. When asked about the legal contexts in which they are involved with persons with AD, they typically answered:

“We are involved [with persons with AD] when there is a need to appoint a guardian” (E SW—FG 2). Another participant continues: “Yes, [we are involved with] appointing a guardian for vulnerable persons and for persons with cognitive impairment” (M1, SW, FG 2). Similar role descriptions were identified in other focus groups: “I’m a social worker and I’m involved in guardianship cases involving persons with AD” (I, SW, FG 1). Social workers even stressed a marked increase in the number of guardianship cases brought to the legal system involving persons with AD: “I work in a small city and we see an enormous amount of cases involving guardianship requests. I see 60–70 requests a month and the majority involve persons with cognitive deterioration” (A, SW, FG 1).

The only other legal field mentioned by social workers involved placement issues or, more specifically, decisions regarding moving a community-dwelling person with AD from home to an institution. “It’s not only guardianship… it’s also taking the person out of his home as a result of extreme situations, such as the inability to function at home, being a danger to himself or others” (C, SW, FG 1).

In sum, across all three groups social workers described their involvement in guardianship issues as their main (and almost only) role in legal cases involving persons with AD. This involvement was described as part of the broader (yet unique) professional responsibility of dealing with guardianship issues related to vulnerable persons. Lawyers, on the other hand, reported being involved in a much wider array of legal topics with regards to persons with AD. “In regards to AD or any competence problem, we are involved in many aspects—many more aspects than dealing with guardianship issues for vulnerable persons. We deal with preparing testaments and many other topics related to the legal process” (Y, lawyer, FG3).

Several lawyers in our study said they were experts and knowledgeable in varied areas, in addition to guardianship issues, including financial and criminal issues.

I want to extend it [the topic of discussion] even more. Guardianship and dealing with vulnerable persons are indeed areas that we know very well, but there are many other topics besides guardianship. [We deal] with everything that’s related to bank transactions, many activities that create tension between the older person and his family. (M, lawyer, FG 1)

I had several referrals regarding criminal issues. For example, I was recently asked—regarding a person with dementia, with AD—whether he is competent to stand trial. (M1, lawyer, FG 2)
Breadth of cases involving persons with AD dealt with by social workers and lawyers

Moreover, social workers and lawyers perceived each other as dealing with different aspects of the situation. As described by one of the participants: “We represent two sides of the same coin.”

Overall, social workers described themselves as being those who take care of “the person,” rather than of the procedural-justice aspects involved in legal interventions.

We deal with the topic of whether the vulnerable person receives appropriate treatment, whether he is at the right place, whether his health, mental and social status are being taken care of. … Whether his nutritional status is appropriate, whether he is involved in leisure activities. In a word: we deal with the non-material issues. (V, SW, FG 3)

Lawyers described themselves as being in charge of the procedural justice elements, making sure that formal rights are observed and maintained: “I think we have to extend the picture as we deal with many other things—we deal with all the legal processes” (M, lawyer, FG 1).

Overall, the first shared theme stressed the central and unique role of each profession in the legal system in cases involving persons with AD. Although social workers described their involvement almost exclusively in cases of guardianship, lawyers described themselves as dealing with a variety of legal issues and cases. Moreover, social workers described themselves as the ones “seeing the person” literally and nonliterally, i.e., being the ones taking care of the nonlegal person with AD—his/her needs and requirements. On the other hand, lawyers described themselves as taking care of procedural-justice issues, focusing on legal rights and formalities; as one of the participants reported: “In our case, we don’t see the person with AD; he/she does not meet us at all” (M, lawyer, FG 1).

Theme 2—Improving legal encounters involving persons with AD

Despite the differences noted between the two professional groups in the previous theme, both social workers and lawyers agreed that changes should be made to optimize the process of handling cases involving persons with AD in the legal system. Overall, two main suggestions were expressed by the participants to improve the process: to provide judges and other officials involved in the legal system with more AD-related knowledge and training; and to simplify the complex bureaucracy of the legal process.
Providing training and knowledge regarding dementia to judges

Both social workers and lawyers supported the need to provide judges with training on dementia-related topics. According to the lawyers, the topics of dementia, and aging in general, should be incorporated into the basic law school curriculum.

Today, as far as I know, there are no courses about aging and dementia in law schools. I assume that this is the reason why there is a huge gap between the knowledge that judges have in the areas of divorce, children, and so on, and the knowledge they have in the areas of aging, dementia, guardianship, and services available to these populations. (M1, lawyer, FG 2)

Several lawyers in our focus groups supported the idea of developing expert tracks for judges in the areas of dementia and Alzheimer’s disease or developing a unique tribunal of expert judges trained in these areas: “Yes, expert tracks or establishing professional tribunals composed of persons (judges) who can make appropriate decisions [is a good idea]” (M2, lawyer, FG 2).

Finally, the lawyers reported that there is need to provide training and education to all staff members involved in legal courts dealing with cases involving persons with AD. “You spoke about (training) the judges, but I think about the whole system, also about the clerks. If an old person comes in and needs something,- they [the clerks] don’t know how to react or behave” (M2, lawyer, FG 2).

Social workers, although also stressing the need to provide training and knowledge to judges in the area of dementia, supported a more holistic approach. They suggested that the training and enrichment should be provided by voluntary organizations, such as the Israeli Alzheimer’s Association: “They (judges) need holistic training, something that has to be provided by organizations that provide an interface between all of the professions and all aspects related to the area of dementia” (A, SW, FG 1).

In sum, although both groups of professionals agreed about the need to expand judges’ knowledge about dementia to help them make appropriate decisions, they differed somewhat in the ways they thought this aim should be accomplished. Lawyers were more focused on the narrow knowledge related specifically to dementia; social workers, on the other hand, were interested in conveying broader knowledge, which could be provided by various experts on the topic.

Simplifying the complex bureaucracy of legal processes relating to persons with AD

The need to improve—and simplify—the legal processes involving cases related to persons with AD was a topic that elicited strongly opinionated observations from both groups of professionals participating in the focus groups. The lawyers concentrated mainly on suggesting ways to unify and simplify the many laws
dealing with dementia: “I would make things easier by taking all the laws dealing with the topic (dementia) and building something less complex, more accessible and less bureaucratic” (Y, lawyer, FG 1).

Social workers concentrated more on suggesting structural mechanisms to shorten the length of time that legal procedures take—such as appointing a power of attorney:

We are asking the Ministry of Justice to allow appointing a power of attorney on a fixed base, so that a individuals—when they are still able to make decisions—can decide who will represent them for all types of cases. (N, SW, FG 1)

Another mechanism that social workers suggested was allowing social workers greater freedom to make decisions:

In Israel, judges are the ones who make the final decisions; they represent the highest decision-making entity. Yet, everybody is constantly complaining that they (the judges) cause delays because they are overwhelmed. Since it doesn’t seem that the situation will change any time in the near future, my suggestion is to allow social workers to make more decisions by themselves [without the need of the court’s approval]. (A, SW, FG 2)

Once again, then, although both groups of professionals expressed the need to make changes in the legal system regarding procedures related to the elderly, they differed in their focus. Lawyers stressed consolidating the different laws and making the system more efficient or simple. Social workers, on the other hand, although also trying to simplify the process, placed more emphasis on out-of-court solutions, e.g., continuing powers of attorney or giving more legal authority to social workers. It should be noted that Israeli law does provide social workers with broader legal intervention authorities (e.g., emergency interventions such as placing a person in a protected shelter or providing medical care) even without court preapproval for other special populations (e.g., children or persons with mental illness). However, these legal authorities do not exist in the field of adult/elder protection legislation in Israel.

Discussion

The expected increase in the number of persons with dementia worldwide (Prince et al., 2015) will be accompanied by an increase in the number of cases involving persons with AD going through the legal system. It is, therefore, critical to understand what happens in the courts. Social workers and lawyers may provide a unique insight into understanding the complexities confronting the courts in these cases.

The relationship between lawyers and social workers has attracted a lot of attention over the years. Although in the early years the debate concentrated mainly on the dilemmas and tensions of such relationships, in more recent years the advantages of integrating both professions into working teams dealing with a
variety of topics (including health-related issues) has been stressed and even encouraged (Colvin et al., 2012; Dickens, 2006; Pierce et al., 2001). Our study findings reflect these changes. No clear tensions, contradictions or problematic relationships were noticeable in our focus groups. Neither social workers nor lawyers blamed the other group for any of the problems they identified in the legal system’s treatment of persons with AD. However, different, and sometimes even complementary, interpretations of the same themes did appear during the focus group discussions.

Overall, the findings of our study revealed that social workers and lawyers related mainly to two dimensions of their work: the first dimension related to the role that each one plays in their legal encounters with persons with AD (who does what); the second dimension related to different ways to improve the structural setting of the courts (providing training for the judges and minimizing bureaucratic processes).

Regarding the first dimension, both groups of professionals considered their role to be central in legal cases involving persons with AD and their families. However, although social workers mainly stressed their involvement in guardianship cases, lawyers reported being involved in a wider variety of cases, including financial and criminal cases. This finding is interesting because under Israeli law, social workers are also involved in these types of cases (providing judges with expert opinions and evaluations), but apparently when defining their main contribution to legal cases involving persons with AD, the involvement in other cases was minimized or completely diminished. Indeed, guardianship is one of the main areas of expertise held by social workers within the legal realm (Crampton, 2004). Even in cases in which guardianship is dealt with by an interdisciplinary team of professionals (mostly physicians and psychologists), in most cases social workers are the only ones who actually appear and testify in court (Gibson, 2011). Moreover, lately social workers are increasingly being recognized as being able to provide expert testimony on competence cases (Siegel, 2008).

However, the differences between lawyers and social workers were noted—not only in regard to case types, but also in relation to the roles played by each profession in the courts. Although social workers described themselves as being in charge of caring for the needs of the older persons and their relatives (i.e., “seeing the person”), the lawyers reported being in charge of procedural-justice needs rather than personal needs.

These differences closely follow the traditional definitions of both professions, with social workers being perceived as the ones involved in the caring and psychosocial aspects and lawyers as being involved in the legal and procedural aspects of the cases (Pierce et al., 2001). Interestingly, however, in our study the different priorities, responsibilities, and practices of each professional group were not perceived as competing with one another, but rather as complementing each other.
Nevertheless, regardless of their unique roles, both groups of professionals agreed that there is a need to improve the way in which legal encounters involving persons with AD are handled. Thus, another central theme in the focus groups conversations was how to improve this process. Increasing judges’ knowledge about AD and simplifying the legal process were the main avenues suggested by both professionals.

Training and educating judges and courthouse staff about aging issues has already been stressed as one of the ways of dealing with the increasing number and complexities of the cases brought to the courts involving older adults in general (Rothman & Dunlop, 2006). In our study, this avenue was voiced by both groups of professionals. Within this context, it should be noted that Israel—like the United States—has a common-law based legal system. Moreover, the legal education is also very similar in its structure. However, and unlike some American jurisdiction, all judges in Israel must be lawyers, and all judges receive legal education and training prior to their appointment.

Keeping this context in mind, although social workers referred to holistic training provided by nonacademic sources, such as the Alzheimer Association, the lawyers referred to formal ways of providing training, such as including topics related to aging, in general, and dementia, in particular, in law schools’ curricula. In the area of domestic violence, Forgey and Colarossi (2003) described the inclusion of an educational model aimed at teaching specific knowledge and skills in specific areas, as well as basic principles of interdisciplinary collaboration in the curriculum of social work studies. The lawyers in our study suggested considering a similar model for law schools in the area of dementia. This supports previous calls to strengthen the interdisciplinary legal education in the field of law and aging (Doron & Hoffman, 2005; Doron & Meenan, 2012).

Another possibility expressed by the lawyers in our study to improve the way courts deal with cases involving persons with AD, consisted of establishing special courts to specifically deal with this topic. The concept of Elder Courts, including judges with special training in topics related to the elderly and aging, has already been suggested as one of the ways of dealing with the complexity of the topics facing the courts in aging societies (Rothman & Dunlop, 2006). However, such a court is still not available in Israel.

Alleviating bureaucratic difficulties in legal processes involving persons with AD was reported by both groups of professionals as another possibility for improving the management of these cases. Although lawyers suggested the enactment of new consolidated legal frameworks as a solution to these problems, social workers expressed more interest in finding ways to shorten time delays by allowing social workers to have greater legal authority in these cases. Indeed, this is a solution that has attracted some attention in other areas as well. For example, in the area of mental...
disorders, increased attempts are being made to provide more legal weight and to admit social workers as experts to give testimony in competence trials (Siegel, 2008)—a change that might ameliorate some of the time problems confronting legal courts everywhere.

Before concluding, we acknowledge that this study had several limitations. First, although many advantages are associated with the triangulation of views in qualitative studies, this study relates to a small number of focus groups. We believe that additional focus groups with different stakeholders—such as judges themselves and other members of the legal system—may help to illuminate issues and aspects that were overlooked in this study. At least in Israel, however, including acting judges in such studies is not allowed. Second, participants were selected through a convenience sampling. Due to recruitment difficulties, professionals participating in the focus groups were selected through personal knowledge. Thus, many participants knew each other before, and probably some of the ideas expressed in the focus groups were previously known and discussed.

Despite these limitations, ours is the first qualitative study that describes the experiences and opinions of social workers and lawyers regarding legal cases involving persons with AD. Our study results stressed the importance and contribution of each one of these professions as players in the legal scene when dealing with cases involving persons with AD. Moreover, an incipient recognition of the need to complement and balance each other was expressed by our participants and, contrary to previous studies stressing conflicts and dilemmas between the professions (Dickens, 2006), the discussions in our focus groups were characterized by mutual respect and recognition of the unique help and expertise provided by each one of the professionals.

**Concluding comments**

Both social workers and lawyers recognized the need for persons with AD to be treated appropriately in court proceedings. Moreover, both groups perceived themselves as the ones caring for the rights and needs of persons with AD and their families, and reported judges’ lack of training in dementia and aging and the bureaucratic difficulties of the system as the main obstacles in these cases. However, the solutions they suggested to overcome these difficulties were permeated by their professional socialization, with lawyers concentrating more on legal solutions and social workers on structural ones.

Our results suggest the need to increase the training provided to both of these professionals in the areas of dementia, the legal system and social work aspects and principles. Although interprofessional training and education in the area of AD has been emphasized as important and valuable when involving health and social
care professions (McCaffrey, Tappen, Lichtstein, & Friedland, 2013), in the area of social workers and lawyers there is need to increase the attention to the topic. For example, joint training could be provided to those professionals already involved in the judicial system; it could also be provided uniprofessionally or multiprofessionally by adding these topics to the academic curriculum of both disciplines. The importance of these types of training in the courts context has been reported by Leslie, Young, Valent, and Gudjonsson (2007), who recommended training for legal professionals on the underlying scientific principles of psychology. Similarly, the experience and success of the Medical Legal Partnership model, developed in 1993 to improve the relationships between medical and legal professionals to enhance the health and wellbeing of vulnerable populations (Tyler, Lawton, Conroy, Sandel, & Zuckerman, 2011), might be extended to include social workers and lawyers dealing with cases involving persons with dementia and their families.

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