P. X Proactive detection of abuse and neglect of people with dementia - Dr. Sarah Alon, Tel Aviv University

Rina, aged 79, a widow, lives in a small ground-floor house. Rina suffers from dementia and is recognized as eligible for nursing care of up to 168%. Rina's daughter lives near, in the same courtyard. Rina has occasionally been found wandering the streets, by neighbors and passersby, unsuitably dressed for the weather. At meetings with the family members, the social worker explained to them about dementia and its characteristics. It was recommended to them that they employ a foreign worker and/or a combination of a day center suited to her condition. With time, Rina's cognitive condition and her health deteriorated further. The family members did not understand the severity of her condition and did not provide her with the necessary care. At a home visit from the social worker, Rina was found sitting alone, gaping, and had difficulty understanding what was said to her. Is Rina suffering from inadequate treatment? Abuse? Neglect?

What is elder abuse?

Abuse is behavior that takes place regularly and harms physically or sexually, mentally emotionally or financially. The harm is usually caused by a person or people in the close environment of the elderly person and as a result of this, there is a change in his life-style, causing him suffering and harm and raises the risk of harm to his well-being and his safety.

Abuse includes: physical harm (physical pain or harm expressed by blows, physical or chemical restraint (giving an overdose of tranquillizing medication). **Psychological/mental abuse** causing mental suffering by insult, humiliation, threats and treating the elderly person like a child. **Financial exploitation** – use of, and exploitation of the elder's money, material resources. **Sexual abuse** – intimate contact of any kind without the agreement of the elderly person.

Neglect is defined as lack of the basic needs or necessary services (food, medication, medical care, aid in functioning).

From the description of Rina's condition, it can be seen that she is suffering from inadequate care, and neglect. The care-giving family members are unaware of her changing needs, and her care requirements are unmet. As a result of this the risks to her well-being, health and safety are increased.

Frequency of the phenomenon

Elder Abuse and neglect has been recognized by researchers, professionals and policymakers worldwide as a social and health problem. Findings of the First National Survey on elder abuse and neglect , we learn that 18.4% of all elders reported that they were exposed to abuse of one kind or another during the year preceding the survey. The study also shows that 18.1% of the elders reported neglect, meaning lack of supply of basic needs such as food, hygiene and medical services. In another survey, carried out among elderly people in general hospitals, 21.4% of those examined were identified as suffering from abuse, most of the cases being conditions of neglect.

Risk factors to elder abuse and neglect

Because of the complexity of the phenomenon, researchers have difficulty pointing to one theory or to explain why abuse or neglect takes place. Researchers and professionals therefore focus on three possible groups of risk factors that warn of an abusive event.

1. The first group of factors includes characteristics of the victim: i.e. **advanced age** – usually the victims are aged 75 and over; **health problems and cognitive decline** – elderly people exposed to abuse and neglect often suffer from physical and/or mental handicaps or cognitive decline. Because of this, dependence on their surroundings increases (on whoever is supposed to be helping them). This dependence can become a potential trigger for harmful events, because of the physical, emotional and financial pressure exerted on the family member and/or the principal caregiver; **joint residency** with the abuser; **social loneliness and limited support network.**
2. The second group is linked to the characteristics of the abuser, i.e. **family connection** – the abusers are in most cases family members, primary caregivers (spouses or adult children); particularly if they suffer from a mental or physical handicap, or are financially dependent on the older adult(income or for residency); **joint residency**, with the victim becomes fertile ground for tensions and conflicts; **reduced support network and social loneliness.** Particularly when the family members serve as primary caregivers; **addiction to alcohol and drugs** has been found a strong predictor of abusive events. It was also found that difficulty in coping with life crises such as financial problems, lack of work and difficulty in coping with the burden of caring for an elderly spouse /parent can be additional factors.
3. The third group of factors includes **environmental factors**: environment unsuited to the physical and mental needs and the safety of the elderly person can be a risk factor for abuse. This is demonstrated in a house that is not fitted out suitably and is unsuited to the needs of the elderly person and his limitations; unsafe external environment; inaccessibility to the services in the immediate vicinity and social loneliness.

Dementia as a risk factor for abuse and neglect

Cognitive decline and dementia were found to be factors liable to increase the risk of abusive events and neglect. With the development of the illness and reduction in the level of functioning, care-giving needs increase and with them dependence on the environment, as demonstrated in the description of Rina's condition. The illness and the caring of the sick person affect all members of the family. Family members usually show obligation and devotion and give many hours of care. However, beside the devoted care, family members also feel emotional difficulties, tension and wear as a result of the burden of care; financial difficulties and health problems.

About behavior – changes such as unexpected behavior of the sick person, wandering, getting lost, restlessness and aggitation, demand being on guard unceasingly. A person with Dementia who behaves aggressively and violently as a symptom of the illness increases the risk of becoming a victim of abuse by his primary caregiver, who might use restraining devices on the sick person. In addition, aggressive behavior by the older person can create confrontation, leading to aggressive behavior towards him.

On the financial side – the care of dementia illnesses involves financial costs. Sometimes the resources of the old person are not sufficient to finance these costs and the family is called upon to join forces and help. In addition, as the illness progresses, the sick person might lose the ability to manage his finances, property and all his affairs. In such conditions the family members, neighbors or friends, and sometimes even caregivers are liable to find themselves in complete control of the life, property and resources of the sick person. This is liable to lead to financial exploitation when they use money for other needs and not for the benefit of the sick person.

In various studies, people with dementia were found to be at risk of abuse, financial exploitation and neglect twice as high in comparison with other elderly people. Dyer and colleagues (Dyer et al. 2000) found that among elderly people hospitalized, the number of people with dementia who were victims of abuse and neglect was higher than among other elderly people. In another study

examining family members who were principal caregivers of Alzheimer's patients, 12% of those examined reported that they had physically abused the patient at least once since they became primary caregivers.

Difficulties in detecting and identifying abuse

Despite our knowledge of the extent of the problem and risk factors linked to its occurrence, most of these incidents are unidentified and are untreated.

Like other types of abuse in the family, elder abuse and neglect usually occurs behind closed doors, a fact that hinders detection of the event and its exposure. This is liable to happen from lack of awareness of the victim himself or his inability to speak about it. Feelings of shame, guilt or embarrassment, a feeling of helplessness, betrayal and failure in educating his offspring can withhold from him the wish or the ability to expose the abuse and complain. There is also the wish to defend the abusing family member from causing him harm. There is often dependence of the elder upon the abuser, fear of him or concern about the results of intervention (fear of abandonment, fear of destruction of the family framework, harm to the solidarity of the family, fear of being removed from his house to an institution).

The abuser himself has feelings such as denial, embarrassment and guilt, fear of anticipated punishment or fear of losing the benefits and pension payments, such as place of residence or material resources, so he declines receiving aid. As against this, the other family members try to keep the "secret" in the family. They also find it difficult to acknowledge and admit the abuse that is occurring and they are also afraid of the abusive family member. In consequence of this, the victim is often forced to live with a minimal support network, ignorant of existing services available to him.

In addition, reservations of professionals make it difficult to detect abuse and neglect, such as insufficient awareness of the phenomenon and detection of the signs, and as a result of this, there is difficulty in defining abuse or neglect and determining that abusive behavior has indeed taken place. Professionals sometimes abstain from reporting abusive behavior, fearing the reaction of the abuser, or because they feel professional helplessness. This feeling is liable to come from the perception that there are no available responses or suitable services in the community, or because of the burden of work and the bureaucratic difficulties in coping with the problem. In addition to this, beliefs and values regarding the privacy of the family's life, the responsibility and the obligation of the family members to care for the elderly person, are liable to cause restraint or hesitation about intervention in such complex, complicated family situations. Ultimately, ethical and professional dilemmas arise during the process (e.g. in cases of exposure, the damage is liable to cause the victim an increase in the abuse, or separation of the family from the elderly person), causing non-reporting of the abuse/neglect by the professionals. These stumbling blocks make reporting difficult and sometimes thwart exposure of the "secret," treatment of the abused/neglected victim and the cessation of the abuse.

Screening Tools to detect elderly people at risk of abuse and neglect

The many obstacles in the way of identifying elders suffering from abuse and neglect, prompted professionals to act in developing a strategy for evaluating the risk of abusive events. This means that at every professional meeting (caregivers or volunteers) with the elderly person in general and in particular with people suffering from functional handicaps and cognitive decline, it will be possible to check proactively whether the elder is at risk of abuse or neglect. A screening tool could be the only way to detect situations of abuse or neglect and prevent their continuation.

In light of the complexity of abusive events and the difficulty in identifying them and determining that abuse or neglect is indeed occurring, a three-dimensional tool was developed by Cohen and her colleagues (2010) for identifying elder abuse and neglect. Despite the fact that the tool was validated for all elderly people and not people with dementia, it may be used, or parts of it, for people suffering from cognitive decline. The tool is composed of three dimensions enabling the detection of abuse and neglect: **identification of risk factors for abuse and neglect: direct questioning and examination for signs of abuse/neglect.**

First dimension: identification of risk factors for abuse and neglect – including checking for the likelihood of the existence of risk factors for abusive events based on study findings that report on factors portending abusive events and neglect. Risk factors characterizing the elderly person (family problems, poor mental state, financial dependence loneliness/meager social network, cognitive problems and complex chronic illnesses), and risk factors characterizing the family member/ caregiver (use of alcohol/drugs, psychiatric problems, family problems, meager social network and lack of understanding of the cognitive or physical condition of the elderly person). Risk factors are marked on a scale of 4 degrees, from 1 "not at all" to 4 "very much". Below are details as they appear in the strategy:

Primary level of detection –risk of abuse (detail)

Risk factors – patient	3 – Very much	2 – Moderate	1 – Hardly	0 – Not at all
1. Family problems				
2. Reduced mental state				
3. Financial dependence				
4. Meager social network/loneliness				
5. Cognitive deterioration/dementia				
6. Many chronic illnesses (instability/falling, heart ailments (severe), dialysis, active cancer or metastases, eye diseases, neurological illnesses (Parkinson, CVA, MS), metabolic illnesses				
Risk factors – family member / primary caregiver				
1. Use of alcohol or drugs				
2. Psychiatric problems (personality problems, schizophrenia) / retardation				
3. Financial dependence				
4. Family problems				
5. Meager social framework				
6. Lack of understanding of the patient's condition				

The examined person will be defined as at risk of abuse when:
1) At least seven of the items in the table are marked in the category of 1, 2 or 3.
2) At least one of the categories marked in grey received a grade of 2 or 3.

The second dimension: direct questioning – composed of six items relating to the possibility that the person suffered during the last year from behaviors that point to abuse: psychological, physical, nutritional, financial exploitation, restriction of freedom and sexual abuse. Details appear in the following strategy:

Secondary level of detection – direct questioning

	Yes	No
Are you suspicious of one of your family members or others known to you?		
Has somebody tried to hurt you (hit, shove, shake) or cause you any kind of harm?		
Has anyone in your family spoken to you insultingly, called you names, insulted you or caused you to feel bad?		
Has someone taken from you objects, property or money against your wishes or by force? Made you sign documents?		
Do your family members refuse to give you the help you need?		
Has anyone touched you sexually against your wishes?		

Details: _____

_____

If the answer to one of these questions is positive:
Which of the family members behaved this way? _____
Who else suffers from abusive behavior apart from the interviewee? _____
How often and for how long does the aggression/abuse occur? _____
Have you approached somebody or some authority for help? _____

Third level of detection: identification of signs of abuse or neglect – consisting of a list of signs indicating physical, psychological or sexual abuse, financial exploitation and neglect. Mark yes/no signs of abuse and neglect; signs of financial exploitation; signs of neglect; sexual abuse. Details appear in the following strategy:

Detection of signs of abuse mark only when no other reason is known apart from abuse (for instance: results of an operation, falling, etc – are not signs of abuse).

Physical signs of abuse – <u>if signs are visible during the meeting with the elder</u>

	Yes	No
Unexplained injuries or unsuitable explanation for how they came about.		
Wounds / blows / bruises.		
Scars / fresh or old signs.		
Scars, resembling objects in their shape (fingers, belt).		
Scars on both sides on upper arms.		
Burns in unusual places.		
Unusual type or shape of burns (made by cigarette or smoothing iron).		

Signs of material/financial exploitation – <u>please answer the following questions on the basis of your conversation with the elder.</u>

	Yes	No
Inability to explain why bills were not paid, food or other necessities were not bought.		
Difference between income and means and life-style.		
Displays fear or anxiety when talking about money.		
Exaggerated interest of the family member in the elder's assets.		
Elder's assets, property, management of bank accounts transferred to the other person against his full agreement.		
Transferring of monies from the elder to the other person against his full agreement.		
The interviewee finances son/daughter, grandson/granddaughter in financial difficulties.		

Signs of neglect – mark on the basis of observed signs	Yes	No
Neglected appearance, unaesthetic, unclean.		
Wounds and untreated skin problems		
Clothing unsuited to the weather		
Poor Hygene		
Sudden/unexplained decline in health condition (not from medical reasons)		
Bedsores		
Signs of overdose or lack of correct use of medications		
Unexplained delay in seeking medical help		
Irregular or infrequent check-ups/treatment/medical follow-ups		

Behavior of the family member – based on your impressions during the meeting

The family member is angry or apathetic towards the elder Yes No

The family member refuses to supply him with essential things Yes No

The family member tries to prevent the interviewee from speaking privately or freely with professionals Yes No

The person is nervous about answering questions Yes No

The person appears frightened Yes No

In conclusion, the three detection strategies are found to be reliable, with good validity and sensitivity. Use of the three strategies detailed here is strongly recommended when conditions allow. However, when this is not possible, use may be made of only one or two of the dimentions and in this manner risk conditions for abuse and neglect may be detected.

Detecting abuse and neglect in people with cognitive impairment is more complex. We cannot always interview the sick person or use the direct questioning. In these cases, detection relies mainly in signs of abuse/neglect, or on evaluation of the primary caregiver and assessment of environmental factors.

Thus, for instance, the social worker who visited Rina's home could assess the neglect by her first impression and the presence of risk factors, such as the condition of her mental impairment, the meager support network and her social loneliness, financial dependence and her dementia. Regarding the primary caregiver, lack of understanding of Rina's condition forms a risk factor. Based on the third level of detection and signs of neglect, the social worker could have determine that Rina suffers from neglect.

Conclusion and recommendations

Elder Abuse and neglect is recognized as a social and health problem in Israel and in the world. At the same time, dementia as a risk factor for abuse has yet to receive deserving professional and research recognition. Findings of the national survey in this field report that one in five elders in the country is exposed to abuse and neglect. In light of the estimate that dementia patients are twice as exposed as other elders, it may be assumed that the number of elderly who suffer from abuse and neglect is liable to be higher.

To protect elders, victims of abuse and neglect, much fundamental work and multi-system activity is required, from the level of policy makers, professionals caring for elders, the elders themselves and family members.

At the social level – awareness must be raised regarding dementia and its consequences for the sick person and his family members. Education and training for professionals about the link between dementia and elder abuse and neglect is most essential. Professionals must be aware of the phenomenon and obtain expert knowledge in detecting abuse and neglect, particularly when the patient has difficulty communicating and it is not possible to understand from him whether someone harmed him or not. Use of the evaluation tool for assessing the risk of abusive events and neglect can help in this work.

In addition, links with work colleagues must be made, organizations and co-workers in the country and locally. Only by combined activity can the proportions of the phenomenon be reduced.

At the individual and family level – we must aim for the unification of preventive programs and treatment of the patient and his family members regarding the burden. Providing information about the illness and its stages can help the family in coping more effectively. Providing information about existing services will enable the family and the sick person to utilize their rights using these existing services, such as nursing benefits, day centers, support groups, volunteers and placement when necessary. In cases of restlessness or aggressive behavior, it is recommended to consult the patient's doctor and consider giving medication. Detection and proactive identification of abuse and neglect, with the use of valid tools such as the tool presented in this article, are the first step in coping with the problem. ■