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Voices of spouses living with partners with neuropsychiatric symptoms related to dementia

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ABSTRACT

Persons with dementia, who reside in their own homes, are often cared for by family members. The presence of a family caregiver is said to have a protective effect, postponing admissions to residential care. The majority of persons with dementia develop behavioural and personality changes during the disease trajectory also known as neuropsychiatric symptoms (NPS). Quality of life for both the person with NPS and their caregivers are affected, increasing suffering and risk for hospitalization and admission to long term residential care. Family caregivers to persons with dementia have identified behavioural changes as more distressing than cognitive impairment leading to increased burden of care and admissions to residential care. Knowledge gaps exist regarding how family caregivers living with persons with dementia experience NPS in a community setting. The aim was to describe spouses' experiences of living with partners who have developed NPS related to dementia in a community setting. Semi-structured interviews were carried out with 14 spouses of partners with dementia. The interviews included completion of the Neuropsychiatric Inventory (NPI), (Cummings et al., 1994). Interview data was analyzed using a content analysis approach. The results showed that spouses identified in the NPI that partners with dementia had on average five to eight co-existing symptoms. Frequency, severity and distress varied. Neuropsychiatric symptoms highlighted were within three of four possible symptom categories; Behaviour, Psychosis and Mood. From the narrative data the theme; living on the edge lacking support and time for self, emerged.

The findings of this study suggest that support offered to persons with dementia and their partners should have a person-centered approach meeting individual needs. Safety and welfare of persons with dementia and their partners' residing in their own homes maybe jeopardized in the presence of NPS. A greater awareness is required in the community regarding the well-being of these persons.

Key-words

dementia, community, neuropsychiatric symptoms, spouses'/partners' experiences.

INTRODUCTION

Globally 47.5 million persons are living with a dementia diagnosis, 7.7 million persons are newly diagnosed each year (WHO, 2015). In Sweden, with a population of 9.96 million (Statistics Sweden, 2016) it was estimated in 2014 that 25,000 persons develop dementia each year; the majority of persons are over 65 years. Over half of all people with dementia live in their own homes, a total of approximately 78,000 persons (Swedish Dementia Centre, 2014). The majority of persons with dementia, who reside in their own homes, are cared for by family members or friends. The presence of a family caregiver is said to have a protective effect, delaying or postponing admissions to residential care (Banerjee, Murray, Foley, Atkins, Schneider & Mann, 2003). The social costs for caring for persons with dementia in the community is deemed greater than reported, as costs of informal care are rarely regarded (Wimo et al., 2013; Leicht et al., 2013).

The majority (90 percent) of persons with dementia develop behavioural and personality changes during the disease trajectory (Holtzer, Tang, Devanand, Albert, Wegesin et al., 2003; Fauth & Gibbins, 2014). The term; Neuropsychiatric symptoms (NPS) (Cummings, et al. 1994) is used interchangeably with the term; Behavioural and Psychological Symptoms of Dementia (BPSD) (Finkel, Costa & Silva, 1996). The symptoms referred to are; hallucinations, delusions, agitation/aggression, dysphoria/depression, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behaviour, sleep and night-time behaviour and appetite and eating change (Cummings et al., 1994). The quality of life for both the person with NPS and their caregivers are affected, increasing both suffering and risk for hospitalization (Lee et al., 2004; Fauth & Gibbins, 2014). It is common that the person with dementia has more than one NPS co-existing at the same time (Youn, Lee, Yhoo, Kim, Choo & Woo, 2011). Family caregivers to persons with dementia have identified behavioural changes as more distressing than cognitive impairment leading to increased burden of care and admissions to residential care (Leroi, Voulgari, Breitner & Lyketsos, 2003).

Little is known regarding family members' experiences of living with persons with NPS related to dementia, in a community setting (Moore, Ozanne, Armes & Dow, 2013).

The aim of this study was to describe spouses' experiences of living with partners who have developed NPS related to dementia.

RESEARCH APPROACH

With a view to capture the experiences of participants, qualitative semi-structured face to face interviews were carried out. The interviews were carried out based on the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) Swedish version NPI-NH together with a pre-designed interview guide. The questions in the interview guide were created with the aim of the study in focus (Kvale & Brinkman, 2008) and allowed for qualitative data to compliment the scoring of symptoms on the NPI.

Participants

Spouses/partners to older adults with dementia who resided in a community setting participated. The persons with dementia were 65 years or over and had a diagnosis of; Alzheimer's Disease, Vascular Dementia or combined diagnosis. The couples cohabitated in their own private dwelling and the spouse/partner had good knowledge of both daytime and nighttime activities (Cummings et al., 1994). After gaining approval from the managers of; older adult clinics, an older adult psychiatry unit and a dementia support organization, the recruitment process began. The participants were recruited from urban and suburban areas in Sweden. Demographics were gathered (Table I). A purposeful sampling technique was used (Polit & Beck, 2012). Twenty-one participants were approached and invited to partake in the study. Four persons declined, one person did not wish to participate after consultation with his

spouse, one person had separate living accommodation and one person was not available after initial contact. A total of 14 participants were included in this study. Recruitment and interviews took place over a 12 month period; Nov. 2014 – Nov. 2015. The place of interview was left to the discretion of the participant; the person's own home, the researcher's office or other.

Table I Participants (n=14) and persons with dementia, demographics and clinical characteristics

Participant Age/Gender	*PWD Age/Gender	Diagnosis **AD ***VD	Civil status/Years	Home Care
75yrs/Female	75yrs/Male	AD	Married/50 yrs.	No
80yrs/Female	85yrs/Male	AD + VD	Married/50 yrs.	No
74yrs/Female	74yrs/Male	AD	Partners/27yrs.	No
66yrs/Female	71yrs/Male	AD	Married/40yrs.	No
72yrs/Female	72yrs/Male	AD	Married/50yrs.	No
68yrs/Male	68yrs/Female	AD	Married/40yrs.	Yes
82yrs/Male	82yrs/Female	AD	Married/65yrs.	No
79yrs/Male	80yrs/Female	AD	Married/55yrs.	No
73yrs/Female	80yrs/Male	AD	Married/52yrs.	Yes
64yrs/Female	71yrs/Male	VD	Married/30yrs.	Yes
79yrs/Female	85yrs/Male	VD	Married/45yrs.	No
85yrs/Female	86yrs/Male	AD	Married/61yrs.	No
78yrs/Female	79yrs/Male	AD	Married/55yrs.	No
77yrs/Female	83yrs/Male	AD+ VD	Partners/33yrs.	No

*Person With Dementia, **AD Alzheimer's Disease, ***VD Vascular Dementia.

Data collection

Each interview was opened with a brief introduction to the NPI questionnaire as a compliment to the written information provided prior to the meeting. The NPI questionnaire (Cummings et al.,1994) presents 12 symptoms of dementia, if a symptom was identified then the participant was asked to rank specifics about the symptom; frequency, severity for the person with dementia and finally rank distress (as a family member) in the situation (See Table II). Together with the respondent, the questionnaire was completed. Upon completion of NPI, semi-structured interviews based on a pre-designed interview guide, were carried out. This allowed for in-depth discussion about the symptoms identified and other aspects of daily life, care and support. Consent was obtained from the participants for audio-recording of the in-depth interviews, in total six of the fourteen interviews were recorded for transcription and analysis purposes. During all of the interviews notes were taken by the researcher. The duration of the interviews varied between one and three hours. The first author, a registered nurse, conducted and transcribed all of the interviews in this study.

Data analysis

Recorded interviews were transcribed verbatim; notes were taken during all interviews. Content analysis was used, both latent and manifest to analyses the collected data. Content analysis as described by Krippendorff (2013) is a research approach “for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use” (p.24). The data collected is the point of departure. As a research tool it helps provide new understandings of i.e. specific phenomena which in turn can aid the development of knowledge and provide support for current practice (Krippendorff, 2013).

In response to the aim of this study, a manifest and latent content analysis was carried out on the descriptive data; a theme, categories, sub-categories, interpretive meaning units, condensed meaning units and meaning units were identified. Sub-categories, categories and theme are presented in Table II. The analysis process was inspired by Graneheim and Lundman (2004), applying a cyclical approach, in close collaboration with all members of the research team.

Table: II Qualitative data analysis

SUB-CATEGORIES	CATEGORIES	THEME
Care packages offered not meeting needs Caregiving suggestions for unmet needs	Support needs	
Personality changes Disease dominates	Understanding the impact dementia has on their partner	
Unpredictable behaviour Maintaining a positive approach Distracting from situation Coping with sudden unpredictable hostile situations	Being prepared for sudden unpredictable events	Living on the edge lacking support and time for self
Violence and fear for own safety Seeking immediate assistance Threatening self and others	Feeling vulnerable and facing domestic violence	
Anti-social behaviour Feeling trapped	Feeling socially isolated	

Ethics

This study was approved by the Regional Ethical Review Board in Sweden. Written and verbal information regarding the study was provided for the participants prior to their consent to participate. All of the respondents in this study gave their informed consent in accordance with the Declaration of Helsinki (World Medical Association Declaration of Helsinki, 2013) assuring voluntary participation and confidentiality.

RESULTS

All of the participants in this study identified, that their partners` with dementia had developed NPS in relation to dementia. The symptoms were within three of the NPI's four symptom categories; Behaviour, Psychosis and Mood. Symptoms within the fourth category; Euphoria, were not observed. The persons with dementia had on average five to eight co-existing NPI symptoms. Frequency, severity and distress varied (see table III). Upon analysis of the descriptive data, five categories and one overriding theme emerged (table II).

Table: III Neuropsychiatric Inventory symptoms identified by partners to 14 persons with dementia

NPI Symptom	Prevalence	Frequency	Severity	Distress for spouse
Delusions	8/14	3 - 4	1 - 2	2 – 5
Hallucinations	9/14	3 - 4	1 - 3	3 – 5
Agitation/Aggression	9/14	3 - 4	1 - 3	2 – 5
Depression/Dysphoria	9/14	1 - 3	1 - 3	2 – 5
Anxiety	9/14	1 - 3	1 - 2	2 – 5
Elation/Euphoria	0/14	-	-	-
Apathy/Indifference	11/14	1 - 4	1 - 3	0 – 5
Disinhibition	7/14	1 – 3	1 - 3	1 – 5
Irritability/Lability	12/14	1 – 4	1 - 3	1 – 5
Aberrant motor behaviour	6/14	2 – 4	2 - 3	0 – 4
Sleep & Night time behaviour	6/14	3 – 3	1 - 3	0 – 5
Appetite & Eating disorders	8/14	2 – 4	1 - 3	1 – 5

Living on the edge lacking support and time for self

Support needs

The vast majority of the couples lived in their own homes independently without home care support from the municipality or primary health care services. According to the majority of the participants, the persons with dementia were often in good physical health with a history of actively participating in high level physical activities, during their lifetime. Social care planning meetings were not always optimal and productive with some couples feeling that they were abandoned by the services.

Care packages offered not relevant to needs

Several of the participants stated that there was a standardized approach to the home care support packages offered, they were, what would be regarded in health care as lacking a person-centered approach. The standard support offered focused mainly on basic practical assistance for the person with dementia. This type of assistance was generally not required and did not meet the actual needs of the couples.

“We have been offered help with grocery shopping and cleaning... I just can’t sit down and watch “domestic staff” come into our home and do household chores which I am well able to do myself, and what’s more, get a bill for their services at the end of each month.”

Caregiving suggestions for unmet needs

Suggestions for types of support which were relevant for the person with dementia and the couples’ situations were many. It was primarily of importance to take into consideration that the person with dementia was often in good physical form for their age and accustomed to an active meaningful life. One participant spoke about her partner’s love of golf and the possibility of a companion to go to the golf course with him, another respondent spoke about a companion to go on outings with her husband.

“It would be wonderful if my husband could have a companion who could accompany him on a trip to town and maybe eat lunch or something like that.”

Clarity was sought in regard to how social care planners incorporated the medical information relevant to the person’s dementia diagnosis, when planning care. It appeared that

such unique information was not always taken into account or prioritized while planning for the social care of the person with dementia in the community.

“I would like to be met in a dignified way (by the social care planner) and that the medical information about my husband`s dementia is not disregarded when planning for his future, I informed them about the memory assessment and the recommendations the doctor had made, they said that this was their area and not the doctor`s.”

The participants felt that they were often seen as facilitators by the health care and social services, so the persons with dementia could continue to reside in the home. Their needs were not always in focus when it came to social planning. In some cases the rights of the person with dementia appeared to be valued more than the partners` in regard to assistance and residence, this in turn had an impact on their physical and emotional well-being.

“All the support offered has the “patient” in focus and apparently, indirectly the spouse. There is a feeling that both parties should benefit from the support provided. In my case, I am not helped in the slightest. I do not feel that I am taken into consideration at all. I would like to know who is responsible for my well-being and living conditions?”

Understanding the impact dementia has on their partner

After sharing most of their lives together as a couple, there were often dramatic changes in the balance of relationships due to dementia. In many cases partners with dementia had become passive and no longer interested in their surroundings. A sense of lost identity of the person they once met and shared their lives with was expressed. Parallel to this was a strong appreciation that these changes, in behavior and attitude, were not intentional, they were associated with the disease.

Personality changes

There was an awareness that changes had occurred, sometimes dramatic, in their spouses/partners personalities, making it sometimes difficult to recognize the person they had shared their lives with for so many years.

“The man who is abusive and violent towards me, is not the same person I married.”

Disease dominates

There was an awareness and understanding that these behavioural changes (sometimes extreme in nature) were not voluntary and deliberate, they were a result of a progressive disease. There was a sense of helplessness however attempts were made to accept the situation and see it as disease related and not to take it personally.

“He has gone through so much recently and the fact that he is aware he has Alzheimer`s – It`s so difficult... I can`t reach him in this.”

Being prepared for sudden unpredictable events

The participants shared examples of unpredictable challenging behaviours and their strategies in managing situations. Coping strategies used had often evolved over a longer period of time in correspondence with the progression of their partner`s dementia. What appeared to be, unique strategies, were in fact often commonly applied strategies by other participants in the study.

Unpredictable behaviour

Living life in your own home and not knowing what can happen next was described as challenging. The participants described situations where their partner with dementia had;

mood swings, hallucinations or suddenly became violent and threatening without any obvious reason.

“The mood swings are the toughest, you don’t know what can happen... that really affects me.”

“Gangs of people with a dog can show up in our house (hallucinations), we have to get up and physically check the entire house including the cellar and garden, this can happen several times during the night.”

Maintaining a positive approach

Maintaining a positive approach to life was regarded as important. Taking each day as it comes and not looking too far ahead, was expressed as a means of coping. Due to the often uncertainty of how the day or night would develop, there was a sense of importance in prioritizing a positive approach for own well-being.

“...I just take one day at a time...”

Distracting from the situation

When situations arouse, which were regarded as challenging or uncomfortable, distraction techniques in the form of a change of conversation topic or introducing a new activity was often used. This in turn could reduce the tension of the situation at that point in time, in certain cases. There was a sense, however, that this could be a short-term solution to the problem and that it was important to be prepared for the next challenge ahead.

“I have finally understood not to disagree with him anymore and instead talk about something else, flowers or something...I can never relax, I am always on guard.”

Coping with sudden unpredictable hostile events

In specific cases where volatile situations could occur in the homes, the participants were aware of the risks involved and were prepared to flee their homes for safety, at short notice. To facilitate a quick passage, an easily accessible pre-packed bag, with essential belongings was important to take with them when such situations should arise. This was a common strategy expressed by the participants.

“I am always prepared, and have my bus card in my pocket and my house keys so I can get in if he locks the front door, I also have my jacket and money on standby,... the most important thing of all is actually the bus pass. One time he threw me out of the car when we were parking, he then took off with my handbag left in the car.”

“He has forced me out of my own home and locked me out several times. I had enough during the summer and stayed away for several weeks.”

Feeling vulnerable and facing domestic violence

Hostile and violent situations in the home were described where some of the respondents often feared for their own welfare and safety. These were described as unprovoked episodes, which could occur suddenly day or night, where the person with dementia became extremely threatening and violent. The partners` felt helpless and vulnerable in these situations and applied different strategies to survive.

Violence and fear for own safety

A couple of participants experienced physical violence towards them by their partners with dementia. One respondent explained that the physical abuse began when they were on

vacation abroad, she did not seek assistance or medical help until she returned home to Sweden.

“On Christmas day he started to kick me and then dragged me by the legs through the house. The beatings started when we were abroad to celebrate our 70th birthdays... it was terrible, we were staying in a hotel, you don’t go down to the reception area to seek help for bruising.”

Another participant described how her partner suddenly gets angry and slaps her on the face if she attempted to disagree with him. Several times her partner had thrown her out of her home. The situation worsened when they moved to their summer home. The participant returned to the city earlier than planned as her partner had become more aggressive and driven her out of their home.

“..I just took my backpack and walked... and thought to myself, I can hitch a lift back to the city. He can stay here and take care of himself.”

One participant explained how she would notice a sudden change which comes over her husband’s facial appearance prior to a violent outburst

“He has been verbally and physically aggressive without any prior warning. His face completely changes. I try to be passive and not resist so he won’t beat me so hard... he has ripped off so many of my clothes. The last time it happened I called my neighbour, he came with his dog and guarded the gate, to stop my husband from leaving, until the police arrived...”

Seeking immediate assistance

In cases where the person with dementia became hostile and violent, when safety and welfare were jeopardized, it was important to be able to call for immediate help. The police, a neighbour or family member were named as first line contacts, or simply flee the home. The police were often unable to intervene, due to the nature of the situation.

“if my husband becomes violent there is no point in calling the police, I have done so several times they can’t bring him with them. When they arrive he usually has calmed down and in their eyes no crime has been committed.”

Threatening self and others

Not only was fear for own safety expressed but also fear for the safety of the person with dementia. In one situation the person with dementia had deliberately walked out in front of an oncoming car. Other challenging social behavior was also described which could have negative consequences and put the person with dementia at risk.

“She walked out in front of a car when she was out for a walk with staff from the day care center. Things have also gotten out of hand with inappropriate sexual behavior.”

In another situation an elderly person with dementia left the home in the middle of the night, lightly clothed and was found by a couple who in turn contacted the police. As a result the spouse informed that she was forced to secure the home by installing locks on all windows, balconies and doors.

“We live in a fortress these days. My husband went out in his underwear with my coat and hat on one night, he was lucky that it wasn’t a cold night, he was escorted home by the police.”

One participant explained how her partner with dementia was very active night-time carrying out unnecessary carpentry and other maintenance work in the home using drills or

other such tools. In another case the person with dementia was convinced that her husband was unfaithful with a family member.

“He has started to drill holes in our furniture and dismantle locks during the night... In the morning he doesn’t recall the events and says it was the maintenance staff who did it...”

“She has temper tantrums sometimes, throws stuff at me and writes notes wanting a divorce.”

Feeling socially isolated

Due to the progression of dementia and the presence of NPS, daily life had altered and became restricted for the spouses and their partners with dementia. In the majority of situations it involved that the person with dementia could not be left alone in their home for long periods of times.

Anti-social symptoms

Situations where the person with dementia became unsettled or irritable and because of their actions drew attention from neighbours’ or others outside of the home, was regarded as humiliating and embarrassing.

“When she gets unsettled, she shouts, stamps on the ground, bangs on the table. Sometimes she even goes next door. Our next door neighbors’ have locked their gates now. It is so embarrassing.”

“It is so embarrassing when he shouts at me, all the neighbours’ can hear – it is never ending.”

In one home the person with dementia was insistent that the home was kept in darkness at all times. He became very irritated if his partner tried to open the curtains or put on the lights. The partner had now given up protesting and so they now spend their time indoors in the dark.

“He wants to keep us in darkness all the time. The curtains are closed and the lights are turned off both day and night. I have tried so many times to let some light in, now I have just given up.”

Feeling trapped

The vast majority of the participants were retired and lived with their partners around the clock. Many expressed that they felt isolated and did not have any time for themselves without their partners.

“I have so much on my plate right now, I would love some time to myself.”

Many of the participants felt that they were required to be available around the clock, seven days a week. There was a sense of frustration in their situation that they were confined to the home and their partners` with dementia.

“I feel trapped and need some time for myself.”

DISCUSSION

The individual qualitative interview facilitated the participant to complete and discuss the NPI together with the researcher. This allowed time to reflect and identify over possible changes in their partners` psychological status and behaviour in relation to dementia. Caregiver stress related to symptoms was identified. The levels varied from person to person and from symptom to symptom (see table II). Neil and Bowie (2008), used two instruments to measure carer distress; NPI and Behavioural and Psychological Symptoms Questionnaire (BPSQ). They found that caregiver distress was underrated using the NPI compared to the self-reported scores from the carers in BPSQ. Prior to this study, many of the participants were not familiar with the term “neuropsychiatric symptoms” or “behavioural and

psychological symptoms of dementia” and that persons with dementia commonly experienced such symptoms.

The original NPI questionnaire devised by Cummings et al., (1994) is written in English. In this study the Swedish version of NPI-NH was used. NPI-NH is often used in residential facilities to assess NPS symptoms in residents with dementia. Certain terms, pertaining to a nursing home environment were removed in the interviews carried out in this study.

The results describe the current experiences of the participants at the time of interview and their practical needs. A desire to help others in the same situation and potentially influence support services was expressed by several of the participants as a motivator for participation in the study. This is in keeping with Avent et al., 2013 that highlighted two main motivational factors for participating in their study on dementia were; to help others and to help themselves.

Each participant in this study was in a long term relationship with a partner with dementia, each couple on average had lived together for over 46 yrs. In several interviews it was the first time the participants had openly addressed that their partners` had neuropsychiatric symptoms. Cummings et al., (1994) requires that the person answering the NPI (on behalf of the person with dementia) must have good current knowledge of the person with dementia and their daily and nightly activities. The NPI is generally completed within residential care facilities. Using an established symptom questionnaire as a platform for the interviews in this study, may have established a “norm” surrounding the presence of neuropsychiatric symptoms and created an accepting, open forum to discuss, often sensitive related experiences.

The qualitative data was read through several times and a manifest and latent content analysis was carried out (see Table II) inspired by Krippendorff (2013).

Upon completion of the interview, the participants were asked to provide feedback on the interview, the majority were satisfied with the interview and felt the questions posed were relevant to their situations. One participant suggested that physical aspects of their partner’s dementia illness should be addressed in the NPI questionnaire. In this case the person’s partner (due to progression of dementia) had both fecal and urine incontinence, which in turn was very distressing for the spouse. According to Lliffe et al., 2015 the presence of incontinence among persons with dementia residing in the community, is two times greater compared to peers, this aspect of dementia care remains under-investigated.

According to previous research it is said that 90 percent of all persons with dementia develop NPS during the disease trajectory (Holtzer, Devanand, Albert, Wegesin, Marder et al., 2003; Fauth & Gibbins, 2014). It is common that more than one symptom of NPS co-exists at the same time (Youn, Lee, Yhoo, Kim, Choo & Woo, 2011). In this study all 14 participants identified that their partners with dementia had on average five to six co-existing NPS. Several of the participants identified that their partners had eight or more co-existing symptoms of a possible 12 stated in the NPI.

The vast majority of the couples lived in their own homes independently without home care support from the municipality or primary health care services. Participants stated that formal support offered to them in their homes was standardized and did not always meet their partners` individual needs. Persons with dementia, in this study, were often physically fit for their age and were not in need of personal care assistance or domestic services which were offered. Suggestions were made regarding a desire for a more person-centered support which encouraged outdoor activities and social activities. According to Hendriks, van Vliet, Gerritsen and Dröes, (2016) person-centered outdoor nature activities have positive effects for persons with dementia helping to reduce levels of negative behavior. Accessing the right level

of support at the right time is vital so the person with dementia and their family can live well in the community (Brannely, 2016).

Several of the participants were aware that their presence in the home was essential in order for their partner with dementia to continue living at home. This is in line with the study carried out by Banerjee et al., (2003) stating that the presence of a family caregiver has a protective effect, delaying or postponing admissions to residential care.

Common strategies of preparedness were used in the event of aggressive or threatening situation. Several of the participants spoke about the importance of having an easily accessible bag packed with necessities to leave their homes in a hurry. Maintaining a positive attitude and taking one day at a time was expressed as an important aspect in coping with daily life. Nogales-González, et al., (2015) highlighted in their study that family caregivers dealing with high frequency of NPS, who held high levels of self-efficacy resulted in reduced caregiver distress as opposed to caregivers with lower levels of self-efficacy.

An awareness that their partner was a changed person with risk of or having lost their identity to the disease was present. All of the participants had been in long term relationships with their partners (see Table I) which often entailed a commitment to each other despite setbacks. Feast, et al., (2016) in a systematic review identified, that caregivers found two main areas of challenge; changes in communication and changes in relationship. These changes resulted in family members experiencing a sense of bereavement for the person with dementia.

In cases where participants faced violence and hostile situations in their homes where safety and welfare were threatened, it was important to access immediate assistance outside of the home. The police were mentioned as one first line response; however they were rarely able to assist due to the nature of the situation. In several incidents the partner with dementia had calmed down when the police officers entered the home. In another incident, as a result of extreme domestic violence, a neighbor was called upon to protect the spouse from further violence and prevent the person with dementia from leaving the home. While waiting for the police officers to arrive, the neighbor guarded the gate with his dog. According to a literature review carried out by Cipriani et al., (2015) elderly persons with dementia have a significantly higher risk of physical violence towards their partners than persons without a dementia diagnosis. However, there is little known about the prevalence of aggressive and violent behaviour in persons with dementia. This may be due to under-reporting, uncertainties regarding definitions of violence and finally how the behaviour is interpreted. The Swedish national center for knowledge on men's violence against women (NCK) report, (2016) on "Violence towards older women", highlights the fact that many older women who have been subject to abuse in a near relationship, do not seek help. There is a need to heighten awareness and professional competence to deal with abuse in older persons in society.

Anti-social and unpredictable behaviour often due to the person with dementia experiencing sudden mood swings, aggressive outbursts and hallucinations were possible factors which lead to social isolation. According to Van der Lee, Bakker, Duivenvoorden and Dröes, (2015) the severity of the persons' NPS are strongly related to how the caregiver copes with the burden of care. Ask et al., (2014) describe how spouses to partners with dementia experience more symptoms of anxiety, depression and rate life satisfaction lower than their peers who reside with partners without dementia. A greater awareness of the presence, frequency and severity of NPS experienced by persons with dementia residing in the community is required

Conclusion

The findings of this study suggest that support offered to persons with dementia and their partners should have a person-centered approach meeting individual needs. The safety and welfare of persons with dementia and their partners' residing in their own homes maybe

jeopardized in the presence of NPS. A greater awareness is required in the community regarding the well-being of these persons.

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