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Uncontrolled Sexual Behaviour in Dementia

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1. Introduction

Uncontrolled sexual behaviour in dementia is considered as a symptom of the behavioural disturbances seen in dementia, such as agitation, disinhibition, apathy, depression, and psychotic behaviour. The combination of these behavioural problems and progressive cognitive dysfunctions are the main characteristics of dementia. The behavioural problems, are present in 80-95% of the patients with dementia [1]. These symptoms decrease the quality of life of patients, increase the likelihood of institutionalization, and contribute most to caregivers burden. Although less common than most other behavioural problems, uncontrolled sexual behaviour is often more disruptive and upsetting to a spouse, institutional staff and other residents [2-4]. Therefore, these sexual behaviours are a tremendous challenge for health care providers in institutional care settings. However, a literature search utilizing Pubmed showed that only 0,5% of the literature addressing dementia concerns sexual functioning, and even less focuses on uncontrolled sexual behaviour. Thus, uncontrolled sexual behaviour is a serious neglected area in this field, while the majority of health care providers agree that more information and institutional training is needed [2, 5, 6].

2. Uncontrolled sexual behaviour

Uncontrolled sexual behaviour is labelled and defined in many ways in the literature. Synonyms used are 'Disinhibited sexual behaviour' [7], 'Inappropriate sexual behaviour' [8, 9], 'Inappropriate sexual expression' [2], 'Increased sexual activity' [10], and 'Hypersexuality' [11]. All phrases imply that this behaviour is a sexual act (verbal or physical) which is unacceptable, inappropriate, disinhibited, or uncontrolled within the (social) context in which it is carried out. Examples are sexual comments, masturbation in public, grabbing at the genitals and/or breasts of other persons, chasing other residents for sexual purposes, and exposing

one's genitals in public. Some of these behaviours may be inappropriate only because they are performed in public and therefore should not be confused with sexual appetite and behaviour in older people due to a normal sex drive. There is no widely agreed definition of when this behaviour becomes inappropriate and so it is subject to subjective interpretation of the observer. In this chapter, 'uncontrolled' is used reflecting a reduced capacity to manage an impulsive response to a situation.

There are several types of behaviours identified in the literature to cluster uncontrolled sexual behaviour. In some reviews of the literature, three types were suggested, i.e. sex talk, sexual acts, and implied sexual acts [11-13]. Sex talk is regarded as the most common form and involves inappropriate language, that is not in line with the patient's premorbid personality. Sexual acts include touching grabbing, exposing or masturbating in public or in private settings. Implied sexual acts involve reading pornographic material in public or requesting unnecessary genital care. In an observational study that included 40 patients with dementia living in a nursing home [14], research assistants scored whether exposed sexual behaviour was appropriate, ambiguous or inappropriate. The patients were systematically observed on nine separate five minute occasions in the nursing home during different situations, such as at meals, being groomed or dressed, in their rooms. Most sexual behaviour was coded as inappropriate or ambiguous. Overall, this scoring leaves substantial gaps for individual interpretation of the observer. Besides, the three types of sexual behaviour were not based on empirical evidence.

More recently, two observational studies shed more light on the definition and measurement of uncontrolled sexual behaviour. In the first study [15], sexual behaviours were observed and afterwards clustered in several types. Based on an observational study which included 12 patients with dementia, aged between 53 and 84 years of age, nineteen sexual behaviours were obtained from observations and interviews with their caregivers and categorised by the authors in three types, i.e. 'sexual acts with contact with others', 'sexual acts with non-contact with others', and 'verbal sexual behaviour'. The most frequently observed sexual behaviours consisted of patients stroking their own genitals in private, touching areas of another person and verbal provocation. In the second study [16], 68 health professionals were questioned, working in institutions with patients with progressive neurological disease or patients with acquired brain injury, which resulted in 145 examples of uncontrolled sexual behaviours. Incidents of touching others inappropriately was the most common uncontrolled sexual behaviour.

Based on the abovementioned study in which an observation instrument was developed [16, 17], items were identified for the development of a questionnaire regarding sexual behaviour in dementia (SBDQ; [6]). The questionnaire consisted of four discrete behaviour categories: verbal comments, non-contact behaviour, exposure, and touching others. 115 health professionals were asked to rank the behavioural descriptors in terms of severity. This resulted in four levels of severity for each behaviour category. The rankings resulted in categorisations of uncontrolled sexual behaviours that are more evidence based and initiated a methodological tool that may have value for clinical use and research purposes. The validity and reliability of this scale was investigated and established (see also, [6]).

3. Uncontrolled sexual behaviour in dementia

Because of the limited coverage of uncontrolled sexual behaviour within the literature and the use of different definitions and categorisations, it is difficult to obtain a robust view of prevalence of these behaviours in dementia. Nevertheless, there are some studies which offer an insight in the frequency of uncontrolled sexual behaviour in dementia. For example, Burns et al. (1990) found that 7% of 178 patients with Alzheimer's disease showed sexual inappropriate behaviour (i.e. exposure, obscene sex language, masturbation, propositioning others). A more recent study [19] showed nearly a similar prevalence rate (8%) of references to sexual behaviour in medical records of 165 older people with dementia living in a residential care facility. The prevalence is substantially lower in a mixed cohort with patient living in nursing homes and patients living in the community. Of the 2278 participants only 41 (i.e. 1,8%) had a documentation of verbal or physical aberrant sexual behaviour [8]. In an observational study, there was a clear difference in prevalence rates between types of dementia, such as Alzheimer's disease, vascular dementia, pick's disease [14]. Patients with Alzheimer's disease expressed less uncontrolled sexual behaviour compared to patients diagnosed with other types of dementia (i.e. 9% versus 28%). This difference was also seen in other studies. For example, Alagiakrishnan (2005) demonstrated that 53,6% of the patients expressing uncontrolled sexual behaviour were diagnosed with vascular dementia, while 22% was diagnosed with Alzheimer. And even in the sample of twenty patients expressing uncontrolled sexual behaviour of De Medeiros et al. (2008), this difference was significant ($p < 0.01$). The higher percentages of uncontrolled sexual behaviour in non-Alzheimer's types of dementia may be explained by a relatively higher likelihood of brain pathology that is associated with hyper sexuality (e.g. striatum, frontal lobes, temporo-limbic system and hypothalamus (e.g. [12])).

It not clear whether uncontrolled sexual behaviour is more prevalent in men than women or in patient with more severe dementia. Most studies only included men and dementia severity was often not investigated with regard to uncontrolled sexual behaviour. In studies that focused on uncontrolled sexual behaviour and included severity of dementia, the results were inconclusive. Burns et al. (1990) found a positive association with severity of dementia, while De Medeiros et al. (2008) concluded that half of the subjects with uncontrolled sexual behaviour had mild dementia, whereas most subjects with non-sexual behaviours had severe dementia. However, this difference did not reached significance. In both studies the frequency of sexual behaviour was equal for men and women, while two other studies have shown that sexual behaviour was more prevalent in men [5, 8].

In sum, based on these cross-sectional studies, prevalence rates of uncontrolled sexual behaviour in dementia vary between 1,8%-28%, which depends on type of dementia.

4. Etiology

The etiology of uncontrolled sexual behaviour is rather complex and must be considered within a biopsychosocial perspective [20]. Generally, the literature attributes this behaviour to

biological changes associated with dementia, such as changes in brain structures and/or neurotransmitters. Case studies demonstrated that dysfunction of interconnected brain structures may cause uncontrolled sexual behaviour. Four major brain systems have been suggested [12, 13], i.e. the frontal lobes, the temporo-limbic system, the striatum, and the hypothalamus. Head trauma to the frontal and temporal lobes may decrease inhibitory impulses often needed to keep sexual feeling in control and therefore result in uncontrolled sexual behaviour. Pick's disease and Kluver-Bucy syndrome is associated with frontal and temporal pathology. These patients are characterized by social inappropriate behaviour, including uncontrolled sexual behaviour. Injury to the striatal region, as in Huntingtons and Parkinson disease, may result in obsessive-compulsive sexual behaviour [21]. Lesions to the right hypothalamus can cause manic symptoms, including increased sexual desire.

Psychological factors may also contribute to uncontrolled sexual behaviour or maintain this behaviour. First, some behavioural problems, including depression, hyperactivity, or mania, may increase sexual interest and result in uncontrolled sexual behaviour [19]. Other diagnoses, such as delirium, epileptic seizures and alcohol abuse may also cause uncontrolled sexual behaviour [7, 21]. Second, the amount of sexual interest is also determined by premorbid patterns of sexual activity [20]. Third, uncontrolled sexual behaviour may be due to disorientation, which is often seen in the patient with dementia. For example, because of the cognitive impairments, the patient with dementia may not be aware of his or her surroundings, and display behaviour considered normal in private but not in public. Similarly, a patient may misidentify another person as their spouse, and display behaviour appropriate for a married couple [9].

Psychosocial factors that may be associated with uncontrolled sexual behaviour are lack of a usual partner, lack of privacy, or an under stimulating environments. Older adults in residents may lack physical closeness, especially when they don't have a partner. Physical closeness might reduce loneliness and anxiety of the patient with dementia. When this need is not met, it is possible that this may take the form of physical aggression in persons not knowing how to appropriately meet their needs for closeness and intimacy. In nursing homes, there is often a lack of privacy and less opportunities for patients to be intimate with their partner. This may even be aggravated by the relatively passive and conservative attitude in some health professionals toward older people sex issues [2, 5]. In addition, an under stimulating environment may increase boredom and loneliness, which may result in disruptive sexual behaviour. In conclusion, the etiology of uncontrolled sexual behaviour is rather complex and there are many factors that could cause or maintain uncontrolled sexual behaviour.

Empirical studies addressing the etiological factors of uncontrolled sexual behaviour in dementia are very sparse. Since uncontrolled sexual behaviour may have an immense impact on patients and their relationship with others, family, caregivers, and institutional staff, it is important to gain more information on uncontrolled sexual behaviour and its etiology. More insight in uncontrolled sexual behaviour in dementia and the etiology, would be useful in diagnosing symptoms of uncontrolled sexual behaviour and could provide directions for interventions in order to help the patient, health professionals, and families to deal with this behaviour.

5. Management

The management of uncontrolled sexual behaviour is often a challenge. Less is known about the best way to act, while the need for evidence based guidelines is growing. Overall, management of uncontrolled sexual behaviour can be divided in behavioural strategies and pharmacological treatment. Because many of the drugs carry significant risk of adverse side effects, it is important to start with a solid assessment of the situation (including the degree of risk to others) and appropriate behavioural treatment.

5.1. Assessment

First of all, the exact target behaviour, context and involved factors need to be defined; what form? In what context? Frequency? What factors contribute? What is known from the (sexual) history? Is it a desire for closeness, comfort, or lack of privacy? Is it a problem and to whom? Are there any risks and to whom? Do the patient have insight? What is the mental/cognitive status? [12, 20]. These questions may be answered by direct observation of the patient, in an open discussion with main staff and significant others, and/or a standardised measurement, like the SBDQ [6]. In addition, it is important to rule out delirium and consider mood disorders or psychosis. These disorders need other management than uncontrolled sexual behaviour. Examining physical status and current medications is needed to determine (bio)medical causes. Different classes of medications have shown to induce uncontrolled sexual behaviour, in clinical settings [22]. For example, atypical antipsychotics can induce uncontrolled sexual behaviour by blocking the effects of selective serotonin reuptake inhibitors [23]. The reason for this is, that selective serotonin reuptake inhibitors typically suppresses sexual drive [7, 24-26]. In sum, a careful assessment provides information to choose an appropriate treatment (strategy) and a good baseline to properly evaluate the process and the effects of treatments.

5.2. Behavioural treatment

After a careful assessment, it is possible to develop a care plan with the involved care professionals and it is recommended to involve significant others. A care plan may include elements that are directed to the patient, significant others, other residents, and the staff. To the patient, many behavioural strategies may be initiated depending on the form of behaviour, the contributing factors, and the patients cognitive functioning (possibilities for new learning). Examples of behavioural strategies are distraction during presence of uncontrolled sexual behaviour via substitution of other activities, redirecting via conversation or humour, ignore unwanted behaviour and encourage appropriate behaviour, modification of social cues that are being misinterpreted, removing 'triggers' of the behaviour, substitute caregivers to the sex that does not match their sexual preference, avoidance of external cues such as over stimulating television or radio programs, trousers that open in the back or with zippers in case of exposing behaviour, providing single rooms, "not disturb" signs, and/or allowing doors to remain shut to provide privacy to let the patient satisfy their sexual needs [9, 12, 27-29]. To the significant others or spouses it is useful to give additional information to reframe the behaviour and reassurance that these behaviours are not a reflection of their relationship.

Providing staff supervision and additional education may be extremely helpful, because care professionals report that it is often difficult to cope with these behaviours or it is distressing for them [2, 30]. There should be a good balance between openness to the patients need for normal sexual expression while preventing uncontrolled sexual behaviour [12]. It is also critical to prepare students for uncontrolled sexual behaviour. In a study in which a young student introduced herself to several residents, she was confronted with uncontrolled sexual behaviour and responded with guilt, confusion, and distress [30]. More reflection on own behaviour and small changes in the appearance, like another manner of dressing, may help in provoking less uncontrolled sexual behaviour. In addition, providing more information on the etiology of the behaviour may aid to reduce guilt and confusion of the student or care professional. Because students and care professionals may be uncomfortable discussing uncontrolled sexual behaviour, it is important that the supervisor initiates the topic and provide coping strategies to them. Specific methods, like role playing, may be quite helpful to prepare the student for uncontrolled sexual behaviour [30].

After all, it is important that evidence based guidelines will be developed in addition to a policy and procedures within an organisation.

5.3. Pharmacological treatment

Different classes of medication (e.g. antidepressant, antiandrogen, antipsychotic, and anticonvulsant medications) have been proposed in the treatment of uncontrolled sexual behaviour [31]. The basis for medication treatment comes from the similarities of paraphilias with sexual behaviour [32]. Paraphilias and hypersexual behaviour, both involve uncontrolled sexual behaviour. Hence, pharmacological treatment of uncontrolled sexual behaviour is focused on pharmacological agents that affect monoamine neurotransmitters and that enhance central serotonergic function in particular (see also, [33]). However, there is not yet convincing data supporting the use of a particular medication. Most evidence is in the form of case reports and data are also lacking with regard to the advantage of any medication over placebo or in comparison with other medications [31, 34].

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