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Health professionals working with persons with Alzheimer's. Reflections for new training courses.

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Abstract

Health professionals working with a person suffering from Alzheimer's disease have to face with considerable communicational and relational difficulties. Therefore, training programs focused on the cognitive or medical aspects of the disease may not be sufficient to deal with the complexity of this condition. Starting from the contributions of Kitwood (1997) and the approach of Bender (2003), this study aims to discuss an alternative paradigm to dementia-care, providing suggestions about the daily care work of health professionals. Some expressive and narrative activities are presented in order to facilitate an effective relationship between operators and patients.

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1. Introduction

Population aging comes with an exponentially increasing number of aging related diseases like dementia, whose most common type is Alzheimer's disease (50-60% of cases). According to the medical approach the dominant narrative describes Alzheimer's as being "the big neuropsychiatric disorder of our time" (Longmore, Wilkinson, Rajagopalan, 2005). However, due to the important changes in personality and affectivity, Alzheimer's is often considered as a mental illness. It is a frequent source of stereotypes and prejudices (Behuniak, 2011; Herskovitz, 2009; Jolley & Benbow, 2000; Goffman, 1963), given that it undermines the concepts of independence and efficiency that underpin Western society. Dementia's stigma is also based on stereotypes concerning *ageism* which implies the association "aging-decline" (De Beauvoir, 1970; Powell & Longino, 2001; Nelson, 2004). Therefore this disease embodies the fear of aging, disability and loss of the self (Hashmi, 2009). The gradual reorganization of time, space, lifestyle and roles required when taking care of a person with dementia, exposes caregivers to many pressures that need preparation and flexibility. The majority of patients are assisted within the family, but an increasing number of relatives ask the support of professional caregivers or rely on specialized clinics. Theories, beliefs and meanings attributed by health workers to dementia guide their care practice. Health workers themselves often share cultural fears and stereotypes on aging and dementia that could hamper the relationship with the patient. Establishing an effective relationship with a person with severe cognitive impairment is essential for the well-being, both of the patient and the health worker, and it also enables to obtain a good patient's compliance. However, the urgency of certain treatments and the lack of adequate time, often lead the professionals to focus their attention more

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on basic tasks (e.g. washing, cleaning, nourishment…) rather than on communicational patterns. Focusing on the communicational and relational aspects is fundamental in caring professions, as relationship is the basis of the work itself: caregiving is based on the constant and mutual interaction between people (Kittay, Jennings, Wasunna, 2005; Nussbaum, 2000) therefore activities as cleaning or nourishment are not just an automatic execution of tasks, but they are relational activities. The "caring role" involves the whole person: his/her values, beliefs and emotions. Therefore, caring professions need to have access to educational opportunities focused on the relationship, as well as moments of supervision, in order to provide the adequate support for a job so challenging. Training courses should also provide a space for reflection to gain awareness of the impact that the approach to the patient has on the daily care. In order to achieve these goals it is therefore necessary to reflect on the implicit theories that guide the work of health workers and to provide a new theoretical framework which focus on the person, rather than on the disease (Kitwood, 1997). The aim of this work is to propose a relationship-centered perspective for the training courses aimed at health professionals. Starting from the pioneering contribution of Kitwood (1997, 1997, 1900) and from the studies of Bender (2003), the paper open a reflection about the relationship with a person with dementia, according to a constructivist and socio-constructionist perspective (Bruner, 1990; Gergen 1985; Kelly, 1955). Finally, some practical activities based on narrative, will be presented.

2. Theoretical considerations: a new paradigm in dementia-care

Kitwood (1997,1997) introduced a paradigm shift in dementia-care, suggesting a new approach based on the concept of person-centered-care. The author proposed a psycho-social and dialectic model of dementia, that would be conceptualized as a phenomenon rooted in the society where the neurological decline interacts with the social environment surrounding the patient. Kitwood queried the so-called "standard paradigm" (Kitwood, 1990), linked to the Western biomedical model, that states that there would be a direct and exclusive causal relationship between brain neuropathology and cognitive impairment. The author, introducing the concept of "personhood", conceptualized the patient in relation to his/her social context and valued the patient's subjectivity and personal experience. In particular, Kitwood defined "malignant social psychology" those kinds of behaviour, frequently taken against people with dementia, which determine the process of depersonalization of the patient. Therefore, many of the patient's "behavioral disorders" may not only be caused by a cognitive impairment, but could be seen as a way to communicate with a disabling environment, thus establishing a vicious circle which relegates the ill person solely to the passive condition of "patient". Starting from Kitwood's critic, Bender (2003) discussed the validity of the diagnosis of dementia as well as the reasons for which the "standard paradigm" would still be active and widespread in our society and within specialized clinics. Bender developed a constructivist "psychological framework for understanding dementia" (2003) from the point of view of people with dementia ("the client-focused approach"). In this way, an active role is attributed to the ill person and the possibilities of entering into a relationship with him/her are discussed. Based on these recent "person-focused" perspectives, the paper combines a socio-constructionist and constructivist approach to propose the creation of training courses focused on relationship.

3. How to focus on communication and relationship: a socio-constructionist and constructivist framework.

Despite the spread of creative approaches on dementia-care, such as Validation Method (Feil, 1982), Person-centered dementia care (Kitwood, 1997), Gentle care approach (Jones, 1999), Client-focused approach (Bender, 2003) or the PCP perspective on dementia (Morris, 2004), the practical conditions of assistance often make the creation of an effective relationship difficult. The "memory clinics" are often still task-driven and they usually give more importance to the medical treatment (in particular pharmacological and neuropsychological assessments) rather than providing long-term support interventions (Bender, 2003). It is therefore important to consider the possibility of a permanent education that provides operators with useful tools for the care relationship. In literature, contributions about dementia in a constructivist and socio-constructionist perspective, are still few. According to these theoretical frameworks, the professional caregiver and the person with dementia are seen as active subjects in interaction with each other: they actively engage into the generation and negotiation of meanings, thus acting according to them (Salvini, 1998; Harre, 1991; Gergen, 1985; Berger & Luckmann, 1966; Kelly, 1955). The health professional creates his/her own theory about the disease and the ill person, starting from meanings attributed to

his/her experience: cultural norms and shared beliefs influence meanings attributed to dementia, which in turn have a significant impact on the relationship with the patient (Lawrence et al., 2010). Thus it is important for health professionals to reflect upon their own way of being in relationship, focusing in particular on their own limitations and difficulties (*reflexivity*). At the same time the ill person him/herself constantly strives to make sense of his/her experience, while cognitive deficits may make this attempt painful and distressing. Fear, anxiety and threat can easily be experienced in front of an unknown and unpredictable world. The same emotions may be experienced by the health professionals: the communicational difficulties can be frustrating and the patient may often seem difficult to approach and understand. "Behavioural disorders" may be considered as the person's best alternative to deal with the condition of disorientation. Interpreting moments of anger or apathy as attempts to cope with an unpredictable experience, can help professionals to understand this difficulty, reassuring him/her instead of starting symmetric interactions (Watzlawick, 1967). According to one of Watzlawick's (1967) human communication's axioms, it is impossible not to communicate. Therefore, even through states of deep depression and passivity, the person communicates something and it is a caregivers' task to interpret his/her intentions. According to a socio-constructivist perspective, the Self is considered as a process: a fluid and multiple Self (Gergen, 1985) that takes place within the conversation with others (Harrè, 1998). The concepts of "relational identity" and *dialogic self* (Hermans, Kempen, van Loon, 1992) express the importance of the cultural and relational context where meanings are negotiated and constructed in interaction with others. According to these assumptions, health professionals have a central role in the support of the ill person: they can propose new meanings and narratives helping him/her to interpret his/her condition. Thus, the ill person can maintain his/her personal identity and take a role in relation to the others. Professional caregivers may get from the patient's point of view (*role-taking*), trying to figure out how he/she could live a certain experience referring to his/her cognitive difficulties, life-story and identity. It is therefore important to use a *credulous approach* (Epting, 1984): suspending judgment and assuming that what patients say to see and feel, is real to them; then they may try to create a "narrative space" where the ill person can express him/herself with him/her abilities. Hence, health caregivers should assume that the ill person perceives what they do, though he/she is often not able to reciprocate. Supporting the person, validating his/her experience (e.g. during hallucinations or unjustified fears/beliefs) is a way to give importance to the person's experience without colluding with it. For this purpose it is useful to focus on non-verbal communication (Watzlawick, 1967), paying attention to the emotions expressed by the patient, rather than the content itself. Communicating with non-verbal language (caresses, body contact, voice tone...) is, in these cases, more effective than using verbal communication. How professional caregivers behave with the person, influences the person's way of perceiving him/herself and his/her way to relate (Sabat, 2003): treating the patient as a person, in his/her uniqueness, can help health professionals to avoid generalizations and stereotyping. In the nursing homes, in fact, prejudices and stereotypes about aging and dementia are often shared and transmitted, so that the term "institutionalized ageism" has been coined (Bowling, 2001). Every person with dementia reacts differently to interventions. The disease courses and cognitive deficits are highly variable, as are the patients' interpretation of events; their behaviors are filtered by their meanings' system, their values and their past life. Therefore, professional caregivers should be informed about the person's life-story and interests in order to improve their connection with the patient. Referring to the past life can help the ill person to find a continuity between past and present, sharing and recognizing his/her narratives. In some cases, it would be important to speak openly with the patient, about the diagnosis and his/her difficulties. In this way, he/she can take an active role in his/her treatment and try to give meaning to his/her condition. Not only it is important to humanize the patient, but also to offset his/her deficit, recognizing and strengthening the residual abilities and improve the social environment. Cooperation between health professionals and patients is central in this process.

4. Expressive and narrative techniques for facilitating relationship

Recently, studies on the identity of people with dementia are increasing (MacRae, 2010; Kontos, 2004; Sabat & Harré, 1992). According to these studies, people with dementia actively engage in a personal process of meaning making of their illness experience. Therefore, a sense of identity and personal continuity could be maintained despite their cognitive deficits. For these reasons, giving voice to the patients may not only be important, but also necessary to help them in their effort to maintain a sense of continuity in their own story and identity (Faccio,

2011; Faccio, Minnini, Centono, 2012; Faccio, Belloni, Castelnuovo, 2012; Salvini, Faccio, Mininni, Romaioli, Cipolletta, Castelnuovo; 2012). It is useful to develop the use of *narrative thinking* (Bruner, 1990), which is often preserved in dementia and through which the person give meaning to and explain his/her story. Starting from these assumptions, some narrative and expressive techniques that may be particularly useful in these health professions, are suggested. *Reminiscence* (life-review) and *story telling* are suitable for the initial and intermediate stages of dementia, while they need to be reviewed for the more advanced stages of the disease.The *reminiscence* activity (Bruce, Hodgson, Schweitzer, 2003) consists in thinking, talking or writing about one's own life-experience, sharing the memory with others and giving continuity to the experience. In order to help to elicit autobiographical memory's episodes (e.g. school, family, marriage, travels...) it is useful to use objects that are familiar to the person (e.g. photos, songs, poems...), avoiding direct or unclear questions. Sensory stimulation can facilitate the recollection (e.g. smelling spices or perfumes; touching materials such as fabrics or work tools; listening to songs...).The use of life stories helps the person to regain positive feelings, valuing his/her story and emotions, developing a sense of identity and allowing the person to attribute consequentiality to his/her experience (Viney, 1993) explaining it through a *retrospective teleology* (Brockmeier, 1997). This may represent an interesting opportunity for professionals to relate with the patient through *active listening* (Sclavi, 2003). In order to organize an effective activity, it is important to have some information about the person's past life and his/her cultural and historical background. This technique is not interested in identifying the "truth" or the "historic truth" about the patient's life. *Reminiscence* focuses primarily on the *narrative truth* (Bruner, 1990) which consists in the emotions and personal meanings that the ill person communicate through the recalling activity. The *story-telling* activity consists in creating a fairy tale in co-operation with the professional. Through the classic fairy tale's structure and characters (Propp, 1966; Rodari, 1973), this activity facilitates the expression of patient's values, fears and desires, stimulating his/her creativity. The *story-telling* can be divided into five stages: (1) Several images representing the possible characters of the tale (heroes, antagonists, animals, helpers...) and magic objects are presented to the person. (2) The person chooses the elements that more attract him/her explaining why, then the person characterize them. (3) The plot is created, with the help of the professional, following some of the fairy tale's classic phases (Propp, 1966). (4) The operator rewrites the tale. (5) The patient draws tale's salient moments during an artistic activity. It is important for the activity to have a concrete purpose, like creating a book that could later be read to an audience. This can help to increase the patient's self-efficacy, giving him/her an active role. Through the tale, people with dementia indirectly express parts of themselves and their life through symbols and images. The difficulties related to communication and logical thinking can become a creative element in the tale (Rodari, 1973), whose magical elements make the impossible allowed. According to some authors (Pasin, 2010; Santagostino2006), the *story-telling* activity is therapeutic itself because it proposes, works out and finds solutions to a problem working on non-verbalized elements. Both activities can be done individually or in groups, but it is preferable to carry them out into small groups. Social interactions' restriction, loss of role and ageism's internalization (Bender, 2003) are some of the aspects of greatest vulnerability for people with dementia and may increase their disorientation. The contributions on the relationship between social-support and health (House, Robbins, Metzher, 1982) demonstrate the importance of teamwork: the person with dementia will have the opportunity to share his/her experience, to create relationships and thereby to increase his/her self-esteem and confidence in the social context. Health professionals may facilitate patients to gain a significant and satisfying role in the group, stimulating their interactions.

5. Conclusion and discussion

The importance of activating a continuing education for health professionals has been discussed. Care work is based on relationship, therefore it requires a constant and continuous redefinition of techniques and communicational strategies. Through some theoretical considerations about the recent contributions on dementia-care and the presentation of two narrative team-techniques, the attention has been focused on how to get in touch with the person suffering of dementia. Using these sort of techniques may help to improve the patient's quality of life and treatment compliance, as well as the professional caregiver's satisfaction and quality of work. However, the delicate work of long-term care presents some difficulties that need to be considered. Carrying out the group-activities or activating communicational strategies requires time and attention; however, achieving these goals could

be difficult because of the space and time management imposed by the institution. To address these difficulties, it would be necessary to share the same values and theoretical assumptions among the all nursing homes' staff. Creating work-groups among health professionals and providing them of a constant supervision, can help them to implement the reflexivity in their work. The awareness to be part of a network and the opportunity to share doubts or difficulties can be a precious mean to counteract the feelings of worthlessness that can easily characterize professions dealing with death and chronic disability. To optimize the continuity of these interventions, the patient's family should also be involved. The institution may provide some training sessions, which could help to share the same values and principles underlying the relationship-centered approach. It is also important to increase, within the nursing homes, opportunities for external exchange, in order to give the patients a sense of continuity with the community and to reduce their isolation. Finallyit should be necessary to develop further studies on communicational and relational skills of people with dementia, including both empirical researches and theoretical reflections.

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