

EDITORIAL

Insight in coping with dementia: Listening to the voice of those who suffer from it

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Coping with chronic illnesses is a theme that has been studied for many years (Lewis, 1998; Moos & Tsu, 1977; Stanton, Revenson, & Tennen, 2006), however, until recently very little has been published on coping with dementia. Even in educational textbooks the theme was widely neglected before the mid 1990s, at least from the perspective of the person with dementia.

Coping with dementia from different theoretical perspectives

One of the first authors who wrote about coping in dementia, now thirty years ago, was Verwoerd (1976, 1981). From a psychodynamic perspective he interpreted specific psychological and behaviour changes in people with dementia as expressions of coping with stress. He described three types of coping strategies: Strategies aimed at mastering and controlling situations that provoke anxiety (e.g. obsessive thoughts and compulsive behaviour); strategies aimed at keeping the threat out of consciousness (e.g. suppression, denial and projection); and regressive strategies (e.g. retreat, regression and giving up). Another author who wrote specifically on coping in dementia at that time was Gainotti (1975). He found that confabulation in people with dementia was associated with premorbid personality. Conscientious people for whom independency, prestige and superiority had been central values were shown to confabulate more often. He therefore considered confabulation to be a sign of reorganisation or coping rather than disintegration. Inspired by Kubler-Ross and based on many clinical interviews with people with Alzheimer's disease, Cohen, Kennedy and

Eisdorfer (1984) conceptualised a series of psychological reactions or phases in people with Alzheimer's disease: *Prediagnosis*—recognition and concern; *during diagnosis*—denial; *post-diagnosis*—anger, guilt and sadness; coping; maturation and separation of self, respectively. Kiyak (1988; Kiyak & Borson, 1992) investigated coping in community dwelling persons with dementia and found that acceptance was the primary mode of coping and that emotion-focused strategies, such as becoming angry, bitter or resentful, were much more frequently used than problem-focused coping and hopefulness.

In the last two decades several theoretical models have been proposed to understand how people react to and cope with the consequences of their dementia (Finnema, Dröes, Ribbe & van Tilburg, 2000a). Feil (1982), for instance, proposed the Developmental Stage model of Erikson (1963) to understand part of the disoriented and regressed behaviour of elderly people with dementia as resulting from unsolved psychological problems in earlier stages in life. Hall and Buckwalter (1987) developed the Progressively Lowered Stress Threshold (PLST) model based on the coping theories of Lazarus and Selye (Lazarus & Folkman, 1984). The PLST-model describes how the stress threshold is lowered as the disease progresses and therefore specifically focuses on the influence of the care environment. Miesen (1990; see also Browne & Shlosberg, 2006) applied the Attachment theory of Bowlby to explain certain behaviour in dementia, such as parent fixation, as a reaction to feelings of unsafety provoked by the cognitive decline and the environment. Dröes (1991) introduced the Adaptation-Coping model to describe the cognitive, emotional and social adaptation and

coping process in people with dementia and investigated whether general adaptive tasks as described by Moos and Tsu (1977) for acute and chronic physical illnesses were also relevant for people with dementia. A first attempt to validate the Adaptation-Coping model in a nursing home setting demonstrated that adaptive tasks like preserving an emotional balance and maintaining social relationships seemed indeed relevant for people with mild to moderate dementia (Dröes & van Tilburg, 1996).

Listening to the voice of people with dementia

Until the middle of the 1990s most of the publications on coping in dementia were based on individual clinical observations and experiences of professionals in care practice (Bahro, 1995; Haupt & Kurz, 1990; Verdult, 1993; Verwoerd, 1976, 1981). Only a few publications were based on systematic empirical studies (Cotrell & Lein, 1993; Dröes, 1991; Kiyak, 1988). One may ask why coping with dementia had rarely been the subject of systematic empirical research (in contrast to coping with other chronic diseases, such as cancer, cardiovascular diseases and rheumatic diseases) and why the voice of people with dementia wasn't heard. Undoubtedly, one of the reasons is that it was generally believed that people with dementia lacked awareness due to the cognitive decline and therefore did not cope at all with their illness. This belief was probably also fostered by the general fear of progressive cognitive decline and of losing one's mind in our society, in which intellectual ability remains one of the highest values. This fear was probably at least as important a reason why, until recently, it was very uncommon to discuss openly with people with dementia their experiences, even in the early stages of the disease. If they were not aware of their illness why take the risk of making them aware by discussing it openly?

Though the taboo to discuss the consequences of their disease with people with dementia still partly exists, and a recent study in the Netherlands demonstrated that more than half of the general practitioners still disclosed the diagnosis only to the spouse or family carer and not to the person with dementia (Hout et al., 2006), in the last ten years much has changed in care practice and research. The Alzheimer cafés (Miesen & Jones, 2004; Morrissey, 2006) disseminated and supported by the Alzheimer Associations in several European countries and the Dutch meeting centers for people with dementia and their carers (Dröes, Breebaart, van Tilburg, & Mellenbergh, 2000; Dröes, Meiland, Schmitz, & van Tilburg, 2004) are examples of initiatives that help people with dementia, family members and professionals to break the taboo on discussing the disease openly with each other. Another example of activities that facilitate 'disclosure' are the support and discussion groups for people with dementia

(LaBarge & Trtanj, 1995; Marshall, 2004; Mourik & Haex, 2005).

Stimulated by the developments to discuss the disease more openly with those who suffer from it, empirical research, in which people with mild dementia all interviewed about their experience of the disease and their way of coping with concrete losses, has considerably increased in the last decade (Clare, 2004; Steeman, Dierckx de Casterle, Godderis, & Grypdonck, 2006). Thanks to these qualitative studies, authors like Clare (2003), Keady, Nolan and Gilliard (1995), Keady and Gilliard (2001), Pearce, Clare and Pistrang (2002) and van Dijkhuizen, Clare and Pearce (2006) were able to identify and describe specific coping strategies used by people with dementia in their struggle to find a new balance in their changing life and to retain a sense of connectedness with others and the environment and a sense of self. The studies also provided insight into the (positive and negative) influences that carers, informal and professional, can have on this coping process (see also van der Kooij, 2003; de Lange, 2004). Both these aims of coping and the influence of external factors are also mentioned by people with dementia when they are asked 'What is important for your quality of life?' (Dröes et al., 2006).

The importance of insight into coping for care practice

Mainly because of the growing insight into the way people with dementia cope with the consequences of the disease, the interest in how these people can be supported in their coping process and everyday life has increased considerably in recent years. Take the rapidly increased attention for, and application of, person-centred care and emotion-oriented care for example (Finnema et al., 2000b; Kitwood, 1997) but also the growing interest in the application of supportive technology in the homes of people with dementia (also known as domotics or smart houses) to enable them to continue living in their own environment as long as possible with an acceptable quality of life (Fritschy, Kessels, & Postma, 2004; Magnusson & Hanson, 2005; Stefanov, Bien, & Bang, 2004). Though several interventions, such as reminiscence, validation therapy, psychomotor therapy, music therapy, snoezelen and integrated emotion-oriented care aimed at supporting people with dementia in adapting to and coping with the psychological, emotional and social consequences in the different stages of the disease proved successful in many trials (Dröes, 1997; Dröes et al., 2000, 2004; Finnema et al., 2000b, 2005; de Lange, 2004; Livingston, Johnston, Katona, Paton, & Lyketsos, 2005), a better insight into the way people cope with their dementia will certainly help to provide for more tailor-made proactive care and support.

In this special section on coping with dementia, two papers report on qualitative studies aiming to

develop a better understanding of what it means for elderly people to live with dementia at the beginning of the disease (Steeman, Godderis, Grypdonck, de Bal, & Dierckx de Castele, 2007) and to inventory the range of coping methods and strategies they use (Preston, Marshall, & Bucks, 2007). A third paper reports on coping in dementia from quite a different perspective: Nygård and Starkhammer (2007) explored in their ethnographic study the difficulties in, and impediments to, the use of everyday technology by persons with mild to moderate dementia living alone in the community.

The study of Steeman et al. reveals that though living with dementia was often presented as a positive narrative, people with mild dementia are constantly struggling to balance their feelings of being someone retaining their value and losing their value.

Preston et al. identify three major themes in coping approaches: Managing identity in relation to dementia; making sense of dementia; and coping strategies and mechanisms. The latter were divided into everyday individual strategies (cognitive and behavioural methods, such as using visual prompts and formal memory techniques, seeking information, emotional expression), coping in relation to others (talking and sharing, being with similar people, getting help) and personal attitude (being positive and accepting the disease versus fighting it). In addition to the themes in coping approaches, two themes in the coping process were identified: Issues of context (ways of coping were dependent on specific contexts) and issues of conflict and control (coping strategies worked only for part of the experienced difficulties).

The everyday technology studied by Nygård and Starkhammer included both newly-developed technology, such as mobile phones, and common well-known artifacts and services, such as washing machines, digital watches, coffee machines and transistor-radios. The results show that, regardless of whether the technology was familiar or new, people experienced difficulties in four domains: Conditions that interfered with the use of technology, such as memory deficits and pressure experienced from the external environment; lack of knowledge of the technology, such as confusing the washing machine and the tumble dryer; communication between users and their technology, for instance not understanding information on computers and mobile phones; and limitations in the use of instructions. Problems appeared mainly in complex combinations, very rarely did one single difficulty obstruct the use.

In a time when many researchers still focus on the treatment of behavioural and psychological symptoms in dementia (Finkel & Burns, 2000) without thoroughly discussing or investigating the possible psychological, emotional and social causes, the papers of Steeman et al., Preston et al., and

Nygård and Starkhammer should be highly valued in my opinion. All three studies help us to better understand what causes coping difficulties in daily life in people with dementia and also provide very useful information for those who are involved in dementia care.

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