

CAREGIVER STYLE – LET’S RECOGNISE AND TEACH IT!

Abstract

In 2004 a group of researchers from Maastricht University published a paper identifying different caregiving styles and how these influenced behaviours of people with dementia, and caregiver burden. They demonstrated a “Supporting” style was better at minimising caregiver burden and reducing negative behaviours than “Nurturing” or “Non-Adapting” styles.

This presentation will discuss these caregiving styles and their effects on caregivers and people with dementia.

It will conclude by recommending intervention and training programmes for new caregivers should include an evaluation of caregiving style.

I am a believer in people with dementia having as much independence and control over their lives as possible. Sometimes I think we are inclined to provide too much care and this may cause problems for both the person with dementia and those trying to help them.

I would like to talk about the finding of the group of researchers from the University of Maastricht who published a paper in 2004 entitled "Do caregiver management strategies influence patient behaviour in dementia?" They identified three different strategies, although I prefer the use of the word style, used by supporters and carers. These descriptions are taken directly from the paper:

Non-adapting. These caregivers were characterized by a lack of understanding of the patient or of acceptance of the situation. They primarily approached the patient with impatience, irritation or anger. They tried to manage behavioural problems by confronting or ignoring the patient, for example by walking away.

As a daughter said "I don't think I manage her the right way, because sometimes I get irritated....Recently I said to her that it was better for me to go home, because she started telling stories that weren't true. At that moment I interrupted her and said that it wasn't right what she was telling. I know that's wrong, but I can't help myself."

Nurturing. Nurturing indicates efforts to manage the patient by using a 'parent-child approach', in which the patient is 'taken by the hand' and is no longer regarded as an equal. In this approach caregivers felt responsible for doing most of the daily chores. They tried to protect the patient or tended to focus on personal care tasks, such as physical assistance with self-care and providing meals.

As one wife said "I take more care of him. I have always been a caring person, but now I feel that I'm taking care of a child. I don't know how to do it otherwise. But I believe this is the right way."

Supporting. Supporting describes efforts to manage the patient by adapting to the patient's level of functioning and by stimulating his or her existing abilities. These caregivers allow the patient to 'lead the way'. Several aspects of supporting were identified. First, caregivers tried to supervise the activities of the patient, assisting the patient when needed or supporting the patient by discussing things. Second, caregivers tended to be patient with the patient adopting a calm and cautious manner and tried to manage behavioural problems with compliance. Third, caregivers tried to stimulate the patient to undertake physical, social or household activities or they did pleasant activities together.

As a husband said "I let my wife live her own life. I don't tell her what to do.... I don't do that. I let her go her own way, because that's important to her. You have to be careful with these patients and not give her the feeling that I'm constantly watching her."

The researchers measured a number of factors on both the person with dementia and their caregiver and these were the results:

	Non- adapting	Nurturing	Supporting
Caregiver Sense of competence	18.2	22.3	25.9
Caregiver distress	14.6	12.6	9.2
Caregiver depression	11.3	9.9	7.1
Caregiver Neuroticism	36.1	32.2	28.3
Patient Hyperactivity	11.3	9.4	3.9
Strategy percent	17%	30%	53%
Caregiver gender M/F*	12 /20	15 / 38	73 /42
Relationship Spouse/Child*	13 /23	27 / 34	60 /43

* Figures adjusted to 100 each of male/female and spouse/child

These figures are taken from their paper and simplified for presentation to a non-technical audience. For a full explanation of the measures, their measurement and the statistical significance, I would refer you to the full paper.

The caregiver results are pretty much self-explanatory and show a supporting style is the best. I think they are the result of the Patient Hyperactivity. When being continually challenged by their non-adapting caregiver, or being treated as a child by their Nurturing caregiver, the person with dementia is reacting negatively and this in turn is increasing the burden on the caregiver.

At the bottom of the Table are figures showing the distribution of caring styles among the study participants. It's good to see a majority of carers, although only by a small margin, were adopting a Supporting style. In looking at gender and relationship trends, it's interesting to see male caregivers are more likely to adopt a supporting style, and that spouse carers are more likely to be supporters than their children.

To quote some of the conclusions of the study:

“The caregivers who used a supporting strategy seemed to be most effective in dealing with patient problems and reduced the risk of hyperactive behaviour. Their efforts to adjust to the behaviour and abilities of the patient probably creates a safe environment and minimizes patient frustration”

“Inadequate caregiver management strategies may put caregivers at risk of experiencing a higher burden and may increase patient agitation.”

“Intervention programs should aim at training caregivers to use adequate management strategies, which could increase caregiver competence and decrease patient problem behaviour.”

It's this last conclusion that I would like to consider now. It is my experience that adopting a supporting care style, along with a strong reserve of love going into the journey, has been essential to my survival as a supporter/ carer for my wife Shirley. I think that consideration of caring style should be part of training for all carers of dementia affected people, and I think that reference to this study has some important benefits. Firstly by identifying different types of caring style that are easily recognised, it highlights the features of good caring style compared to styles that are more

likely to cause problems. And secondly, it is backed by clinical evidence in the form of the peer reviewed study. I think this is important to counter the cynics, perhaps mostly nurturers, who think it is nonsense and won't be changing.

By including such training for partners and family of newly diagnosed people with dementia, it will be useful for the majority of naturally supportive style carers to give them extra confidence, and it will hopefully show the non-accepting "non-adopters" that challenging doesn't work, and the "nurturers" that mollycoddling can cause resistance and frustration for everyone.

As a parting thought, I would like express my disapproval for the terms "carer" and particularly "Caregiver". When first diagnosed, a person with dementia is normally capable of functioning independently and making many of their own decisions. To have their spouse or another family member labelled their "Carer" or "caregiver" is frankly quite dangerous. It encourages the spouse or family member to think they need do more than minimum to help, and it's a putdown for the person with dementia. We are now quite used to the concept of a "supporter" or "support person" going with us to provide moral support and if necessary help when we go to medical, legal or Government department appointments. We're in control and not the supporter.

So when it comes to those helping people with dementia, we should stop using the words "carer" or "caregiver" and instead use the words "supporter" or "support person"!

Reference:

"Do caregiver management strategies influence patient behaviour in dementia?" M.E. DE VUGT *ET AL*, *Int J Geriatr Psychiatry* 2004; **19**: 85-92