

Caring for the carers

★ Caring for a relative with dementia can be both emotionally and psychologically draining, and the burden tends to increase as the disease progresses. We spoke to **Professor Pascal Antoine** about the work of the PACIC project in developing web-based interventions designed to support caregivers, alleviate their distress and enhance their wellbeing.

A lot of attention in research is focused on developing improved treatment for Alzheimer's disease (AD), a neurodegenerative condition for which there is currently no cure. While this is of course a major research priority, it's also important to consider the needs of those who provide care for people with AD, who are often close family members. "Most of the time it's one of the children of the person living with the disease, or their spouse," says Pascal Antoine, Professor of Psychology at the University of Lille. Caring for a person with AD is a demanding and time-consuming task, as the caregiver often has to perform more and more routine tasks as the disease gradually robs them of their abilities. "The caregiver has to perform more and more daily tasks for the person affected by the disease, and to be highly vigilant, to protect them from danger," outlines Professor Antoine.

PACIC project

This imposes a heavy emotional burden on the caregivers themselves, who alongside observing the disease progress, also have to adopt a more controlling attitude towards someone they love, which can cause conflict. As the Principal Investigator of the PACIC project, Professor Antoine is developing three new intervention strategies designed to lessen this psychological burden on caregivers and help them adopt a more positive approach. "We see that there are positive aspects to caregiving. However, when we hold interviews with caregivers, we find that they are often unable to perceive them," he explains. This issue is addressed in the web-based interventions, each of which focuses on different goals within the wider objective of supporting caregivers. "One strategy is about

decreasing rumination and anxiety, while another is about helping caregivers to find enjoyment in their daily lives," continues Professor Antoine. "Another is to gain in psychological flexibility."

A caregiver may be able to deal with daily problems fairly effectively in the early stages of the disease for example, but

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they may find that these strategies are less effective as the condition progresses and the symptoms become more severe. As a caregiver becomes increasingly exhausted and psychologically distressed, it becomes ever more difficult to cope with the evolution of the disease and its impact on the person living with the disease. "They often stick with their initial solution, even if those solutions are not effective any more as the disease evolves," says Professor Antoine. The accumulated impact of this on a caregiver, who may themselves be feeling isolated and lonely, can be serious, and affect their daily motivation and overall state of mind. "The sum of events and daily challenges can lead to a kind of burn-out, as there is a lot of work to do," explains Professor Antoine. "Dealing with this psychological burden can be very draining."

The aim in the project is to develop strategies which will support caregivers in this respect, with researchers assessing three web-based psychological interventions in a randomized clinical trial. These interventions, centred on mindfulness,

positive psychology and acceptance and commitment approaches, have been designed with the needs of caregivers in mind. "We are looking at the effectiveness of these three intervention strategies. We want to compare the benefits that are specific to each intervention and also to identify the common benefits," outlines

Professor Antoine. The interventions include various activities and exercises, which researchers will evaluate over an eight-week period. "We ask caregivers to record the different exercises they did during a day, then to report on how they felt about them and what benefits they bring," says Professor Antoine.

Intervention strategies

This will provide the basis for researchers to build a deeper understanding of the impact of mindfulness, positive psychology and acceptance and commitment approaches in terms of lessening the burden on caregivers. The most effective exercises and activities within these three interventions could eventually be combined, to provide even more effective support. "We want to identify the best activities and exercises that have been proposed in each of the three strategies in order to build a unique intervention strategy," outlines Professor Antoine. This research is very much focused on practical outcomes, and Professor Antoine is keen to translate his work into tangible benefits for caregivers. "I hope that lots of caregivers could benefit from these kinds of intervention and that they could have a positive impact. I would like to move eventually towards wider utilisation of this kind of intervention," he outlines.

The main focus at the moment is on interventions for people caring for individuals with AD, the numbers of which are rising in Europe. However, Professor Antoine believes that these interventions could in future be applied to people caring for individuals with other neurodegenerative diseases. "We are also working with people caring for individuals with Parkinson's disease, then there are also other neurological conditions, such as Huntington's disease. These types of web-based interventions could also be relevant beyond neurodegenerative disease," he continues. With the elderly accounting for a sizeable proportion of the European population, it's important to consider the needs of those who will provide care to people with chronic conditions in future, reinforcing the wider relevance of the project's research. "It's a public health issue. These kinds of intervention could be relevant to any caregiver who is caring for their parents or their spouse," says Professor Antoine.

PACIC

Positive Acceptance and Commitment Interventions for Caregivers

Project Objectives

PACIC aims to first test the feasibility and then the comparative effectiveness of 3 web-based psychological interventions for caregivers of patients with AD. PACIC proposes (1) an innovative caregiving supports centred on well-being and acceptance combined with (2) a web-based and self-training approach.

Project Funding

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- Fondation Alzheimer
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Project Institutions

- Université de Lille
- CNRS

Project Labs/Ecosystem

SCALAB - <https://www.scalab.cnrs.fr>
DISTALZ - <http://distalz.univ-lille2.fr/>
LICEND - <http://licend.fr/>

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Pascal Antoine is Professor of Psychopathology and Clinical Health Psychology at the University of Lille. His main fields of interest are the emotional and psychological issues involved in early diagnosis, disorder awareness deficits and their consequences on access to care, and the assessment of caregivers' needs and difficulties.

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