212 - Involvement, Worries and Loneliness of Family Caregivers of People with Dementia during the COVID-19 Visitor-ban in Long-term Care Facilities

Marleen Prins, Bernadette Willemse, Claudia van der Velden, Anne Margriet Pot & Henriëtte van der Roest

Background

To prevent COVID-19 from spreading in long-term care facilities (LTCFs), the Dutch government took national restrictive measures, including a visitor-ban in LTCFs between mid-March and May 2020. Physical visits were replaced by alternatives as telephone or video calls. This study examines the relationship between the involvement of family caregivers (informal caregivers, ICs) of people with dementia (PwD) living in LTCFs and IC mental health during the visitor-ban. Furthermore, we examine whether this relationship is moderated by the frequency of contact with PwD during the visitor-ban and resilience of ICs.

Methods

A cross-sectional study was carried out, 375 Dutch long-term care organizations were invited by email to participate. LTCFs sent eligible ICs a link to an anonymous online survey. Family involvement was assessed by the visiting frequency and doing social (e.g. drinking coffee), or social and task-related (e.g. laundry) activities during visits before the visitor-ban.

Results

958 ICs of PwD participated. Contact frequency increased for 17% ICs and decreased for 25% compared to visiting frequency. 43% of ICs did only social activities and 57% social and task-related activities. ICs who visited their relatives at least once a week before the visitor-ban were more worried during the visitor-ban than those with less regular visits (main effect). Contact frequency during the visitor-ban was a moderating factor, ICs who visited the PwD daily before, but had at least weekly contact during the visitor-ban, worried less. No main effects for activity type were found on loneliness , however resilience was a moderating factor. Resilient ICs who did more diverse activities (task and social related) before the visitor-ban, experienced less loneliness during the visitor ban.

Conclusions

The results implicate that to reduce worries amongst ICs, LTCFs should facilitate in continuing contact with PwD during a visitor-ban, specifically in highly involved ICs. Also, non-resilient ICs that generally only do social activities are more prone to loneliness. It is advisable for healthcare and welfare professionals to reach out to this group, to help them with overcoming their loneliness.

213 - ECT-AD: Ethics and informed consent issues

Presenter: Louis Nykamp, M.D.

Co-authors:

Brent P. Forester, M.D., M.Sc. Adriana P. Hermida, M.D. Martina Mueller, Ph.D. Georgios Petrides, M.D. Hannah Heintz, B.A. Maria I. Lapid, M.D.

Preferred Presentation Type: Free/Oral Communication Presentations

Keywords: advanced dementia, electroconvulsive therapy, agitation, aggression, BPSD, vulnerable population, decisional capacity, surrogate decision making

Topic: Capacity

Abstract:

Agitation is experienced by over 90% of individuals with Alzheimer's disease (AD) which increases morbidity and mortality and contribute to caregiver burden. There are no FDA-approved treatments for severe agitation in people with advanced dementia. Behavioral interventions are first-line management strategies but are not effective in the most severely agitated patients. Off-label use of psychotropic medications have limited efficacy and risk for adverse effects. New management strategies for severe agitation in AD refractory to psychopharmacologic and behavioral interventions are timely and warranted. Preliminary studies provide evidence for the safety and efficacy of acute electroconvulsive therapy (ECT) in reducing agitation in this population.

The ECT-AD study is a multi-site NIH-funded randomized single-blind randomized controlled trial to investigate the safety and efficacy of ECT in severe and treatment refractory agitation and aggression in AD. In a vulnerable population with advanced dementia and lack of capacity to provide informed consent, there are ethical and consent issues that need to be considered. In this presentation, we will describe the human research subject aspects of working with this population, the process of informed consent and variation of state laws, and efforts to ensure participant safety and minimize undue influence or coercion.

214 - End-of-life decision-making capacity in older people with serious mental illnessCarla Kotzé, Louw Roos, René Ehlers

ABSTRACT

Objectives:

The study's main aim was to assess the end-of-life decision-making capacity and health-related values of older people with serious mental illness.

Design, Setting, and Participants:

This was a cross-sectional, observational study, done at Weskoppies Psychiatric Hospital, Gauteng Province, South Africa that included 100 adults older than 60 years of age and diagnosed with serious mental illness.

Measurements:

Socio-demographic, diagnostic, and treatment data were collected before administration of the Mini-Cog and a semi-structured clinical assessment of end-of-life decision-making capacity. Finally, the standardized interview, Assessment of Capacity to Consent to Treatment, was administered. This standardised instrument uses a hypothetical vignette to assess decision-making capacity and explores healthcare-related values.

Results:

According to the semi-structured decision-making capacity assessment, 65% of participants had decision-making capacity for end-of-life decisions. The Assessment of Capacity to Consent to Treatment scores were significant (p<0.001) when compared to decision-making capacity. Significant correlations