The Concerns and Recommendations of Informal and Professional Caregivers for COVID-19 Policy for Homecare and Long-Term Care For People with Dementia: A Qualitative Study

Authors: Hanneke J. A. Smaling, Mandy Visser

Abstract : One way to reduce the risk of COVID-19 infection is by preventing close interpersonal contact with distancing measures. These social distancing measures presented challenges to the health and wellbeing of people with dementia and their informal and professional caregivers. This study describes the concerns and recommendations of informal and professional caregivers for COVID-19 policy for home care and long-term care for people with dementia during the first and second COVID-19 wave in the Netherlands. In this qualitative interview study, 20 informal caregivers and 20 professional caregivers from home care services and long-term care participated. Interviews were analyzed using an inductive thematic analysis approach. Both informal and professional caregivers worried about getting infected or infecting others with COVID-19, the consequences of the distancing measures, and quality of care. There was a general agreement that policy in the second wave was better informed compared to the first wave. At an organizational level, the policy was remarkably flexible. Recommendations were given for dementia care (need to offer meaningful activities, improve the organization of care, more support for informal caregivers), policy (national vs. locally organization, social isolation measures, visitor policy), and communication. Our study contributes to the foundation of future care decisions by (inter)national policymakers, politicians, and healthcare organizations during the course of the COVID-19 pandemic, underlining the need for balance between safety and autonomy for people with dementia.

Keywords: covid-19, dementia, home care, long-term care, policy

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