Barriers to Accessing Care for Dementia Caregivers: Preliminary Findings of the Primary Care for Caregivers Study in Nova Scotia, Canada

Main Objective

The main objective of this research was to generate knowledge about issues concerning primary health care and support for caregivers of individuals with Alzheimer Disease (AD) and other dementias in Nova Scotia, Canada. In particular, we examined how health care professionals work together to provide care for unpaid caregivers. Ultimately, this research aims to extend the current literature on caregiver health and support needs in order to provide a foundation from which to create a model of care to be used by health providers, community organizations, and policy makers.

Research Questions

1. How are primary health professionals providing care and support to caregivers of individuals with AD and dementia?
2. What are the barriers to providing this support?

Data Collection and Recruitment

Data was collected via one-on-one interviews with key informants from both urban and rural regions of Nova Scotia, Canada. Five of the nine District Health Authorities in Nova Scotia were represented. Participants were recruited using a variety of methods including advertisements, direct invitation, email list-serves, and snowballing. Recruitment targeted specific groups to ensure a wide variety of perspectives from key informants. A total of 51 key informants were interviewed.

Data Analysis

Interview data was transcribed and coded using MAXQDA software. Analysis was conducted using an Interpretative Phenomenological theoretical framework.

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Findings and Discussion

How are caregivers accessing services in Nova Scotia?

Family caregivers have access to a wide variety of health care and support services in Nova Scotia (family medicine, geriatric medicine, nursing, home care, respite, community occupational therapy and physiotherapy, social work, and support groups). The accessibility of services depends on a number of factors including eligibility, caregiver resource knowledge, and health care provider resource knowledge. Caregivers may access a variety of services through various avenues including referrals, information lines, the Internet, private services, and informal networks.

I think caregivers will look to the family doctor for direction and sometimes they get really good advice and a lot of help and other times they don’t. So I think there’s a lot of room for improvement in how we all practice but especially in primary care, that first request for help or the first admission that there’s a problem or some difficulty needs to be listened to very carefully. And responded to as best that you can. (Social Worker)

Caregiver Identification

Care providers reported that caregivers often failed to recognize their caregiving role and those that did rarely recognized their need for support. Care providers expressed difficulty determining how to direct care for caregivers when they do not self-identify their role.

The unfortunate thing is if you are a caregiver and you are not really aware that the person has Alzheimer’s, you never think to ask. So it’s not the fault of the service provider or the caregiver because you never know ... I guess probably the only way is the family doctor. (Female Caregiver to Spouse)

Perception of Need

Perceptions of AD and related care were seen as a barrier to accessing care. Participants believed that care providers often did not understand the seriousness of the issues faced by caregivers. At the same time, caregivers were reluctant to access services and advocate for themselves due to stigma, stoicism, desire to maintain independence, and a feeling that only they could provide quality care.

And many families are, you know, don’t want to talk about Mom. Mom is doing some things. And there’s a great sense of, you know, social etiquette out there. ...It’s nice to be able to break through that and say, you know, it’s okay to talk about that, that this (behaviour) is common. And there are things (services) out there that can help you... (Physician)

Availability of Appropriate Services and Continuity of Care

Many participants believed available services were not designed to meet caregiver needs. For example, home care was seen to be task-oriented and did not provide consistency of workers. Hours of programs were inflexible and many programs could not accommodate dementia clients. Care provision was perceived to be fragmented due to poor communication between care providers. In some cases, such as psychological support and 24-hour in-home care, publicly-funded services were not available. Information about available resources was not perceived to be readily available to caregivers or care providers.

You get care that has been decided upon by and assessed by somebody else. You are not necessarily getting the care you want. And you get it when they say you are going to get it, not necessarily when you want it ...for example, respite care. If you are assessed and you qualify for let’s say 4 hours of respite care, ...they decide when you get that. (Nurse)

Implications and Recommendations

• Develop a caregiver screening process and implement public education to assist caregivers with self-identification
• Improve care provider education on caregiver needs, and AD and dementia care including issues regarding progression of disease
• Improve links between family physicians and available caregiver resources
• Automatic referral to the Alzheimer Society for every dementia diagnosis
• Evaluation and modification of current services to ensure they meet caregiver needs
• Implementation of caregiver support services such as 24hr in-home respite

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