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THE EXPERIENCE OF MYELOMA CAREGIVERS DURING HOME-BASED ORAL CHEMOTHERAPY TREATMENT: A QUALITATIVE STUDY

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OBJECTIVE: *The primary aim of this qualitative study was to explore myeloma carers/caregivers experience during outpatient-based oral treatment for patients with multiple myeloma (MM).*

DATA SOURCES: *Literature review. In-depth, open-ended interviews of seven purposively selected caregivers of MM patients in the United Kingdom.*

CONCLUSION: *Findings showed that carers were involved in practical and emotional caregiving activities, assisting the patient with managing complex oral combination treatments, and monitoring side effects. Care-giving activities continued after treatment, and experiences were described within the context of the MM journey and fear and uncertainty about the future. Caregivers also experienced a range of emotions, which they often kept hidden from the MM patients and other family members. Difficulties balancing caring responsibilities, particularly for those with jobs, were expressed.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses need to understand the importance of considering carers' involvement when assessing patients, and the need to address caregivers' continuing support and information needs. Problems*

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navigating health and social care processes should be anticipated, and nurses can direct the carers to appropriate resources to meet their needs.

KEY WORDS: *caregivers, carers, myeloma, family, experiences, oral chemotherapy, support.*

Multiple myeloma (MM) is a hematologic cancer with complications of hypercalcemia, bone lesions, renal impairment and anemia.[1] The median survival is currently just over 5 years,[2] with a disease course typified by periods of treatment, remission, and relapse. The introduction of novel agents to treat MM has transformed the management of MM in recent years and reflects the wider move in the delivery of cancer treatment from inpatient to outpatient or home settings.[3,4] The involvement of families in cancer care is thus increasing, but the impact on family members of managing MM treatments at home is not clearly understood.[5-7] This article provides an overview of a study undertaken in the United Kingdom to better understand the experiences of the carers/caregivers of MM patients having home-based, oral chemotherapy.

BACKGROUND

Carers are described as those who spend a significant amount of time providing unpaid support to family or friends.[8] In the United Kingdom, the importance of carers in cancer care is reflected in government policy and acknowledged by support organizations.[9-11] The need for information and support for carers is recognized in national guidance and their experiences are increasingly used in measuring quality of healthcare.[12] Carers are integral to patients' treatment adherence and side effect management.[13-15] Carers can face strain and the importance of screening carers for psychological distress has been highlighted by general practitioners (GPs).[16] The educational needs of carers in assisting patients with MM in terms of oral medication administration, side effect management, and other routine needs must be better elucidated to improve the quality of care for MM patients at home.

REVIEW OF THE LITERATURE

To determine existing literature as it relates to carers of MM patients, a range of databases were explored, including Medline, CINAHL, PsychINFO, Cochrane Database of Systematic Reviews, Pubmed, and Internurse. Worldwide research was considered, and priority given to studies performed in the United Kingdom, where systems of health care and cultural aspects are similar. Studies from other countries were included, where the breadth and focus was pertinent to the study. A search for relevant literature indicated that the majority of research into carers' experiences has been with common cancers and palliative care; few studies focused on the needs of carers with MM. In the general literature, the following emergent themes were identified: (1) the tasks caregivers undertake, (2) the effects of the carer role, and (3) carers' information and support needs.

Tasks the Caregivers Undertake

Within the United Kingdom, a pivotal study of 262 carers of cancer patients documented the care-giving work and emotional work they undertook.[14,17,18] Caregiving work included help with activities of daily living, household tasks, symptom management, transportation, and finances. This assistance became more significant during times of aggressive medical treatment and varied with the comorbidity of the patient and carer. An American study reported the burden of caregivers undertaking clinical work such as administering medicines, changing dressings, and making clinical decisions. These findings may reflect an increase in the range of tasks caregivers undertake as treatment complexity increases, or potential differences in the role of family caregivers within the United States.[19] An Australian study of 21 MM patients and carers describes how both groups "work" to develop organizational skills and knowledge to manage risk to their well-being, and that carers have to balance their own needs with those of the patient and other family members.[20]

The Effects of the Caregiver Role

The effects of the caregiver role on UK carers for MM patients was reported by Molassiotis and colleagues who surveyed the needs, quality of life, and psychological symptoms of 93 partners of MM