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The *AJCN* aims to provide a forum where debate and the exchange of views can take place. We welcome papers on contemporary professional policy or practice issues of concern and interest to cancer nurses.

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The role of the nurse in patient education and follow-up of people receiving oral anti-cancer treatment: an Australian survey

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Abstract

Introduction

The use of oral anti-cancer treatment (OCT) is increasingly common and it is accepted that for patients OCT provides a sense of control, fewer disruptions to lifestyle, reduced costs for travel and care and eliminates the discomfort of intravenous treatment. OCT use also poses safety challenges with implications for both patients and health care workers. These challenges include new toxicity profiles and adherence issues. Whilst not new, these challenges are especially relevant to nurses who are the primary providers of patient education, side effect management and follow-up.

Objectives

A national cross-sectional survey of Australian nurses working in cancer care was undertaken to assess the nursing role in the education and follow-up of patients receiving OCT.

Methodology

A survey was distributed to members of the Cancer Nurses Society of Australia (CNSA) using snowball sampling; survey data was analysed using descriptive statistics in SPSS. One hundred and eighty-two survey responses were received. The study has received Human Research Ethics Committee approval.

Results

Variation in processes for providing information about OCT to patients was highlighted. The shifting treatment paradigm from intravenous chemotherapy to OCT has reduced the opportunity for contact with patients to monitor toxicities and provide education via traditional avenues. Nurses are also confronted with new side effect and symptom management profiles associated with novel OCT.

Conclusion

Workflow, organisational processes and resources have not kept pace with increasing use of OCT in cancer treatment. This exposes patients to increased risk of harm and poses new challenges for providing optimal nursing care.

Introduction

There have been major advances in the management of cancer and the use of oral anti-cancer agents is increasing as a preferred treatment option. It is estimated that almost half of the new agents in development are oral¹. The availability of oral anti-cancer treatment (OCT) permits the management of patients in the community setting, reducing the need for patients to attend the hospital for treatment. For the patient, OCT offers a sense of control over treatment and can reduce interference with work, social activities, travel time, costs associated with care and discomfort from intravenous treatment². There are also perceived cost and resource advantages of OCT for the health system, achieved through management of patients in the community setting, minimising the need for patients to travel to or stay in a hospital for prolonged periods.

Historically, the majority of anti-cancer treatment has been administered intravenously in a designated treatment centre with specialist cancer doctors, pharmacists and nurses involved in checking the regimen and ensuring the correct dose and administration of the treatment. The shifting treatment paradigm to OCTs has led to the tightly controlled environment of specialist checks in the hospital environment being circumvented. A recent study of 577 Oncology Nursing Society (ONS) members reported that 56% of participants indicated their workplace had a reliable system to alert nurses when patients receive prescriptions for oral chemotherapy³. The perception that OCT is easier, less expensive and has fewer side effects may also have reduced the impetus by health care providers to institute the same rigorous specialist education and monitoring programs provided to patients receiving intravenous anti-cancer treatment^{4,5}.

OCT also presents new challenges in the form of new toxicity profiles and issues related to adherence to prescribed regimens. The literature uses the terms “adherence”, “compliance” and “observance” interchangeably⁴.

Recognition of problems associated with sub-optimal medication adherence is not new; in 2003 the World Health Organization identified that adherence to long-term therapy for chronic illness is only approximately 50% in developed countries, leading to adverse health outcomes and increased health care costs⁵⁷. Adherence rates for patients receiving OCT vary from 20% to 100%⁸. Suboptimal adherence to the prescribed regimen can result in over- or under-medication⁹. Medication adherence may be associated with patient, treatment, clinician or environmental factors⁸. Factors include patient choice, forgetfulness, dietary restrictions, side effects, inadequate understanding of information and/or education provided by the health care team. In addition, financial inability to fund treatment, poor social support and poly-pharmacy in an ageing population might reflect a failure of the health care team to adapt their clinical practice and patient education programs to this shifting treatment paradigm^{18,9}.

A brief review of the literature (2007–2011) was undertaken to explore the role of nurses in the education and follow-up of patients receiving OCT. The search terms included: oral chemotherapy, medication adherence, and patient education. During our review we identified a survey, conducted in Turkey during 2005, reported by Dr Sultan Kav and reproduced internationally by the Multinational Association for Supportive Care in Cancer (MASCC) in 2006²⁰. The survey explored the role of the nurse in patient education and follow-up of people receiving oral chemotherapy. Based on the findings of the MASCC survey and earlier work undertaken by Dr Kav, the MASCC teaching tool for patients receiving oral agents for cancer was developed²¹.

Given the increased use of OCT since these initial surveys, we considered that it was timely in 2012 to assess and describe the Australian experience of oncology nurses caring for patients receiving OCT.

Study objectives

The primary objectives of the study were to explore the nursing role in education and follow-up of patients who are taking OCT across Australia and to identify any deficiencies and gaps in patient education about OCT.

Study design

The MASCC survey was adapted to the Australian setting by including an additional four questions to reflect changes in the availability of new OCTs, to capture demographic information and to assess the use of the MASCC Teaching Tool for Patients Receiving Oral Agents for Cancer.

Ethical considerations

Ethics approval was obtained from the Hunter New England Human Research Ethics Committee and permission was granted from the Cancer Nurses Society of Australia (CNSA) Research Committee to access their membership to distribute the survey. Permission to reproduce the MASCC survey was granted².

Survey methods and sampling

An invitation to participate in an online, national cross-sectional survey, consisting of 20 multiple-choice and open-ended questions, was distributed to 721 CNSA members via an email alert. The research team did not have direct access to potential participants. A second email alert was sent to members two weeks after the initial invitation. Study participants remained anonymous and snowball sampling was encouraged. Due to the effect of the snowball sampling method, it is impossible to determine a response rate as the number of nurses the survey reached is not known.

Survey data

The survey collected data across three main areas:

- Demographics including institution and geographical location.
- Nursing experience and educational history including nursing qualifications and nursing experience.
- OCT-specific data including drugs, patient and system processes.

Survey results

There were 182 survey responses from nurses in all states and territories except the Northern Territory. The demographics are detailed in Table 1. The demographic characteristics identified that the majority of participants were employed in a metropolitan-based public hospital and had been working as a nurse for more than 16 years. Forty-six per cent had been employed in their current position for six years or more.

Nurse demographics

All respondents indicated they had routine experience with seven or more of the 22 OCTs listed in the survey. They also indicated their practice used a number of newly emerging and experimental treatments. The most commonly used treatments included: Capecitabine, Cyclophosphamide, *Erlotinib*^{*}, Etoposide, *Imatinib*^{*}, *Lapatinib*^{*}, Methotrexate, *Sunitinib*^{*}, Temozolomide, *Thalidomide*^{*} and *Vinorelbine*^{*}. The agents marked with “*” indicate newer treatments that were not in use at the time of the MASCC survey. This reflects the rapid development of experimental and emerging treatments during the seven-year period from the MASCC report to this survey.

In comparison to the MASCC survey results, our findings (Table 2) indicated fewer nurses working in inpatient settings reported