



Challenges of Caregivers of Cancer Patients who are on Oral Oncolytic Therapy

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ARTICLE INFO

Key Words:

caregivers
cancer
oral oncolytic therapy
education
care training

ABSTRACT

Objective: To describe the major challenges faced by caregivers of patients receiving oral oncolytic therapy (OOT).

Data Sources: Published literature, national clinical practice guidelines, standards of care.

Conclusion: Caregivers of patients receiving OOT have unmet needs. Caregivers need standardized OOT education and coping support to improve patient outcomes through enhanced drug safety practices, better management of complex treatment regimens and adherence, patient symptoms, treatment side effects, care decision-making, and financial assistance for costly OOT.

Implications for Nursing Practice: Nurses are well-positioned to take leadership roles in facilitating optimal utilization of multidisciplinary health care resources necessary to support caregivers and improve outcomes in patients receiving OOT.

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The landscape of cancer treatment is changing with the expansive use of oral oncolytic therapy (OOT). OOT accounts for over half of new cancer treatments approved by the US Food and Drug Administration¹ and is expected to increase because of more clinical trials involving OOT. Although OOT is identified for treatment of numerous cancers at various stages of illness, these medications are commonly prescribed for solid tumors after intravenous chemotherapy ceases to be effective. OOT has changed the cancer care delivery model. The responsibility of costly, complex oncolytic medication administration and adherence, self-management of symptoms and side effects, and monitoring for interactions has shifted to the patient and their caregivers.^{2–5} While OOT offers a convenient modality of cancer treatment,^{6,7} caregivers are now faced with new challenges specific to oncolytic medication.^{3,6} Such challenges have implications for how oncology professionals, especially oncology nurses, deliver care.⁸

This article identifies the major challenges faced by caregivers of patients receiving OOT from the current body of literature and synthesizes the most salient implications for nursing practice to support these caregivers. In addition, clinical guidelines and standards of care from the Oncology Nursing Society⁹ and the American Society of Clinical Oncology¹⁰ specific to OOT are outlined. Evidence in the literature suggests the following six major challenges for caregivers supporting patients receiving OOT:

- (1) Drug safety risks associated with handling the medication and exposure to patient's bodily fluids.
- (2) Overseeing administration and adherence of complex treatment regimens.
- (3) Monitoring, decision-making, and managing symptoms, side effects, toxicities, and drug-drug or food-drug interactions.
- (4) Heavy burden of financial worry specific to OOT.
- (5) Limited coping support associated with therapy changes along the OOT trajectory.
- (6) Lack of standardized OOT education and care training for caregivers.

Each challenge is detailed along with recommendations to improve care for patients receiving OOT (see [Table 1](#)).

Drug Safety Risks

Safety concerns for caregivers of patients receiving OOT is evident. There are both direct and indirect risks for caregivers related to contact with oncolytic medication during administration or contact with active drug metabolites in patients' wastes, such as saliva, urine, feces, semen, sweat, and vomit.^{11,12} Consequences of contact with the medication or bodily fluids can vary based on how the drug is metabolized or excreted.¹¹ Risks may be greater for those caring for geriatric or pediatric patients, who have difficulty swallowing and who require that tablets be crushed because of the repeated exposure to medication with each administration.^{11–13}

Caregivers may not be prepared to handle unexpected situations regarding disposal of contaminated or compromised medication

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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<https://doi.org/10.1016/j.soncn.2019.06.009>

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from spills or improper storage.¹⁴ Some caregivers may receive initial education about handling oral oncolytic medication or exposure to bodily fluids when patients take these medications, but such education can produce anxiety about OOT.⁶ Other caregivers may not receive, understand, or comply with drug safety education recommendations and therefore partake in unsafe handling practices that can place them and others at risk for exposure.^{6,15}

Recommendations for oncology nurses

Caregivers require strict instruction³ and ongoing care training on how to safely manage oncolytic medication, such as handwashing before and after preparing the medication,^{14,16} whether wearing gloves is recommended,¹⁴ and how to handle bodily fluids and contaminated bed linens or clothes.^{11,13,16} Caregivers need to provide return demonstrations of the preparation and administration of oncolytic medication in the presence of the oncology nurse to ensure safe practices (eg, proper handwashing, application and disposal of gloves). It is necessary for the oncology nurse and pharmacist to provide detailed steps on how to manage medication that has dropped on the floor or when medication is compromised (eg, exposure to excessive heat or cold). Caregivers need to be instructed on how to handle sharing bathrooms and the importance of double flushing after patient use.¹⁶ Handouts outlining drug safety best practices for oncolytic medication and bodily fluids will need to be provided in an appropriate reading level for the caregiver.¹⁷ Such handouts can be provided by the cancer center or can be accessed from trusted oncology sources (see [Table 2](#)).

Caregivers must be educated on the potential for exposure to others when they enter the home, especially young children. Nurses and pharmacists will need to describe and encourage caregivers to keep oncolytic medication properly stored and out of reach of children to prevent accidental exposure. Nurses may want to refer caregivers to trusted online resources provided (see [Table 2](#)) for support on oral oncolytics.

Complex Treatment Regimen and Adherence

Caregivers are responsible for ensuring patients take their OOT as prescribed, but medications can be complex and difficult to manage. Varying dosing regimens, such as adjustments in doses, cycling, combined therapy, and temporary or permanent interruptions to treatment, can be extremely challenging for caregivers to track.^{15,18,19} Patients may have comorbid conditions or supportive medication agents that require additional consideration, such as drug interactions, scheduling administration, and management of side effects.¹⁵ If not properly educated, there is potential for medication errors when caregivers assume responsibility of the five rights of medication administration (ie, right patient, right medication, right dose, right time, and right route of administration).^{13,15} In addition, caregivers may need to prepare the medication in pill boxes and mix or dilute medications, which adds to the complexity of administration and increases the potential for errors.^{3,20}

Recommendations for oncology nurses

Oncology nurses often provide much of the initial education regarding OOT. Before initiating treatment, nurses must provide the patient and caregiver with information on the oncolytic medication (eg, name, dosage, route, and administration schedule) and what should be done in the event a dose is missed or accidentally doubled.²¹ As part of a multidisciplinary health care team, nurses will need to work with oncologists and retail or specialty pharmacists to simplify treatment instructions and ensure consistency with education. Oncology nurses must confirm with caregivers that the prescription label on the oncolytic medication bottle is correct, confirm prescribed dose and

timing is correctly verbalized by the caregiver, and ensure questions regarding OOT are answered.²¹ Oncology nurses and pharmacists may also provide support to caregivers by creating medication calendars and update as needed with medication dose or schedule changes.^{6,20} Caregivers will need to be provided with suggested tools to remember to administer medication, such as digital reminders in the form of mobile or smartphone applications, text messaging, wrist watch and phone alarms, and pill bottle reminders, which prompt caregivers that the next dose of OOT is scheduled.²² In conjunction with oncologists and pharmacists, oncology nurses will need to review the importance of adherence and outcomes of nonadherence, including missing doses or taking more than prescribed.²³ Oncology nurses may want to suggest pill organizers for non-cancer medications to ease the burden of managing multiple medications at once. Medication lists must remain updated. Any attempts to simplify the oncolytic medication regimen should be implemented to minimize the complexity of the treatment.²³ Oncology nurses will need to serve as liaisons with specialty or retail pharmacies dispensing OOT to ensure proper instructions, administration, and oversight of adherence.

Symptom Management

Caregivers are faced with the responsibilities of monitoring and decision-making in managing symptoms, side effects,^{18,22} OOT toxicities, and potential drug-drug or food-drug interactions. Caregivers often prepare patient meals and need to understand the potential for food interactions with OOT, such as grapefruit, as well as the fact that OOT regimens may require the patient to take the medication with or without food to avoid certain symptoms and side effects. For example, certain drugs can increase adverse side effects if taken with food because of slowed metabolism of the medication. (eg, temozolomide), while other drugs must be taken with food to avoid adverse side effects (capecitabine).²⁴ Additionally, caregivers must understand symptoms and side effects to expect and when to report symptoms and side effects to oncology professionals.¹⁹ This can be challenging when symptoms and side effects are mild, and with toxicities that go unnoticed or come on quickly.¹⁵ For example, reporting a fever is essential because it may be a sign of a serious infection and may go unnoticed by the caregiver if the patient does not report any symptoms of a fever. This is compounded by the fact that patients receiving OOT are seen in oncology clinics less often than those receiving traditional intravenous or radiation therapies and thus have less clinical oversight and monitoring. Caregivers need education on potential symptoms to be aware of and how to appropriately manage and report. When caregivers are unable to help relieve symptoms and side effects for the patient in the home environment, it can negatively impact them by causing anxiety, feelings of incompetency, and loss of control.⁶

Recommendations for oncology nurses

Prior to the patient initiating a new OOT regimen, the oncology nurse needs to offer both verbal and written decision-making steps for caregivers and patients regarding what symptoms and side effects to expect, which symptoms and side effects to report, when to contact the oncology professional, and when to seek emergent help.²⁰ For example, fever would be important to report to the doctor or nurse. Caregivers need to know how to properly take the patient's temperature and how high the fever is before they should be concerned. In addition, caregivers need to be educated on what accompanying signs and symptoms of fever to be aware of, such as chills, signs of infection, shortness of breath, confusion, or extreme fatigue that could be especially concerning and indicate a more serious illness. All education should be simplified and reiterated consistently among the multidisciplinary health care team of oncologists, nurses, and pharmacists. Contact information for the oncology practice will need to be

Table 1
Recommendations for oncology nurses providing support to caregivers.

| Caregiver Challenge | Recommendations |
|---|--|
| Drug safety risks | Handouts outlining safe handling of oncolytic medication and bodily fluids to include: <ul style="list-style-type: none"> • handwashing prior to and after touching the medication • wearing gloves when recommended • role play the preparation and administration of the oncolytic medication • virtual reality simulation • double flushing after the patient has used the restroom • proper storage instructions • potential for exposure to others entering the home |
| Complex treatment regimen and adherence | Provide both patient and caregiver with information on the oncolytic medication (name, dosage, route, and administration schedule) including: <ul style="list-style-type: none"> • review the importance of adherence and the outcomes of non-adherence • what should be done in the event a dose is missed or doubled • creating medication calendars that are updated as needed when the medication dose or schedule changes • suggest tools to remember to administer or to help the patients to administer medication, such as phone alarms • use of pill organizers for non-cancer medication • update medication lists as needed • minimize the complexity of the treatment regimen • act as the liaison between the specialty or retail pharmacies dispensing the oncolytic medication to ensure proper administration and oversight of adherence |
| Symptom management | Provide both verbal and written decision-making steps regarding: <ul style="list-style-type: none"> • what symptoms and side effects to expect • which symptoms and side effects to report • when to contact the oncology professional • when to seek emergent help • provide written contact information for the oncology practice, including on-call or after hours numbers, to display at home and access quickly • provide additional pocket-size information sheet with contact information • use symptom toolkits that describe specific symptoms, what causes the symptoms, treatments the caregivers can implement in the home, and when to report the symptoms to the oncology professional • implement weekly telephone well checks to support the caregiver and assess any reported patient symptoms or side effects • provide list of potential drug-drug interactions • review and update patient's medication list each clinic visit and as needed, especially those taking medications for other comorbid conditions • provide a list of specific food-drug interactions with foods or drinks to avoid |
| Financial burden | Ease the amount of financial worry by: <ul style="list-style-type: none"> • oversee distribution of OOT-specific grant funding opportunities • assist patients and caregivers to apply for funding or refer to a team member who can supply appropriate information • answer questions regarding insurance coverage • act as patient and caregiver advocate when negotiating copay amounts • assist with insurance denials and/or appeals • provide emotional support when the treatment must be delayed or altered because of cost • advocate for affordable cost of cancer medications through local, state, and national platforms • meet with senators and congressmen or women to ensure affordable cancer medication policies are addressed |
| Coping support along treatment trajectory | Establish clear expectations of treatment plan to include: <ul style="list-style-type: none"> • curative v palliative • reasons for changes to treatment plan (tolerance of the oncolytic medication, symptoms, side effects, disease progression, or non-response to treatment) • potential of interruptions to OOT (temporary or permanent) • what to expect should oncolytic medication be permanently stopped • provide support for the next steps if patient transitions to palliative care, hospice care, or end-of-life planning • what to expect if oncolytic medication is temporarily stopped (when to resume and update medication calendars) |
| Standardized OOT education for caregivers | Base caregiver education on current guidelines outlined by the Oncology Nursing Society and the American Society of Clinical Oncology and provide: <ul style="list-style-type: none"> • ongoing education and care education to patients and caregivers at each clinic visit and by telephone • needs assessment at each clinic visit and by telephone • toolkits that assist nurses in caregiver education • support by advocating for policy change to allow reimbursed phone triage and home visits for patients and caregivers to provide ongoing education and support |

provided in written form, including on-call or after-hours numbers so caregivers can easily display these numbers at home and access quickly if needed. An additional pocket-size information sheet with contact information may also be helpful for caregivers when traveling or any time they are away from home. Nurses may need to provide caregivers with symptom toolkits or trusted online resources that describe specific symptoms, what may cause symptoms, treatments to implement at home, and when to report symptoms to oncology professionals (see Table 2).²⁵ Oncology nurses may also implement weekly wellness checks with caregivers via telephone to assess any reported patient symptoms or side effects, thus offering supportive care to develop coping skills in both patient and caregiver.

Nurses can advocate for supportive care interventions and be actively involved in monitoring and addressing patient symptoms remotely. Internet-based computer reporting systems,²⁶ text messaging, and mobile applications are also available for supportive cancer care, including symptom management.^{27,28} Such technology can deliver real-time symptom reporting to oncology professionals and help patients and caregivers self-manage symptoms from the home environment.²⁹ Some technologies are set to pre-specified symptoms thresholds and will report only symptoms that meet or exceed these thresholds of severity.²⁷

Potential drug-drug interactions should be reviewed with caregivers, and patient medication lists will need to be updated each

Table 2
Resources for oncology nurses providing support to caregivers.

| Resource | Description |
|--|---|
| American Cancer Society https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/american-cancer-society-caregiver-resource-guide.pdf | The <i>American Cancer Society Caregiver Resource Guide</i> is a tool for people who are caring for someone with cancer. It can help you: <ul style="list-style-type: none"> • Learn how to care for yourself as a caregiver. • Better understand what your loved one is going through. • Develop skills for coping and caring. • Take steps to help protect your health and well-being. |
| American Society of Clinical Oncology: Updated 2016 Chemotherapy Safety Standards https://www.asco.org/practice-guidelines/quality-guidelines/standards/chemotherapy-safety-standards | Purpose: To update the American Society of Clinical Oncology (ASCO)/Oncology Nursing Society (ONS) Chemotherapy Administration Safety Standards. |
| Association of Community Cancer Centers https://www.accc-cancer.org/docs/documents/oncology-issues/articles/nd14/nd14-oral-chemotherapy-what-your-patients-need-to-know.pdf?sfvrsn=ce01f7e17 | Education program to support nurses in delivering what your patients need to know about oral chemotherapy. |
| National Cancer Institute https://www.cancer.gov/about-cancer/treatment/side-effects | Provides patients and caregivers a list of potential side effects and discusses steps to take to prevent or manage cancer and cancer treatment-related side effects. |
| National Cancer Institute https://www.cancer.gov/about-cancer/coping/caregiver-support | Provides an overview of cancer caregiving and information on: <ul style="list-style-type: none"> • Dealing with being a caregiver. • Taking care of yourself as a caregiver. • Long-distance caregiving. • Caregiving in advanced cancer. |
| National Cancer Institute https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq#section/28 | Includes help for the cancer caregiver including: <ul style="list-style-type: none"> • Education and information. • Coping skills. • Counseling. • Conducting family meetings. • Home care help. • Hospice care for the cancer patient. |
| Oncology Nursing Society: Oral Adherence Toolkit https://www.ons.org/sites/default/files/2017-06/ONS_Toolkit_ONLINE.pdf | Includes a patient assessment for ability to obtain and administer OOT; drug safety education; pharmacy description, benefits, and concerns; financial resources; food, drug and pathway interactions, and effects; sample treatment calendars; factors and methods influencing adherence; traditional counseling v motivational interviewing; medication reconciliation and tracking; readiness-to-change scale; and patient and provider resource list. |
| Oncology Nursing Society: Oral Chemo Guide https://www.onsoralchemoguide.com/ | An educational video (<4 minutes) regarding oral cancer drugs, following your treatment plan, managing side effects, safety, disposal, and glossary of terms. |
| Oncology Nursing Society: Oral Chemotherapy Education Sheets https://www.ons.org/toolkits/oral-chemotherapy-education-sheets | Overview: Empower your patients to take a more active role in their cancer treatment with free oral chemo patient education sheets that answer common drug-related questions, developed by the National Community Oncology Dispensing Association, Inc., Association of Community Cancer Centers, Hematology Oncology Pharmacy Association, and Oncology Nursing Society. |
| Oncology Nursing Society: ONS Center for Advocacy and Health Policy https://www.ons.org/make-difference/ons-center-advocacy-and-health-policy?ref=RO | Outlines Oncology Nursing Society policy priorities, position statements, provides health policy resources, and information on policy summits. This Web site offers nurses information about how to get involved to support oncology health-related policy efforts (eg, improved payment models and improving patient/caregiver education), including lobbying and meeting with members of Congress. |

clinic visit and as needed, especially those taking medications for other comorbid conditions.²¹ In addition, specific food-drug interactions must be clearly stated, and a list of foods or drinks to avoid will need to be provided and discussed with the caregiver.

Financial Burden

Financial worry can be a heavy burden for caregivers who are managing OOT regimens and attempting to balance work responsibilities¹⁸ while overseeing the administration and monitoring patients in the home environment. The cost of OOT can be in excess of \$10,000 per month. Funding support in the form of charity or other financial assistance may be needed, despite having health insurance coverage.³⁰ If

OOT is covered under the medical benefit as opposed to the pharmacy benefit of the insurance plan, high out-of-pocket costs ensue that can impact clinical outcomes such as access to the medication, adherence, and psychological distress.³¹ The cost of medication can result in patients paying out of pocket, using their life savings, withdrawals from retirement accounts, or borrowing money.^{32,33} Because of this financial consideration, caregivers often need to be involved in obtaining funding for medication assistance or sorting out insurance issues surrounding OOT. Caregivers are involved in decisions regarding out-of-pocket costs, which could delay initiation of treatment or continuation of treatment without access to pharmaceutical drug coupons, grants, insurance, or other financial assistance.^{6,15} Caregivers may need assistance with applying for OOT funding for medication

assistance through various organizations, and require additional documentation and guidance to navigate insurance denials or appeals, which only add to the heavy burden of financial worry.¹⁵

Recommendations for oncology nurses

Oncology nurses and pharmacists can help ease the amount of financial worry experienced in caregivers by overseeing distribution and application for OOT-specific grant funding opportunities or providing a referral to another member of the multidisciplinary health care team, such as an oncology social worker, who can supply appropriate resource information. Nurses and pharmacists may need to assist with finding answers to questions regarding insurance coverage and financial assistance programs, advocate for patients and caregivers when negotiating copay amounts, and assist with insurance denials and/or appeals. Establishing a network of contacts within insurance companies, pharmaceutical companies, and funding agencies to call upon when necessary is key for nurses to facilitate solution-based options for financial barriers to OOT. Nurses will need to be prepared to provide support when OOT must be delayed or altered because of cost, and adjustments will need to be made to medication calendars. It is important that nurses, pharmacists, and oncologists advocate for affordable cost of cancer medications through local, state, and national platforms, and meet with their senators and congressmen or women to ensure such policies are addressed (see [Table 2](#)).

Coping Support Along Treatment Trajectory

It is also important that goals of treatment (eg, curative v palliative) are discussed to ensure both patient and caregiver have clear expectations about the treatment regimen. If information about the goals of treatment is not clearly stated, it is difficult for caregivers to effectively cope or adjust to changes that may occur during treatment with OOT. During the OOT treatment trajectory, temporary or permanent medication interruptions can occur. Although access to oncology professionals is available to patients and caregivers, coping support for changes in the OOT trajectory is often inadequate. Caregivers who are involved with overseeing administration and adherence of these medications in the home environment may have a difficult time with OOT interruptions, the complexity of treatment, and the uncertainty of changes in treatment because this changes a part of their role in ensuring the OOT was followed as directed.⁶ In addition, caregivers may feel responsible if treatment is interrupted because of toxicities or unmanaged symptoms. As a result, negative emotions such as a sense of failure, loss of control, and fear may develop.⁶ Therefore, proactive ongoing coping support for caregivers is warranted along the treatment trajectory.

Recommendations for oncology nurses

Before initiating OOT, nurses should discuss goals of treatment (eg, curative v palliative) to ensure both patient and caregiver have clear expectations about the treatment regimen. Nurses should inform patients and caregivers that changes to treatment may occur and why (eg, tolerance of the oncolytic medication, symptoms, side effects, disease progression, or non-response to treatment). Nurses should describe the implications for any changes to the OOT regimen and next steps. Such conversations will need to be consistent with the oncologist's discussion about goals of treatment and may set the stage for further discussion about palliative or hospice care or planning for the future (end-of-life planning and discussing patient wishes). Nurse communications with caregivers detailing changes that may occur along the OOT treatment course and rationale for changes could better prepare caregivers for potential regimen adjustments (dose or type of medication), medication dose reductions, or interruptions to treatment, whether temporary or permanent. Caregivers may not be prepared for such changes along the OOT trajectory so educating them on

expected changes may help ease anxiety and distress should such adjustments to treatment be needed. Nurses will need to prepare caregivers for what to expect should the oncolytic medication be permanently stopped, and provide support to better cope with the next steps, as patients may transition to palliative care, hospice care, or end-of-life planning.^{34,35} If OOT is temporarily stopped, nurses will need to educate caregivers on when to resume, and update medication calendars accordingly. Coping support can be as simple as asking caregivers how they are adapting to caring for patients on OOT treatment and addressing their concerns or needs accordingly.

Standardized OOT Caregiver Education

There is no standardized education for caregivers of patients receiving OOT,^{14,15,36} and some caregivers are not included in any of the initial education before initiation of treatment.³⁷ In rare events, patient and caregiver education can be missed altogether prior to initiating a new OOT regimen.²¹ It is important that caregivers are thoroughly educated regarding OOT,^{18,19} including care training (demonstrating skill in a task specific to OOT) programs for drug safety best practices, proper management of bodily fluids,¹¹ oncolytic medication preparation and administration, importance of adherence and consequences of nonadherence, drug-drug and drug-food interaction monitoring, outcomes of treatment, and monitoring symptoms, side effects, and toxicities of treatment.^{23,37} Patients receiving OOT are not seen in the oncology clinic as often as patients receiving traditional chemotherapy or radiation, underlining the importance of quality, consistent, and ongoing education. Lack of standardized OOT education leads to inconsistent information from oncology professionals, creates confusion and uncertainty among caregivers, and can negatively impact patient outcomes.

Recommendations for oncology nurses

Appropriate education and care training programs can positively impact outcomes of treatment with OOT in the home environment,²¹ including successful adherence, symptom management, and safe handling of medication. Patients receiving OOT do not see oncology professionals as often as patients on traditional cancer therapies; therefore, caregivers lose opportunities to ask questions. Many oncolytic medications are prepared and delivered by specialty pharmacies, which further removes caregivers from face-to-face education opportunities or consultations.¹³ Oncology nurses have a crucial role in educating patients and caregivers regarding OOT and should base education on current evidence and guidelines outlined by the Oncology Nursing Society and the American Society of Clinical Oncology (see [Tables 1](#) and [2](#)). Ongoing education should be provided for patients and caregivers, along with both of their needs assessed at each clinic visit and by telephone to ensure all questions regarding OOT and patient care are answered.²¹ Caregiver support groups or OOT classes are also outlets to ensure proper caregiver education. The Oncology Nursing Society³⁵ provides toolkits that can assist nurses with education for caregivers (see [Table 2](#)). Oncology nurses, pharmacists, and oncologists need to advocate for policy change to allow for reimbursed care such as phone triage and telehealth for the in-home setting. Individualized ongoing telecommunication support for both caregivers and patients could improve outcomes through improved regimen adherence and symptom management (see [Table 2](#)). Previous research has shown that home-based care provided by oncology nurses improved both patient and caregiver outcomes, including effective symptom management, better treatment adherence, decreased oncology health care utilization, and improved quality of life.³⁸ Leveraging technology to provide reimbursable, precision OOT care visits, ongoing education, care training, and coping support into the home setting would be prudent.

Discussion

This article identifies major challenges faced by caregivers of patients receiving OOT and offers recommendations for oncology nurses to prepare caregivers and support their unmet needs (see Table 1). Many of the recommendations are supported by resources obtained from national oncology organizations (see Table 2).^{10,17,39–42} There are limited studies specific to challenges of caregivers and OOT. No current intervention studies were found in the literature involving caregivers of patients receiving OOT, despite the growing needs of these caregivers. There are several literature reviews describing drug safety concerns^{13–15,19} and adherence,²³ but other challenges faced by caregivers are not well described. Only one systematic review was identified regarding caregivers of patients receiving OOT.¹¹ Several studies are descriptive or observational, and were completed at a single oncology center, which limits the generalizability of results.^{14,37,43} Many review articles are out of date given the growing number and complexity in treatment regimens of new oral oncolytic agents. Qualitative work has offered rich data regarding caregiver perceptions of OOT. But this data has limitations: limited sample sizes; do not include male caregivers; varied times patients received oncolytic medication; specific to one type of cancer; and underrepresent the perspectives of younger caregivers.^{6,18} Only one retrospective study was found to describe the characteristics and clinical outcomes with OOT, with the focus being more on patients than caregivers.⁷ Other articles lack validated questionnaires or focused on only one type of oncolytic medication.^{2,43} In summary, there is a significant gap in the literature on interventions that support caregivers of patients receiving OOT, despite the growing use of OOT and the growing number of caregivers with unmet needs.

Implications for Nursing Practice

The number of patients receiving OOT in the home setting is growing. As models of cancer treatment change, nurses must rethink the way care is delivered and how patients and caregivers are supported. Optimal care for patients receiving OOT includes providing education and support for their caregivers. Caregivers need standardized education regarding the safe handling of OOT, adherence, and symptom management. They need information regarding financial resources for patients receiving OOT. Finally caregivers need coping support for changes along the OOT trajectory. Nurses must assess, identify, and address caregiver needs throughout the treatment trajectory and facilitate optimal utilization of multidisciplinary health care resources to improve outcomes in patients receiving OOT. Nurses need to plan for caregiver education, provide consistent information on decision-making regarding OOT care, and monitor how caregivers are coping. Insights from the unmet needs of caregivers of patients receiving OOT will expectantly inform nursing research interventions that promote caregiver well-being, coping skills, care training programs that ultimately help them better manage care and improve patient outcomes.

Implications for Nursing Research

The largest area of research related to caregivers of patients receiving OOT has focused on drug safety and adherence. Caregivers are often not included in intervention studies, and left out of crucial education regarding safety and adherence. Additional intervention research is needed to address unmet needs, lack of communication, and empower caregivers to provide safe, high-quality care in the home environment. Future directions for research may include simulation care training programs for caregivers of patients receiving OOT. Simulation interventions would standardize OOT education and provide the means for ongoing training of caregivers as needed. Lastly, there is evidence that home visits by oncology nurses in other

countries improves patient and caregiver outcomes,³⁸ which further stresses the need to advocate for reimbursement of precision OOT care visits in the home setting through telehealth face-to-face visits and telephone wellness checks.

Conclusion

Caregivers who support patients receiving OOT have specific challenges and unmet needs that differ from patients receiving traditional intravenous chemotherapies and radiation.⁶ Caregivers need standardized OOT education and ongoing coping support to improve patient outcomes through enhanced drug safety practices and better management of patient symptoms, drug side effects, care decision-making, and treatment adherence. Clinicians are in need of evidence-based practices and interventions to support caregiver challenges with OOT. Oncology nurses play a critical role in the initial and ongoing education and coping support for caregivers throughout the OOT trajectory. Nurses are well-positioned to take a leadership role in facilitating optimal utilization of multidisciplinary health care resources necessary to support the needs of caregivers and improve outcomes in patients receiving OOT. Leadership, research, and political advocacy are essential for nursing to address the paradigm shift of cancer treatment into the home setting that depend heavily on the role of the caregiver, and meet the changing needs in care for both patients and their caregivers.

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