

Outpatient chemotherapy, family-centered care, electronic information, and education in adolescents and young adults with osteosarcoma

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Abstract: Current osteosarcoma chemotherapy is “standard” (doxorubicin, cisplatin, high-dose methotrexate ± ifosfamide-mesna, and etoposide ± mifamurtide), but current regimens have many short-term, medium-term, and long-term side effects. Generally 12–15 cycles of chemotherapy are given in the hospital over 7–10 months. Even in the absence of new research protocols, improvement in quality of life is now possible, with all osteosarcoma chemotherapy agents now being able to be administered in the outpatient setting. Outpatient chemotherapy is not only less expensive, but in the adolescent and young adult population can result in better quality of life for some. In this paper, we share information to help reduce the frequency of hospitalization and review some tools and strategies to facilitate communication when providing outpatient chemotherapy, family-centered care, and information/education. These include antiemetics with both longer-acting 5HT antagonists and aprepitant, outpatient chemotherapy guidelines, and a 5-week editable calendar that is part of our electronic medical record. Sharing information on absolute lymphocyte count recovery is another means of maintaining hope and increasing understanding of the prognosis of osteosarcoma. Finally, this paper shares an advanced directive/palliative care “checklist” of issues for patients and caregivers to consider at end of life, ie, when “cure of cancer is not the answer”. In summary, better communication at all stages of osteosarcoma care can help reduce hospitalization, improve quality of life, and maintain hope in the adolescent and young adult population with osteosarcoma.

Keywords: family-centered care, adolescent and young adult, flash drives, chemotherapy calendars, outpatient, osteosarcoma, chemotherapy

Introduction

Although it seems like a planned journey with a specific “roadmap” for doctors, physician assistants, and nurses, many families of patients with osteosarcoma consider current therapy to be an odyssey full of unexpected and sometimes unpleasant surprises. Not only is there the possibility of death from cancer, but also fear of disability is very common because local control frequently involves a less-than-perfect surgical option (limb salvage versus amputation). Furthermore, current chemotherapy agents for osteosarcoma (doxorubicin, cisplatin, high-dose methotrexate, ifosfamide ± mesna, and etoposide ± mifamurtide) have many short-term, medium-term, and long-term side effects. No young person goes through chemotherapy for osteosarcoma without some serious side effects.

However, within a couple of months from diagnosis most families gain an in-depth and often expert understanding of osteosarcoma that is really quite remarkable. At this stage, these young patients and their families want to partner more actively

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and effectively with their health care team to achieve fewer side effects and better short-term and long-term outcomes. This is in keeping with the four cornerstones of family-centered care.¹ Table 1 describes these cornerstones and the challenges to adapt family-centered care to adolescents and young adults with cancer.

We feel that the start of each chemotherapy cycle should be seen as an opportunity to learn, educate, and encourage to make each cycle better. It is humbling, but necessary, to accept and act on feedback from adolescents and young adults and their families to improve care. This article reviews some principles and practices that we now routinely incorporate into our mindset for providing the best possible family-centered care to adolescent and young adult patients with osteosarcoma and their families.

Family-centered care

This concept evolved not only to improve the health care experience for families but also to increase staff satisfaction.² With many additional providers of care involved in each episode of hospital care (eg, different nurses, residents, fellows, and attending physicians), continuity of care in the inpatient setting is especially challenging. Family-centered care seeks to put the patient and family at the center of coordination of care to improve satisfaction and outcomes.¹ For example, when patients and families are asked the same questions by multiple providers in the hospital on the same day, this does not inspire confidence in the coordination of care and begs the question: “Doesn’t anybody talk to each other?” Family-centered care seeks not only to empower patients and their families to assume greater roles in providing information and caregiving, but also in making decisions and facilitating continuity of care.³ For more information on family-centered care, interested parties can check the Institute for Patient and Family Centered Care website (<http://www.ipfcc.org>).

Family-centered care was introduced at the MD Anderson Children’s Cancer Hospital in 2007 and continues to be

a theme at pediatric division meetings and continuing education programs. Many service providers (nurses, physicians, child-family life specialists, social workers, and others) have attended a 3-day seminar sponsored by the Institute for Patient and Family Centered Care. Continued momentum and improvement in adoption of family-centered care has been maintained and facilitated by hiring a director of family-centered care and a parent of a child with osteosarcoma to coordinate family-centered care initiatives. The family advisory council is a committee that empowers families in decision-making, such as planning of hospital and clinic renovations. This family-centered care advisory council has representation from families of children with cancer, nurses, physicians, child-family life specialists, social workers, chaplaincy, public relations specialists, and teachers in our charter school at the MD Anderson Children’s Cancer Hospital.

Considerations for adolescent and young adult patients with osteosarcoma

- The highest incidence of osteosarcoma is in the adolescent and young adult population (about 75% of patients are aged 14–21 years)
- There is a survival plateau⁴ of about 60%–75% overall survival which has not changed in 20 years
- We have tried hard to make current therapy not only effective, but more adolescent and young adult friendly
- Our institution has benefited from a separate adolescent and young adult advisory council that has advocated for facilities and services, including fertility counseling, education, and vocational counseling, special “teen areas”, and provision of music, books and Internet access for adolescents and young adults in both the clinic and hospital.

Reliable, efficient, portable pumps (Figure 1) have made outpatient chemotherapy possible for osteosarcoma. To get families and providers of care up to speed “at a glance”, we currently make a one-page summary at diagnosis and continually update this during clinic visits⁵ (Table 2 and Figure 2). This summary is an MS Word document that can be edited and printed or placed on a flash-drive. It contains basic information to help current and new providers (eg, emergency room personnel, nurses, physicians, or others involved in care) understand better where the patient is in treatment as well as some personal details (eg, names of parents and siblings, best contact information, education, what they want to do when they grow up, problem list, and action plan).

Table 1 Four cornerstones of family-centered care and challenges in cancer care for adolescents and young adults

Cornerstone	Challenge for adolescent and adult patients with cancer
Dignity/respect Information-sharing	Many caregivers, loss of autonomy in hospital Although “routine” for staff, may not be for adolescents and adults
Collaboration	Follow protocol versus what works well in adolescents and adults
Participation	Including adolescents and adults and family in decision-making



Figure 1 Outpatient osteosarcoma chemotherapy.

Notes: A portable pump + intravenous fluid bag + tubing are placed in a backpack. This allows complete outpatient protocols for provision of all cycles of chemotherapy using transdermal, intravenous, or oral antiemetics, the Gemstar® pump, and intravenous fluids.

The summary makes caring and connecting much easier, and even when you cannot remember the details, it is there! This makes information exchange with families more timely, informative, and meaningful because the routine stuff of their increasingly rich narrative is readily available. This also facilitates having more time for productive and meaningful discussions about facilitating better health, process

Table 2 Components of a one-page summary of the patient's own health information (compliant with the Portable Health Insurance Portability and Accountability Act)

- Name, date of birth, medical record number
- Photograph of patient and x-rays, eg, positron emission tomography-computed tomography
- Diagnosis/location
- Metastases/location (or nonmetastatic)
- Allergies
- Family names (parents, caregivers, siblings)
- Family address and contact information including mobile phones, email
- Primary physician and clinic contact information
- Referring physician
- Overall treatment plan (one sentence)
- Consultants (eg, orthopedic surgeon)
- Current education level and goal(s) in life
- Height, weight, body surface area, body mass index
- History (brief)
- Last clinic visit date, issues addressed, counts, and week of therapy
- Current medications
- Problem list including:
 - local control
 - chemotherapy and control of short-term side effects (eg, nausea, cytopenia, fever/neutropenia)
 - markers and scans (eg, alkaline phosphatase at diagnosis, current); how to tell pattern of improvement
 - long-term monitoring (eg, heart, hearing, renal, lung growth)

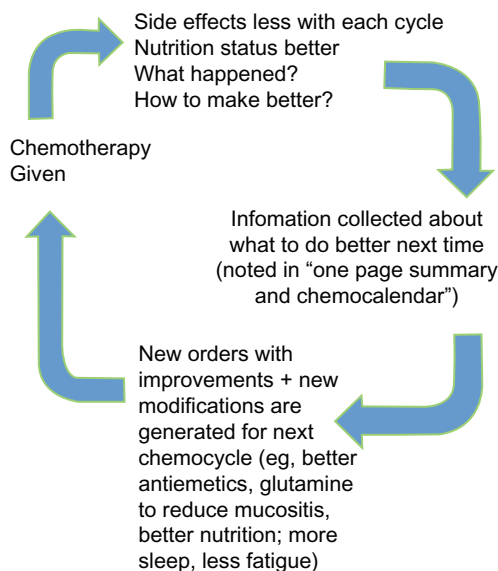
improvement, sharing feelings, hopes, and dreams, ie, the stuff which makes providing oncology care so rewarding. With many people involved with episodes of care, the issue arises of how to avoid confusion. We rely on calendars, weekly inpatient and outpatient clinic team meetings, nursing and physician hand-off during hospital admission, and above all, a family-centered attitude. The family must be clearly informed about what is going on, and have an excellent understanding of the recommended therapy and interventions for adolescent and young adult patients with osteosarcoma. Using information at each chemotherapy cycle should become better (Figure 2), and information on flash drives (Figure 3) and calendars that are also available in the electronic medical record (Figure 4) help to keep everyone knowing the schedule at a glance and to keep tasks on track.

Personal and personalized care: outpatient chemotherapy for osteosarcoma

Advances in cardioprotection^{6,7} and antiemetics (eg, aprepitant for delayed nausea, transdermal granisetron, intravenous palonosetron once daily), use of portable pumps (eg, Gemstar®, Figure 1) for 1–7-day intravenous infusions,⁸ PEGylated granulocyte colony-stimulating factor to promote neutrophil recovery, giving ifosfamide,^{8–15} and rapid communication (e-mail, mobile phones, “My MD Anderson”) for access to laboratory results, outpatient clinic staff, and/or on-call team, have made outpatient therapy not only feasible but preferred by most adolescent and young adult patients with osteosarcoma and their families, if given the choice. Appendix 1 provides details and summarizes inpatient versus outpatient approaches for commonly used chemotherapy agents in osteosarcoma.

Outpatient therapy is less disruptive to the daily routines of other members of the family, and the family can eat dinner together and sleep in their own beds. Figure 1 shows the outpatient pump, a 3 L bag of fluid, and a portable pump. Finally, because hospitalization is the major cost (about 75%) of cancer therapy in the first year following diagnosis,¹⁶ trying to develop an outpatient mindset becomes important when reviewing utilization of oncology resources. It is now possible to have fewer hospitalizations for routine chemotherapy in osteosarcoma. To date, we have not had insurance or third party payer issues when providing outpatient chemotherapy, which is less expensive than inpatient chemotherapy. Figures 2–4 depict information exchange tools used by staff, referring physicians, care providers, families, and adolescent

VIRTUOUS cycles of chemotherapy (each cycle with fewer side effects)



VICIOUS Cycles of chemotherapy (continued and more problems)

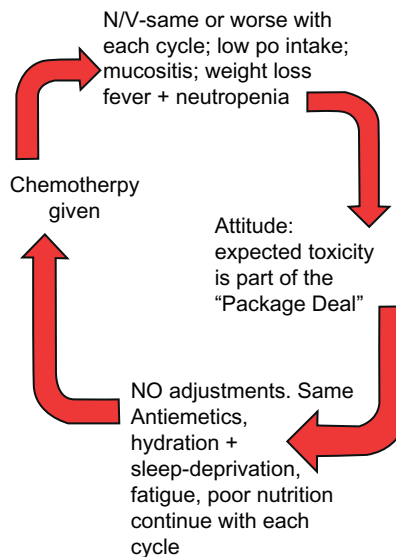


Figure 2 Virtuous versus vicious cycles: feedback to improve care is necessary to improve quality of life while receiving chemotherapy for osteosarcoma or reducing the risk of having similar or worse side effects.

Abbreviations: N/V, nausea and/or vomiting; po, oral.

and young adult patients with electronic information and education.

Considerations in a teaching hospital

Many pediatric oncologists, medical sarcoma experts, and orthopedic oncology surgeons provide care for adolescent and young adult patients with osteosarcoma in teaching hospitals. Although all of these highly trained and experienced

physicians were once in the learning stages themselves and understand the importance of teaching, it can be very intimidating for adolescent and young adult patients with osteosarcoma and their families to see a “herd of doctors and nurses” at hospital inpatient rounds. We suggest the following to reduce family anxiety and to facilitate communication and information sharing in the inpatient setting:

- when rounding at the bedside pull up a chair and sit down
- do not appear to be too busy (OR that your team is too busy) to be asked questions
- use written or electronic means (eg, problem list/action plan on whiteboards in hospital rooms; future appointments on “My MD Anderson”) to communicate with the family, nursing staff, and those that missed morning rounds about progress and steps needed to get out of hospital and follow-up
- plan in advance not only for the admission but also for discharge and follow-up.

Facilitating family-centered care for adolescents and young adults with osteosarcoma

New fellows receive a family-centered care orientation. When teaching residents or fellows in the outpatient clinic, there should be an attitude of facilitating the best possible care using the help and skills of the fellow or resident and



Figure 3 A 2 GB flash drive is provided to our adolescent and young adult patients with osteosarcoma.

Notes: This flash drive contains a “one-page summary” that is done during the initial consultation, updated at each visit, and includes folders for “road map” calendars, chemotherapy orders (pdf), articles, and additional information (eg, pdf of pulmonary function tests, echocardiogram, laboratory tests, glutamine suspension recipe, and photographs).

Click here to reset form



Date Printed: 11/20/2012 MRN: [redacted]

Pt Name: [redacted]

DOB: [redacted] Sex: [redacted]

Outpatient Pediatric Calendar

Attending Physician: Peter M. Anderson, MD

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Time Period (dates): [redacted]

Allergies: [redacted]

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
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Additional Comments: [redacted]

Pediatric Plan of Care

File under: Allied Health/Pathways

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Figure 4 Sample 5-week editable calendar in the MD Anderson clinic station electronic medical record.

Notes: This is created, printed, or saved as a pdf and placed on a flash drive. The calendar is also useful for helping families to know what lies ahead and assists physicians, advanced practice nurses, physician assistants in creating and/or verifying orders, and inpatient and outpatient nurses checking chemotherapy orders for correct doses and sequence of interventions. The same editable calendar is available as an Adobe document (email Pete Anderson or Maritza Salazar-Abshire at pmanders@mdanderson.org or msala@mdanderson.org and he/she will send you one). Copyright © 2008, The University of Texas M.D. Anderson Cancer Center. Reproduced with permission.

the family to arrive at good decisions and plans. If the fellow is “primary” for the patients, as occurs in many programs, the attending should mentor the fellow to foster thinking ahead, accepting shared responsibility with the family (partnering), and anticipating and preventing problems instead of reacting to problems after they occur. Also, it is important for the fellow in training to understand why things are done, and not just follow recipes. For example,

I always encourage the fellow to complete the “roadmap” calendar and justify chemotherapy doses and antiemetic choices before writing the actual electronic chemotherapy order. If such habits become part of their approach to care, these physicians-in-training learn to make excellent shared decisions and also become more confident with the families of the adolescent and young adult patients with osteosarcoma under their care.

Additional information for patients during interpretation of percent tumor necrosis after surgery

There have been many studies about the predictive value of microscopic analysis of chemotherapy after removal of primary osteosarcoma tumors.¹⁷⁻¹⁹ Because of this,

many families and patients become fixated on the “percent necrosis” number on the pathology report. Because so many families know that this predicts a good or bad prognosis (in general, but not necessarily for any given patient), we also obtain and calculate the absolute lymphocyte count on day 14 in cycle 1 of chemotherapy to have the most information

Allowing a Natural Death (instead of ICU or CPR- which would be futile and cause pain)

- At first this concept seems overwhelming, but advance planning can greatly improve the process for patients, families, and care providers.
- Advance directives to provide specific guidance about issues likely or unlikely to be encountered can help everyone do their best to keep on task so you can be as functional as possible with best quality of life in the days/weeks/months ahead
- Let's discuss.....

- What are likely things that will happen to me?
- Are there other tasks I should be doing or want to do with my time?
- What treatments do I want?
- Advance directives: how do I make these known?
- Do I need a will and/or living will?
- If I am unable to speak for myself, who should be designated to carry out my wishes? (durable power of attorney for health related issues)
- Financial or legal issues to be considered
- Family issues; talking with other family members
- Will I become a burden to my family? When should I get hospice involved?
- Spiritual and psychological issues important to me
- List of people I want to talk to or write to in the days/weeks/months ahead
- Legacy. What do I want to pass on? Consider writing letters for special people in my life to be opened in the future.

Contact information for _____

Email: _____@_____

office: _____; clinic: _____

mobile _____ (for texts)

pager: _____ (leave call back #)

Adapted from TJ Smith and BE Hillner *The Oncologist* 2010;15(suppl1):65-72

Figure 5 Checklist for palliative care and advance directives.

Notes: This is a tool to facilitate discussion of common issues and information-sharing when “cure of the cancer is not the answer”. Republished with permission of The Oncologist from Concrete options and ideas for increasing value in oncology care: the view from one trench, Smith TJ and Hillner BE, 15(Suppl 1) 2010; permission conveyed through Copyright Clearance Center, Inc.²²

about risk stratification when there is a discussion of “percent necrosis”. It has been shown that recovery of the absolute lymphocyte count on day 14 after cycle 1 of osteosarcoma chemotherapy (doxorubicin-cisplatin) is a superior predictor of outcome than per cent necrosis.^{20,21} If absolute lymphocyte count is >800, this provides hope.

Most of the histologic “good responder” patients and families will feel comfortable about continuing successful therapy. However, if there is a low percent of necrosis, the absolute lymphocyte count can then help to determine what else can or should be done and how to accomplish that.²¹ If the absolute lymphocyte count is >800 (associated with a good prognosis), then probably no additional imaging or interventions are indicated. However, if recovery of absolute lymphocyte count is poor and percent necrosis is low, such patients will benefit from reinforcement of the message that regular computed tomography chest scans can help determine if/when lung surgery will be needed (if ever). It may be best to rely on surgery instead of drugs to control future measurable and/or evaluable disease, and more not less therapy may be required.

Palliative care and advance directives

Unfortunately about 40% of patients with osteosarcoma die of their disease. Many times this is because of metastatic disease at diagnosis or unfavorable axial sites where local control is challenging and difficult. If disease reduction with drugs and surgery fails and tumor burden is increasing with no reasonable hope of local control (eg, too many metastases, bad location(s) of disease, marginal lung function, or poor performance for further interventions), then meaningful and unhurried discussion of advance directives and effective palliative measures is indicated. This is extremely hard for everyone. To stay on task and avoid the patient and/or family feeling abandoned when facing the prospect of a limited life span, we have developed a checklist (Figure 5, adapted from Smith and Hillner)²² of potential issues to discuss and/or think about in the future during these unforgettable and very difficult conversations. Clear advance directives and checklists can assist families and help the health care team to concentrate on facilitating function in a caring and loving way instead of repeated and unproductive “code status” discussions. Success of palliative and hospice care is not measured by length of survival but by patient and family satisfaction.

Follow-up phase of therapy

If a patient lives a considerable distance from the hospital and the major follow-up test is chest computed tomography,

our clinic will often recommend having scans done closer to home by a local medical or pediatric oncologist and that the images are sent to us on CD in DICOM format for review and uploading into the electronic medical record. We will then become more involved in care as needed for orthopedic issues and relapses. After 5 years of no evidence of active disease, patients are referred to our long-term follow-up/survivor clinic. This clinic helps them with long-term issues and interactions with their primary physicians. We also provide educational, vocational, and career counseling (Appendix 2 lists activities and resource links).

Conclusion

Treatment for osteosarcoma can be very challenging, especially during the first year of therapy. EURAMOS (European and American Osteosarcoma Study Group) and other “standard of care” protocols may require more than 17 hospitalizations and often there are additional hospital admissions for fever/neutropenia, nausea/vomiting, and/or hydration. There have been many improvements in the delivery of current chemotherapy, including portable pumps and better antiemetics that facilitate outpatient chemotherapy for osteosarcoma. Communication can help make care more planned and predictable for adolescent and young adult patients with osteosarcoma and their families.

Outpatient chemotherapy in a setting that supports family-centered care as well as tools for rapid communication and sharing of information between families and care providers, family, friends, and others with the same disease are now routine events in care for osteosarcoma that we could not have predicted 10–15 years ago. Successful adoption of more outpatient and adolescent and young adult friendly strategies, including outpatient chemotherapy and a family-centered attitude to care, can greatly facilitate relationships with families of patients with osteosarcoma, improve staff satisfaction, and probably reduce the cost of care. We are entering a new era of not only personalized care, but personal and family-centered care, too.

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Disclosure

The authors report no conflicts of interest in this work.

References

1. Johnson B, Ford D, Abraham M. Collaborating with patients and their families. *J Healthc Risk Manag*. 2010;29(4):15–21.
2. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*. 2007;335(7609):24–27.
3. Johnson BH, Abraham MR, Shelton TL. Patient- and family-centered care: partnerships for quality and safety. *N C Med J*. 2009;70(2):125–130.
4. Smith MA, Seibel NL, Altekruze SF, et al. Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *J Clin Oncol*. 2010;28(15):2625–2634.
5. Anderson P, Salazar-Abshire M. Improving outcomes in difficult bone cancers using multimodality therapy, including radiation: physician and nursing perspectives. *Curr Oncol Rep*. 2006;8(6):415–222.
6. Wexler LH, Andrich MP, Venzon D, et al. Randomized trial of the cardioprotective agent ICRF-187 in pediatric sarcoma patients treated with doxorubicin. *J Clin Oncol*. 1996;14(2):362–372.
7. Huh WW, Jaffe N, Durand JB, Munsell MF, Herzog CE. Comparison of doxorubicin cardiotoxicity in pediatric sarcoma patients when given with dexrazoxane versus as continuous infusion. *Pediatr Hematol Oncol*. 2010;27(7):546–557.
8. Anderson P. Continuously improving ifosfamide/mesna: a winning combination. *Pediatr Blood Cancer*. 2010;55(4):599–600.
9. Goorin AM, Harris MB, Bernstein M, et al. Phase II/III trial of etoposide and high-dose ifosfamide in newly diagnosed metastatic osteosarcoma: a Pediatric Oncology Group trial. *J Clin Oncol*. 2002;20(2):426–433.
10. Skubitz KM, Hamdan H, Thompson RC Jr. Ambulatory continuous infusion ifosfamide with oral etoposide in advanced sarcomas. *Cancer*. 1993;72(10):2963–2969.
11. Aguilera D, Hayes-Jordan A, Anderson P, Woo S, Pearson M, Green H. Outpatient and home chemotherapy with novel local control strategies in desmoplastic small round cell tumor. *Sarcoma*. 2008;2008:261589.
12. Anderson P, Aguilera D, Pearson M, Woo S. Outpatient chemotherapy plus radiotherapy in sarcomas: improving cancer control with radiosensitizing agents. *Cancer Control*. 2008;15(1):38–46.
13. Anderson PM, Pearson M. Novel therapeutic approaches in pediatric and young adult sarcomas. *Curr Oncol Rep*. 2006;8(4):310–315.
14. Meazza C, Casanova M, Luksch R, et al. Prolonged 14-day continuous infusion of high-dose ifosfamide with an external portable pump: feasibility and efficacy in refractory pediatric sarcoma. *Pediatr Blood Cancer*. 2010;55(4):617–620.
15. Meazza C, Bisogno G, Casanova M, Zanetti I, Carli M, Ferrari A. Full-dose ifosfamide can be safely administered to outpatients. *Pediatr Blood Cancer*. 2008;50(2):375–378.
16. Yabroff KR, Lamont EB, Mariotto A, et al. Cost of care for elderly cancer patients in the United States. *J Natl Cancer Inst*. 2008;100(9):630–641.
17. Glasser DB, Lane JM, Huvos AG, Marcove RC, Rosen G. Survival, prognosis, and therapeutic response in osteogenic sarcoma. The Memorial Hospital experience. *Cancer*. 1992;69(3):698–708.
18. Wunder JS, Paulian G, Huvos AG, Heller G, Meyers PA, Healey JH. The histological response to chemotherapy as a predictor of the oncological outcome of operative treatment of Ewing sarcoma. *J Bone Joint Surg Am*. 1998;80(7):1020–1033.
19. Hendershot E, Pappo A, Malkin D, Sung L. Tumor necrosis in pediatric osteosarcoma: impact of modern therapies. *J Pediatr Oncol Nurs*. 2006;23(4):176–181.
20. Moore C, Eslin D, Levy A, Roberson J, Giusti V, Sutphin R. Prognostic significance of early lymphocyte recovery in pediatric osteosarcoma. *Pediatr Blood Cancer*. 2010;55(6):1096–1102.
21. Anderson P. Predicting and facilitating survival of pediatric cancer patients: the ALC story. *Pediatr Blood Cancer*. 2010;55(6):1041–1042.
22. Smith TJ, Hillner BE. Concrete options and ideas for increasing value in oncology care: the view from one trench. *Oncologist*. 2010;15 Suppl 1:65–72.

Appendices

Appendix I Inpatient and outpatient therapy for osteosarcoma

Drug	Dose	Approach (details and comments)	
		Inpatient	Outpatient
Doxorubicin	75 mg/m ²	CI × 48–72 hours (more mucositis)	Dexrazoxane 750 mg/m ² (15 minutes) then doxorubicin 75 mg/m ² (15 minutes) Less mucositis and more cardioprotection
Cisplatin 120 mg/m ²	60 mg/m ²	4 hours × 2 days Hydration days 1–4 (3 L/m ²) More urine output and Sleep deprivation	60 mg/m ² /day in 3 L NS as a continuous infusion daily × 2 days, then 3 L NS hydration days 3 and 4 Adequate urine output Allows sleep
Methotrexate HDMTX	12 g/m ²	Hydrate until urine pH > 6.5 Ondansetron + hydration HDMTX 1 L IV over 4 hours Hydration 250 mL/m ² /hour	Oral bicarbonate (650 mg q 1–2 h) to alkalinize + oral hydration before clinic IV palonosetron, then HDMTX 1 L IV over 4 hours then 3 L IVF with 40 mEq/L sodium acetate × 20 hours on day 1, × 24 hours on days 2–5 LV 10 mg IV at hour 24, the LV 10 mg PO [MTX] 24, 48, 72, then q6h using 12- Return to clinic for labs, IVF bag change [MTX] BUN, Cr only Stop LV when [MTX] < 0.1 μM Eat and sleep at home
Ifosfamide	14 gm/m ²	At hour 24 begin LV 10 mg IV q6h; 6-12-6 schedule (any time of day) Lab/hydration any time daily Stop LV when [MTX] < 0.1 μM Often sleep-deprived	2.8 g/m ² + Mesna 2.8 g/m ² × 23 hours also can do 1 g/m ² /day × 14 days CI If drinking okay, no hydration needed Sleep in own bed; IV palonosetron daily or transdermal granisetron
Etoposide	100 mg/m ²	2.8 g/m ² IV over 3 hours × 5 days Mesna × 3 hours, then bolus × 3 2 × maintenance IV hydration (sleep-deprived if do this) ondansetron	IV over 1 hour or 200 mg/m ² PO during clinic (in daytime)
Antiemetics (commonly used)		IV over 1 hour Sometimes at night Ondansetron prechemotherapy then ondansetron IV/PO prn* (if prn logistics may delay so “Patient Receives Nothing”) Lorazepam (anticipatory) Nausea and vomiting IV diphenhydramine Scopolamine patch	Palonosetron IV daily × 1–5 days or granisetron PO or patch × 1 week and aprepitant with cisplatin cycles and Marinol for appetite, if needed Lorazepam (anticipatory) Nausea and vomiting Oral diphenhydramine Scopolamine patch
Hydration + laboratories (common approaches)		IV pump, 1 L bag changes Nursing labor-intensive Expensive Beeps to disrupt sleep Many more laboratory draws	Portable Gemstar® pump/3 L Backpack Little nursing involved Quiet and “worry-free” Daily and/or minimal laboratory monitoring

Abbreviations: BUN, blood urea nitrogen; CI, continuous infusion; Cr, creatinine; NS, normal saline; HDMTX, high-dose methotrexate; LV, leucovorin; L, liter; IV, intravenous; PO, oral; prn, as needed; q 1–2h, every 1–2 hours; q6h, every 6 hours; MTX, methotrexate level; IVF, intravenous fluid.

Appendix 2 Tools, information, care specialists, and links for better communication with adolescents and young adults

Task/issue	Tool, program, or care specialist(s) to facilitate
Education	IEP, teacher/charter school at MDACC school liaison
Therapeutic play and fun	Child family life, music therapy
Coping skills	Pediatric psychology, clinic nurses, child family life
Maintaining peer contact	Welcome friends to clinic and hospital, computer access
Same questions/same page?	One-page summary with problem list and action plan
Health information ownership	Flash drive that is the patient's/family property
Osteosarcoma information	Articles (pdf) on flash drive
Drug information	MDACC drug info sheets (pdf) on flash drive
Chemotherapy schedules	Calendar – in EMR and on flash drive (pdf)
Appointments	“My MD Anderson” to communicate with clinic staff
Keeping family up to date	Caringbridge.org, carepages.org; Facebook
Finances, parking, lodging	Social work
Family pitching in for tasks	MyHelpinghands.org
Sharing experience + information**	Osteo-sarcoma@listserve.acor.org
Something to look forward to	Social work helps with Make-wish or trip at end of therapy
Advance directives	Checklist for “when cure of cancer is not the answer”
Palliative care information	*Resource book “My Child Isn't Getting Better”
Funeral information	**Resource book “Funeral Planning and Information”
What will I be when I grow up?	Educational/vocational consultation
Survivor's health issues	Long-term follow-up clinic

Notes: *Helpful guide for parents by parents; **parents often share experiences.

Abbreviations: EMR, electronic medical record; IEP, individualized educational plan; MDACC, MD Anderson Cancer Center.

Links for MD Anderson Children's Cancer Hospital support programs

All programs

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/index.html>

Education and creative arts program

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/education-program.html>

Child and adolescent life programs

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/life-program.html>

Adolescent and young adult program

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/aya-program.html>

Arts in medicine program

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/childrens-cancer-hospital-support-programs-arts-in-medicine.html>

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/childrens-cancer-hospital-support-services-career-and-vocational-counseling.html>

Children's art project

<http://www.childrensart.org/>

Candlelighters (parents with experience support other parents)

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/childrens-cancer-hospital-support-services-career-and-vocational-counseling.html>

Career and vocational counseling

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/childrens-cancer-hospital-support-services-career-and-vocational-counseling.html>

Family centered care

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/family-centered-care/index.html>

Multimedia library

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/family-centered-care/index.html>

New patient welcome folder

http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/cch_folder2010.pdf.

Pediatric caregiver telephone support

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/support-programs/phone-support.html>.

Nutrition including recipes

@thetablecookbook

<https://atthetable.mdanderson.org/>.

<http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/healthy-living/healthy-living-nutrition.html>.

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