HHS Public Access

Author manuscript

J Pain Symptom Manage. Author manuscript; available in PMC 2016 March 01.

Published in final edited form as:

J Pain Symptom Manage. 2015 March ; 49(3): 513–520. doi:10.1016/j.jpainsymman.2014.06.011.

Comparison of Seven-Day and Repeated 24-Hour Recall of Symptoms in the First 100 Days Following Hematopoietic Cell Transplantation

William A. Wood, MD, MPH, **Allison M. Deal, MS**, **Antonia V. Bennett, PhD**, **Sandra Mitchell, CRNP, PhD, AOCN**, **Amy P. Abernethy, MD, PhD**, **Ethan Basch, MD**, **Charlotte Bailey, MA**, and **Bryce B. Reeve, PhD**

Lineberger Comprehensive Cancer Center (W.A.W., A.V.B., E.B., C.B., B.B.R.), Biostatistics Core Facility (A.M.D.), and Department of Health Policy and Management (B.B.R.), Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina; Outcomes Research Branch (S.M.), Division of Cancer Control and Population Science, National Cancer Institute, Bethesda Maryland; and Division of Medical Oncology (A.P.A.), Duke University Medical Center, Duke Cancer Institute, Durham, North Carolina, USA

Abstract

Context—Patient-reported outcomes (PROs) provide a way to understand the effects of hematopoietic cell transplantation (HCT)-related stress upon patients' lives. We previously reported that weekly collection of PROs is feasible.

Objectives—Here, we report on the feasibility of daily patient-reported symptom collection and we examine the relationship between daily vs. weekly symptom reporting over time.

Methods—We analyzed data from 32 autologous and allogeneic HCT patients obtained until Day (D)+100. We used questions from the PRO version of the Common Terminology Criteria for Adverse Events to capture symptoms.

Results—We found that overall rates of daily survey completion were moderate to high (range 67%–86%). The effect size of the difference between the maximum daily severity score and the weekly severity score ranged from 0.15 to 0.35, and the concordance correlation coefficient (CCC) ranged from 0.513 to 0.834. Concordance of daily and weekly surveys was higher for maximum daily severity rating and mean daily severity rating than for minimum daily severity rating or most recent daily severity rating.

Address correspondence to: William A Wood MD, MPH, Lineberger Comprehensive Cancer Center, Division of Hematology and Oncology, University of North Carolina at Chapel Hill, Campus Box 7305, 3rd Floor Physicians' Office Building, 170 Manning Drive, Chapel Hill, NC 27599-7305, USA, wawood@med.unc.edu.

Disclosures

There are no conflicts of interest to report.

Conclusion—We conclude that a seven-day recall period for symptom severity provides acceptable accuracy and precision in the first 100 days following HCT. Further studies to explore the utility of daily symptom reporting within specific clinical contexts may be warranted.

Keywords

hematopoietic stem cell transplantation; patient-reported outcomes; symptom burden; PRO-CTCAE

Introduction

Patient-reported outcomes (PROs) represent an important way to understand the effects of transplantation-related physiologic stress upon patients' lives (1, 2). We previously reported that weekly collection of patient-reported symptoms and health-related quality of life (HRQOL) is feasible and provides meaningful information (3). These data quantify the impact of transplantation upon physiologic function over time, and discriminate groups of patients by the intensity of pre-transplant conditioning chemotherapy. We also demonstrated that the early post-transplant symptom burden has a direct correlation with physical aspects of HRQOL. These results were based on weekly patient recall of symptoms and HRQOL. However, it is not known whether meaningful daily symptom variation was missed or whether it is feasible to collect this information on a daily basis.

In the early post-transplant period the presence and severity of symptoms can change over hours to days (3). Based on cognitive theory (4) and the circumstances of the post-transplant period, there are reasons to believe that weekly retrospective recall of symptom experiences may miss changes in day-to-day symptoms that post-transplant patients experience. This concern has empirical support in other clinical contexts, such as urinary incontinence (5–7), physical activity (8, 9), and alcohol consumption (10,11), where the observed correlations of short-term retrospective recall and 24-hour recall have varied from 0.33 to 0.89. Additional work utilizing ecological momentary assessment has demonstrated moderately high group-level correspondence between real-time and retrospective reports (of pain, for example), but low within-person correspondence (12, 13). Other studies comparing repetitive daily vs. weekly symptom reporting within specific non-cancer disease cohorts have shown consistency between seven-day and daily recall (4, 14), and small mean differences that were constant over time (15).

The purpose of the present study was to determine the feasibility of daily symptom reporting in the early post-transplant period, and to examine the relationship between daily and weekly symptom reporting over time. We hypothesized that daily symptom reporting was likely to be more feasible in an inpatient environment in which patients could more easily complete their questionnaires, as compared with an outpatient setting where patients are seen less frequently and receive less frequent survey completion reminders. We further hypothesized that, because the weekly surveys asked respondents to recall the worst severity of a particular symptom, the concordance of daily vs. weekly surveys would be highest for the maximum daily severity score within a given week for a given symptom. Last, we hypothesized that the concordance of daily vs. weekly surveys would be lowest during

periods of time and for patient populations in which symptom variability was expected to be greatest, such as full intensity conditioning of allogeneic transplant patients during the inpatient period. To test these hypotheses, we analyzed data from a prospective cohort study of autologous and allogeneic transplant recipients who were asked to electronically complete daily and weekly symptom surveys for 21 specified symptoms.

Methods

Patients

The symptom questionnaire data were collected as part of an observational pilot study enrolling patients undergoing HCT at the University of North Carolina (UNC) Cancer Hospital. Patients were recruited into autologous, reduced intensity allogeneic, or full intensity allogeneic cohorts, with a targeted enrollment of 10 patients per cohort. Eligibility criteria included age greater than 18 years and ability to read English. These patients have been previously described (3).

Study Design

All patients provided informed consent before enrollment using a form approved by UNC's Lineberger Comprehensive Cancer Center Protocol Review Committee and UNC's Biomedical Institutional Review Board. The study period was from the time of enrollment in the outpatient environment prior to planned hospitalization for transplantation, until day 100 (D+100) following infusion of stem cells. Autologous HCT recipients completed daily symptom surveys from the first day of conditioning chemotherapy until initial hospital discharge. Allogeneic HCT recipients (both full intensity and reduced intensity conditioning) completed daily symptom surveys from the first day of conditioning chemotherapy until D+100. In this prospective cohort study, we chose only to have allogeneic rather than autologous HCT patients complete daily surveys because of the proximity of allogeneic HCT patients to the transplant center through D+100, and the anticipated logistical difficulties with daily symptom capture in autologous HCT patients who had since moved back to their home communities. All patients completed weekly symptom surveys from the first day of conditioning chemotherapy until D+100.

Measures

The National Cancer Institute's (NCI) Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE) measurement system allows patients to self-report symptomatic adverse events (AEs) (16). The items are intended to be complementary to items in the NCI's CTCAE, an existing lexicon of clinician-reported adverse event items required for use in all NCI-sponsored trials. The PRO-CTCAE item library comprises 124 items that assess different attributes (e.g., presence, frequency, severity, interference with usual or daily activities) of 78 symptoms represented in the CTCAE version 4 AE lexicon. PRO-CTCAE severity items were selected for administration in this study. These items ask patients to rate the worst severity of a specific symptom (What was the severity of your [symptom] at its worst?) during the past seven days using one of five response choices (none, mild, moderate, severe, or very severe). Each symptom is scored from 0 (none) to 4 (very severe). For the purposes of this study, 21 symptom severity

items from the PRO-CTCAE were administered daily, using a 24-hour recall period, and weekly, using a seven-day recall period, according to the schedule described above. Surveys were administered electronically using Qualtrics Survey System (Provo, UT, USA), with paper-and-pencil versions available per patient preference (17), as described previously (3).

Statistical Methods

Feasibility of survey completion was assessed for all participants, and by cohort and post-transplantation time period (two time periods from Day 0 to Day +100 were of interest: days/weeks prior to initial post-transplant discharge, and days/weeks following initial post-transplant hospital discharge). To explore the relationships between daily and weekly symptom reporting on an individual and a group-level basis, each of the 21 symptoms was considered individually. In these analyses, weekly item responses were compared with specific descriptors of daily item responses, including mean score of the daily responses within the corresponding week, maximum score of the daily responses, minimum score of the daily responses, and Day 7 score of the daily responses (on Day 7, participants answered both 24-hour and weekly recall questions for each of the 21 symptoms). For these comparisons, differences between the weekly item scores and daily descriptors at the individual level were reported, as well as effect sizes, which account for the correlation between measures (18). The magnitude of the effect sizes were interpreted according to the criteria proposed by Cohen (19). For each patient, each week where a weekly survey was completed and three or more daily surveys also were completed was used in the analysis. Across all symptoms, this resulted in anywhere from 236 to 244 total weeks for analysis. Concordance between weekly item scores and daily descriptors also was determined by estimating the concordance correlation coefficient (CCC), as previously described (4). The CCC ranges from −1 to +1, where values closer to +1 indicate perfect agreement, values approaching - 1 correspond to perfect negative agreement, and values of 0 indicate no agreement. To interpret the CCC, we reference the criteria generally used for interpreting correlation statistics in PRO validation studies in which a correlation greater than 0.70 is considered a high level of agreement.

Results

Patient Characteristics

A total of 32 patients were enrolled into three cohorts: 10 autologous HCT recipients, 11 full intensity allogeneic HCT recipients, and 11 reduced intensity allogeneic HCT recipients. Median age of the entire population at the time of transplantation was 57.8 years. Thirteen patients (41%) had a high school education or less. Complete details regarding this study population have been previously reported (3). Two of 32 patients (6%) opted to use paper-and-pencil only, and the rest completed daily and weekly surveys electronically.

Daily Survey Response Rates

Feasibility of weekly survey completion has been previously reported (3). For daily surveys, median completion percentages are shown in Table 1. Completion was calculated by dividing the total number of surveys that were completed by the total number that should have been completed by each person for a given time period. The median time to complete

21 symptom severity items for all patients was 4.4 minutes. During the initial transplant hospitalization, the median daily survey completion percentage for all cohorts was 86%: 94% for the autologous transplant cohort, 87% for the reduced intensity allogeneic cohort, and 70% for the full intensity allogeneic cohort. Median daily survey completion percentages were particularly high during the first week after stem cell infusion (overall 86%; autologous 100%, reduced intensity allogeneic 100%, full intensity allogeneic 86%), and remained at least 85% for each subsequent week in each cohort through D+21. Following discharge from the initial transplant hospitalization, median daily completion percentages decreased in the full intensity allogeneic cohort; median post-discharge daily survey completion percentages were 52% for the full intensity cohort and 86% in the reduced intensity cohort.

Prevalence of Daily Symptoms and Relationship of Maximum Daily Score With Weekly Score

Autologous patients contributed daily symptom data for a median of two weeks, reduced intensity allogeneic patients a median of 14 weeks, and the full intensity allogeneic patients a median of 10 weeks. Table 2 displays the pooled means for seven-day recalled severity and maximum daily severity, mean difference between seven-day recalled maximum severity and maximum severity 24-hour recall, effect size of that difference, and CCC for all symptoms. Data are pooled across cohorts and across pre- and post-transplantation discharge time periods. Symptoms are presented in rank order based on the proportion of the study weeks during which respondents had at least one daily score ≥ 1 (signifying the presence of that symptom for at least one of the days during that week). Throughout the entirety of the study period, the most consistently prevalent symptom was fatigue, with 86% of weeks having at least one daily fatigue score of ≥1. For each symptom, Table 2 also depicts the mean and standard deviation for weekly scores and the mean of the maximum daily scores for all respondents within a given week, over all the weeks. Effect sizes ranged from 0.15 (cough and memory) to 0.35 (fatigue); the median effect size was 0.23. Interpreted using criteria proposed by Cohen, five of 21 had an effect size of less than 0.20 (negligible), and 16 of 21 effect sizes were between 0.20 and 0.49 (small). That all of the mean differences were negative and small supports a conclusion that slightly higher symptom severity is reported when 24-hour recall is employed, compared with seven-day recall, despite the fact that the seven-day recall asks the respondent to report their worst severity for each of the symptoms over the past seven days. The CCC ranged from 0.51 (chills) to 0.83 (mouth sores and decreased appetite); the median CCC was 0.762. Nineteen of 21 symptoms had CCC ≥ 0.60, and 14 of 21 had CCC ≥ 0.70, indicating a moderate to high level of agreement.

Comparisons of Weekly Scores With Specific Aspects of Daily Item Responses

Table 3 displays comparisons between additional daily score summary measures and weekly scores, using the CCCs. In addition to focusing on differences in maximum daily scores, Table 3 shows CCCs of weekly scores with the daily survey taken the same day as the weekly survey (Day 7), with the mean of the daily surveys for that week, and with the minimum of the daily surveys for that week. The five symptoms (fatigue, insomnia, loose stools, nausea, and decreased appetite) with the largest mean differences between maximum daily scores and weekly scores were selected for analysis. These data are displayed by

cohort and by post-transplantation time periods. In general, the greatest differences in daily scores and weekly scores were for the minimum daily scores, which also generally had the lowest CCC values. Because participants were asked to provide weekly scores that corresponded with the worst severity of that symptom during the week, this finding was expected. Weekly scores were on average less than the maximum daily scores for all symptoms, and greater than Day 7 scores and the mean daily scores for all symptoms. CCC values were generally higher for the weekly scores and the maximum daily or mean daily scores, rather than with the Day 7 scores. In general, CCC values were higher for all symptoms in the weeks after discharge than prior to discharge. In the weeks prior to discharge, CCC values were generally higher for reduced intensity allogeneic patients than full intensity allogeneic patients.

Fig. 1 displays findings from Tables 2 and 3, showing the distributions of difference scores (difference between maximum daily score and the corresponding weekly score for that week) as a function of agreement limits holding an absolute value of 0, 1, 2, 3 or 4 points. A score of “0” indicates that that the maximum daily scores and weekly scores for that week were the same. For all symptoms, there was a higher frequency of differences between maximum daily scores and weekly scores in the weeks prior to discharge than in the weeks after discharge, and the size of that difference was also larger in the pre-discharge weeks.

Discussion

In this study, we assessed the feasibility of daily symptom reporting in the early post-transplant period and examined the concordance between daily symptom reports with weekly symptom reports. No prior research in HCT has compared PRO recall periods. Such information is important as PROs assume an increasingly prominent role in both research and at the point of care (20–24). Empiric knowledge of whether daily symptom reporting, which incurs respondent burden and requires staff resources to achieve data completeness, offers a more precise and accurate picture of the symptom experience, compared with seven-day recall, and could ultimately be applied to decisions about measurement of PROs during and following HCT. Thus, we sought to determine whether daily symptom severity reporting as compared with seven-day recall offered improved precision and accuracy, and was likely to add benefit for the purposes of trials, research, or clinical care.

In the assessment of feasibility, we found the overall rates of survey completion were moderate to high (range 67 % –86%) depending on the setting. We hypothesized that daily symptom reporting was likely to be most complete in an inpatient environment in which patients had extra time to perform the surveys and availability for reminders. Conversely, we hypothesized that feasibility was likely to be lower in an outpatient environment, particularly for patients with greater illness severity or other issues requiring greater time investment, and for whom it was anticipated that responding to PRO surveys was likely to be a lower priority. We found that this was true, noting lower daily completion rates especially for the full intensity allogeneic transplant recipients in the post-discharge environment (range, 52% (full intensity allogeneic) − 86% (reduced intensity allogeneic) (Table 1)). Inpatient daily survey completion percentages were fairly high, with a few

exceptions (range, 70% –94%). It is possible that we might have achieved greater survey compliance with additional study personnel and regularly scheduled reminders (25).

The effect size of the difference between the maximum daily score and weekly score ranged across the 21 symptoms from 0.15 to 0.35, and the concordance ranged from 0.834 to 0.513. We found that effect size reflecting differences between maximum daily scores and weekly scores was highest for fatigue, with an effect size of 0.35 and CCC of 0.709. However, the absolute difference between the mean maximum daily score and the mean weekly score for fatigue was moderate (−0.35).

Because the weekly surveys asked respondents to recall the worst severity of a particular symptom, we hypothesized that the concordance of daily vs. weekly surveys was likely to be greatest for the maximum daily severity rather than other attributes of the daily surveys such as the minimum daily severity, mean daily severity, or the most recent (Day 7) daily rating of severity. Our observations supported concordance of daily vs. weekly surveys for both maximum daily severity and mean daily severity. Further, we hypothesized that the concordance of daily vs. weekly surveys was likely to be lowest during periods of time in which symptom variability was expected to be greatest, such as within the inpatient environment. Indeed, CCCs were higher after discharge.

We conclude, based on our observed concordance between daily and weekly symptom severity, that a seven-day recall period for symptom severity reports provides acceptable accuracy and precision in the first 100 days following HCT. This conclusion is supported by the high overall CCCs and small absolute differences between maximum daily severity and seven-day recalled severity for all symptoms in our study.

From a clinical care standpoint, it is possible that weekly survey reporting may miss information from potentially relevant daily survey reporting. In the inpatient environment, use of a 24-hour recall period might provide information to inform tailoring of clinical actions. Daily surveys might add to usual care, in which providers routinely ask patients about symptoms, because the full breadth, depth, and change over time of the symptom experience is captured by complete daily survey administration, rather than one or two questions asked on morning rounds. In the outpatient, less monitored environment, daily surveys also might offer information about less prevalent but potentially important symptoms that are clinically actionable. Examples of these kinds of symptoms include: shaking chills (a potential indicator of serious infection), loose stools or rash (potential indicators of graft-vs.-host disease.

Rather than recommending daily survey completion for clinical care purposes, we believe that further study of the clinical utility and value, balanced with the burden and cost of daily PRO reporting, is warranted. Specifically, additional research is needed to examine the extent to which daily PRO reporting influences clinical decision making in the inpatient environment, or earlier clinical encounters in the outpatient environment for new or concerning symptoms. The value of event- and context-triggered daily symptom reporting – i.e., initiating a series of daily symptom reports for patients in specific clinical contexts (e.g.,

cytomegalovirus infection, graftvs.- host disease flare, tapering of immunosuppression) – also should be explored.

We believe that our results support a conclusion that weekly symptom surveys accurately reflect the daily symptom experience in patients who have recently undergone autologous or allogeneic HCT. As suggested above, further studies of patient-reported symptoms in this population appear to be warranted.

Acknowledgments

This work was supported by National Institutes of Health Grant KL2TR000084.

References

1. Lee SJ, Fairclough D, Parsons SK, et al. Recovery after stem-cell transplantation for hematologic diseases. J Clin Oncol. 2001; 19:242–252. [PubMed: 11134219]
2. Wingard JR, Huang IC, Sobocinski KA, et al. Factors associated with self-reported physical and mental health after hematopoietic cell transplantation. Biol Blood Marrow Transplant. 2010; 12:1682–1692. [PubMed: 20685400]
3. Wood WA, Deal AM, Abernethy A, et al. Feasibility of frequent patient-reported outcome surveillance in patients undergoing hematopoietic cell transplantation. Biol Blood Marrow Transplant. 2013; 19:450–459. [PubMed: 23253558]
4. Bennett AV, Patrick DL, Bushnell DM, Chiou CF, Diehr P. Comparison of 7-day and repeated 4-h recall of type 2 diabetes. Qual Life Res. 2011; 20:769–777. [PubMed: 21088912]
5. Homma Y, Ando T, Yoshida M, et al. Voiding and incontinence frequencies: variability of diary data and required diary length. Neurourol Urodyn. 2002; 21:204–209. [PubMed: 11948713]
6. Kenton K, Fitzgerlad MP, Brubaker L. What is a clinician to do--believe the patient or her urinary diary? J Urol. 2006; 176:633–635. [PubMed: 16813908]
7. Elser DM, Fantl JA, McClish DK. Comparison of “subjective” and “objective” measures of severity of urinary incontinence in women. Program for Women Research Group. Neurourol Urodyn. 1995; 14:311–316. [PubMed: 7581467]
8. Richardson MT, Ainsworth BE, Jacobs DR, Leon AS. Validation of the Stanford 7-day recall to assess habitual physical activity. Ann Epidemiol. 2001; 11:145–153. [PubMed: 11164131]
9. Stel VS, Smit JH, Pluijm SM, et al. Comparison of the LASA Physical Activity Questionnaire with a 7-day diary and pedometer. J Clin Epidemiol. 2004; 57:252–258. [PubMed: 15066685]
10. Gmel G, Daeppen JB. Recall bias for seven-day recall measurement of alcohol consumption among emergency department patients: Implications for case-crossover designs. J Stud Alcohol Drugs. 2007; 68:303–310. [PubMed: 17286350]
11. Hilton ME. A comparison of a prospective diary and two summary recall techniques for recording alcohol consumption. Br J Addict. 1989; 84:1085–1092. [PubMed: 2790272]
12. Stone AA, Broderick JE, Kaell AT, DelesPaul PA, Porter LE. Does the peak-end phenomenon observed in laboratory pain studies apply to real-world pain in rheumatoid arthritis? J Pain. 2000; 1:212–217. [PubMed: 14622620]
13. Stone AA, Broderick JE, Shiffman SS, Schwartz JE. Understanding recall of weekly pain from a momentary assessment perspective: absolute agreement, between-and within-person consistency, and judged change in weekly pain. Pain. 2004; 107:61–69. [PubMed: 14715390]
14. Bennett AV, Patrick DL, Lymp JF, Edwards RC, Goss CH. Comparison of 7-day and repeated 24-hour recall of symptoms of cystic fibrosis. J Cyst Fibros. 2010; 9:419–424. [PubMed: 20817624]
15. Bennett AV, Amtmann D, Diehr P, Patrick DL. Comparison of seven day recall and daily diary reports of COPD symptoms and impacts. Value Health. 2012; 15:466–474. [PubMed: 22583457]

16. National Cancer Institute. [Accessed August 20, 2013] Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE). Available from http://outcome.cancer.gov/tools/pro-ctcae.html.
17. Abernethy AP, Herndon JE, Wheeler JL, et al. Improving health care efficiency and quality using tablet personal computers to collect research-quality, patient-reported data. Health Serv Res. 2008; 43:1975–1991. [PubMed: 18761678]
18. Dunlap WP, Cortina JM, Vaslow JB, Burke MJ. Meta-analysis of experiments with matched groups or repeated measures designs. Psychol Methods. 1996; 1:170–177.
19. Cohen, J. Statistical power analysis for the behavioral sciences. 2nd ed.. Hillsdale, NJ: Erlbaum; 1988.
20. Basch E, Artz D, Dulko D, et al. Patient online self-reporting of toxicity symptoms during chemotherapy. J Clin Oncol. 2005; 23:3552–3561. [PubMed: 15908666]
21. Berry DL, Blumenstein BA, Halpenny B, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: a randomized trial. J Clin Oncol. 2011; 29:1029–1035. [PubMed: 21282548]
22. Cleeland CS, Wang XS, Shi Q, et al. Automated symptom alerts reduce postoperative symptom severity after cancer surgery: a randomized controlled clinical trial. J Clin Oncol. 2011; 29:994–1000. [PubMed: 21282546]
23. Basch EM, Reeve BB, Mitchell SA, et al. Electronic toxicity monitoring and patient-reported outcomes. Cancer J. 2011; 17:231–234. [PubMed: 21799330]
24. Wood WA, Abernethy AP, Giralt SA. Pretransplantation assessments and symptom profiles: predicting transplantation-related toxicity and improving patient- centered outcomes. Biol Blood Marrow Transplant. 2012; 18:497–504. [PubMed: 22015992]
25. Basch E, Abernethy AP, Mullins CD, et al. Recommendations for incorporating patient-reported outcomes into clinical comparative effectiveness research in adult oncology. J Clin Oncol. 2012; 30:4249–4255. [PubMed: 23071244]

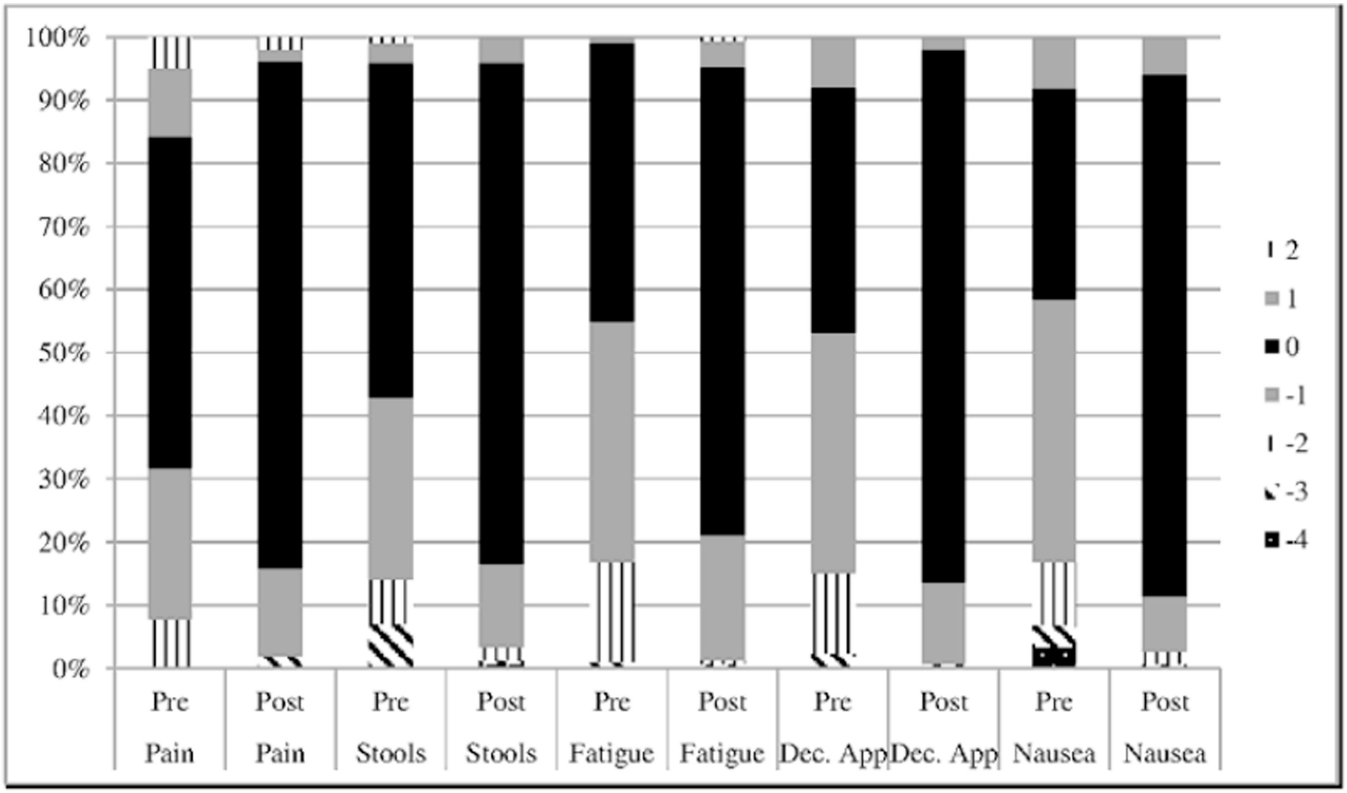

Figure 1.

Percentages of patients in whom the maximum daily scores were different than the corresponding weekly scores for that week, by symptom and by time period. “Pre” means prior to discharge from the initial transplant hospitalization and “post” means after discharge from the initial transplant hospitalization. The color coded numbers refer to the difference between the maximum daily scores and the corresponding weekly scores. A positive number means that the weekly score was greater than the maximum daily score during that week, and the magnitude corresponds to the absolute difference between the two. A negative number means that the weekly score was less than the maximum daily score. “0” means that the weekly score for that week were the same.

Table 1

Summary (median and range) of the Percentage of HSCT Recipients (*n*=30) Completing Daily Symptom Severity Survey, by Week Post-Transplant and by Post-Transplant Phase (Inpatient Hospitalization and Following First Post-Transplant Hospital Discharge)

	Full Intensity Allogeneic (range)	**Reduced Intensity Allogeneic (range)**	**Autologous[a] (range)**	**Overall (range)**
D0-D7	86 (43–100)	100 (57–100)	100 (29–100)	86 (29–100)
D8-D14	86 (29–100)	100 (43–100)	85 (14–100)	86 (14–100)
D15-D21	86 (0–100)	100 (57–100)	-	86 (0–100)
D22-D50	48 (0–90)	90 (31–100)	-	67 (0–100)
D51-D100	48 (0–96)	83 (0–100)	-	70 (0–100)
Initial transplant hospitalization	70 (21–100)	87 (46–100)	94 (37–100)	86 (21–100)
Post-discharge	52 (0–87)	86 (46–100)	-	70 (10–100)

Note: Denominators for allogeneic transplant patients are the first day of conditioning through 100 days following transplantation. The denominator for autologous transplant patients is the first day of conditioning through the day of discharge from the initial hospitalization

[a] Autologous group did not complete daily reports following discharge.

Table 2

Relationship of Maximum Daily Score With Weekly Score

	% Weeks With a Daily Score ≥1	Mean (SD) Weekly Score	Mean (SD) Maximum Daily Score	Mean Difference (Weekly-Max Daily)	Effect Size	CCC
Fatigue	86%	1.42 (0.91)	1.77 (1.05)	−0.35	0.35	0.709
Insomnia	76%	1.15 (0.91)	1.42 (0.98)	−0.27	0.28	0.767
Appetite	70%	1.23 (1.07)	1.49 (1.19)	−0.25	0.22	0.834
Dry Skin	67%	0.90 (0.78)	1.07 (0.83)	−0.17	0.21	0.816
Itchy Skin	52%	0.64 (0.70)	0.87 (0.81)	−0.23	0.30	0.659
Pain	52%	0.86 (1.01)	1.07 (1.11)	−0.21	0.20	0.808
Nausea	46%	0.71 (0.94)	0.97 (1.21)	−0.26	0.22	0.787
Stools	46%	0.75 (1.02)	1.02 (1.18)	−0.27	0.24	0.764
Concentration	46%	0.50 (0.59)	0.68 (0.78)	−0.18	0.25	0.625
Anxiety	42%	0.53 (0.72)	0.73 (0.87)	−0.2	0.24	0.670
Shortness of Breath	41%	0.50 (0.69)	0.62 (0.77)	−0.12	0.17	0.762
Rash	40%	0.47 (0.64)	0.68 (0.84)	−0.2	0.25	0.737
Memory	40%	0.47 (0.65)	0.58 (0.76)	−0.11	0.15	0.801
Abdominal Pain	35%	0.50 (0.78)	0.70 (0.95)	−0.2	0.23	0.773
Dizziness	32%	0.35 (0.54)	0.47 (0.65)	−0.12	0.20	0.632
Headache	29%	0.39 (0.71)	0.53 (0.83)	−0.14	0.18	0.734
Sad/Unhappy Feelings	28%	0.39 (0.73)	0.61 (0.91)	−0.22	0.26	0.643
Mouth Sores	28%	0.54 (1.00)	0.73 (1.17)	−0.18	0.16	0.834
Chills	25%	0.33 (0.68)	0.53 (0.87)	−0.21	0.26	0.513
Cough	19%	0.24 (0.56)	0.34 (0.70)	−0.1	0.15	0.782
Constipation	18%	0.24 (0.59)	0.48 (0.87)	−0.24	0.30	0.563

Symptoms are ranked by the percentage of weeks in the study during which there was at least one daily score of ≥1 for that symptom during that week. Means and standard deviations of both weekly and daily maximums are given, along with the effect size, to allow comparisons across symptoms. The negative numbers for the mean difference between weekly and daily maximums scores indicate the daily maximums scores were most often higher. The concordance correlation coefficient (CCC) shows the strength of the correlation between the maximum daily scores and weekly scores. A CCC of 0 demonstrates no correlation, and a CCC of +1 demonstrates perfect correlation.

Table 3

Mean differences between 24 hour and 7-day recall scores, for the five symptoms with the largest differences between maximum daily scores and weekly scores

CCCs are shown for weekly scores and specific attributes of daily scores (maximum daily score, day 7 daily score; mean daily score, and minimum daily score). CCCs are shown for all weeks, all weeks prior to discharge from the initial transplant hospitalization, and all weeks following discharge from the initial transplant hospitalization.

	All Cohorts				Full Intensity Allo			Reduced Intensity Allo			Autologous		
		All weeks	Pre discharge	Post discharge	All weeks	Pre discharge	Post-discharge	All weeks	Pre discharge	Post-discharge	All weeks	Pre discharge	Post-discharge
	Mean Difference from Weekly (SD)	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC
Fatigue													
Max	−0.35 (0.69)	0.709	0.574	0.780	0.675	0.548	0.661	0.765	0.686	0.831	0.293	0.217	N/A
Day 7	0.14 (0.73)	0.677	0.506	0.805	0.664	0.471	0.788	0.711	0.450	0.812	0.231	0.248	N/A
Mean	0.18 (0.54)	0.786	0.725	0.802	0.732	0.652	0.716	0.823	0.792	0.839	0.626	0.601	N/A
Min	0.60 (0.76)	0.475	0.350	0.595	0.402	0.244	0.595	0.558	0.508	0.595	0.209	0.176	N/A
Insomnia													
Max	−0.27 (0.60)	0.767	0.688	0.792	0.629	0.629	0.466	0.871	0.851	0.862	0.293	0.276	N/A
Day 7	0.12 (0.62)	0.729	0.661	0.732	0.641	0.442	0.855	0.759	0.796	0.692	0.709	0.742	N/A
Mean	0.14 (0.49)	0.822	0.772	0.827	0.735	0.696	0.704	0.865	0.830	0.850	0.688	0.703	N/A
Min	0.53 (0.74)	0.508	0.440	0.529	0.374	0.331	0.513	0.570	0.519	0.522	0.402	0.390	N/A
Loose Stools													
Max	−0.27 (0.72)	0.764	0.710	0.671	0.751	0.669	0.601	0.716	0.590	0.723	0.745	0.815	N/A
Day 7	0.22 (0.70)	0.721	0.679	0.623	0.688	0.528	0.671	0.628	0.735	0.554	0.696	0.781	N/A
Mean	0.20 (0.57)	0.787	0.736	0.761	0.775	0.693	0.697	0.789	0.702	0.818	0.624	0.697	N/A
Min	0.55 (0.84)	0.416	0.403	0.324	0.495	0.433	0.384	0.285	0.315	0.248	0.055	0.098	N/A

	All Cohorts				Full Intensity Allo			Reduced Intensity Allo			Autologous		
		All weeks	Pre discharge	Post discharge	All weeks	Pre discharge	Post-discharge	All weeks	Pre discharge	Post-discharge	All weeks	Pre discharge	Post-discharge
	Mean Difference from Weekly (SD)	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC	CCC
Nausea													
Max	−0.26 (0.67)	0.787	0.696	0.721	0.784	0.743	0.646	0.776	0.684	0.739	0.509	0.489	N/A
Day 7	0.21 (0.63)	0.742	0.686	0.653	0.632	0.482	0.557	0.713	0.615	0.713	0.805	0.82	N/A
Mean	0.18 (0.49)	0.808	0.764	0.671	0.756	0.682	0.63	0.765	0.758	0.631	0.759	0.753	N/A
Min	0.50 (0.75)	0.401	0.338	0.273	0.422	0.363	0.288	0.279	0.309	0.131	0.135	0.114	N/A
Decreased Appetite													
Max	−0.25 (0.61)	0.834	0.677	0.870	0.854	0.614	0.924	0.842	0.781	0.816	0.526	0.528	N/A
Day 7	0.16 (0.68)	0.774	0.621	0.827	0.749	0.535	0.796	0.770	0.579	0.842	0.579	0.598	N/A
Mean	0.18 (0.48)	0.867	0.796	0.868	0.831	0.685	0.869	0.882	0.859	0.854	0.808	0.811	N/A
Min	0.61 (0.76)	0.558	0.434	0.634	0.508	0.289	0.703	0.545	0.491	0.524	0.554	0.576	N/A