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Patient and family caregiver dyadic adherence to the allogeneic hematopoietic cell transplantation medical regimen

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adherence; cancer; dyad; hematopoietic cell transplant; medical regimen; oncology

1 | INTRODUCTION

Allogeneic hematopoietic cell transplantation (HCT) is a potentially curative therapy for hematologic disease.¹ To minimize infection risk and poor outcomes post hospital discharge, patients are required to identify a family caregiver to work with them to adhere to the multicomponent post-HCT medical regimen. In addition to medical surveillance and taking medication as prescribed, the National Marrow Donor Program's recommendations for the first 100 days after HCT include proper catheter care; avoidance of crowds; and reliance on a caregiver for transportation, shopping, and cooking.² Frequent, thorough hand washing is also strongly recommended to reduce the risk of bacterial, viral, and fungal infections,³ and patients typically must monitor their temperature daily to quickly recognize signs of infection. Further, patients who are neutropenic must generally follow a diet that avoids bacteria found in foods, such as fresh fruits and vegetables, salad bars, and fresh deli meats. Despite the importance of adherence,⁴ little research has examined levels of adherence or how patients and caregivers manage task requirements. Adherence is particularly critical over the initial period post hospital discharge, when patients are at highest risk for complications and mortality.⁵

Studies of adherence to medical regimens in other clinical contexts have focused primarily on the patient's role, although family caregivers are often involved. The present study is among the first to describe adherence levels across post-HCT medical regimen tasks and explore the contribution of dyadic factors to successful adherence in HCT. An additional goal was to describe how post-HCT adherence levels differ across tasks and how dyads differ in the division of task responsibilities, and we examine whether division of

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CONFLICT OF INTEREST

The authors have declared no conflicts of interest.

INSTITUTIONAL REVIEW BOARD APPROVAL

This protocol #PRO09020171 was approved by the University of Pittsburgh Internal Review Board.

responsibility is associated with task adherence. We also explored associations between task adherence and demographic, psychological, and clinical factors.

2 | METHODS

2.1 | Participants

We recruited patient-family caregiver dyads from our center's HCT program during an 18-month period. Eligibility criteria were: within 5 months post-allogeneic HCT; in complete remission; assessed at least 2 weeks post hospital discharge; had spent at least the prior 2 weeks at home (rather than back in the hospital or in a nursing facility) prior to the assessment; spoke English; had no major mental health problems recorded in the medical record and had a caregiver also willing to participate. Of the 33 eligible patients, 12 were not enrolled for the following reasons: nursing staff reported patient too sick (8), patient reported caregiver too sick (and thus a dyad could not be enrolled) (2), and patient declined (2).

2.2 | Procedure

The study was approved by the University of Pittsburgh Institutional Review Board. Each participant provided written informed consent and completed interviews separately in the clinic.

2.3 | Measures

2.3.1 | Adherence to the post-HCT medical regimen—Sixteen post-HCT tasks required by the HCT transplant program were assessed (see Table 2). We adapted a validated adherence assessment used in organ transplant recipients, the Health Habits Survey, which includes both patient and informant (family caregiver) reports.⁶ This method is superior to self-report alone.^{7,8} The original adherence assessment, and our adaptation (which was modified from the original only to refer to tasks specific to HCT), followed Feinstein's "clinimetrics" approach⁹ to maximize accurate reporting (eg, attention to item wording to encourage truthful answers; development of rapport with participants). The items have been found to have predictive validity for health outcomes in transplant populations.⁶ Whether or not a task was performed adherently was determined based on the requirements of the transplant team, which are grounded in National Marrow Donor Program guidelines. Patients and caregivers had received written and verbal education from the medical team on adherence requirements before transplant. Scoring was dichotomous (adherent or not adherent). Nonadherence was operationally defined by a report from either the patient or care-giver that the task was not done as prescribed during the previous week.

2.3.2 | Dyadic division of task responsibility—Dyadic responsibilities for ensuring task performance were assessed for each task by a modified version of the Family Responsibility Questionnaire¹⁰ item, "who was mostly responsible for this task being accomplished" (we changed the original version's "family member" to "caregiver" to better match our sample, thus response options: patient; caregiver; or both patient and caregiver had equal responsibility for task; or health professional). Disagreements about shared task responsibility were resolved as follows: if either patient or caregiver reported both parties

were responsible, it was coded to indicate shared task responsibility. Please see Results section for more information about disagreements.

2.3.3 | Patient and family caregiver-related correlates of adherence—

Sociodemographic characteristics (age, gender, race/ethnicity, education, and marital status) were obtained via self-report. We obtained cancer diagnosis, type of donor, HCT date, and hospital discharge date from medical records.

Symptoms of anxiety and depression were assessed with the widely used Hospital Anxiety and Depression Scale.¹¹

Patient-family caregiver relationship quality was assessed with a modified version of the 6-item Quality of Marriage Index,¹² which has been used as a brief measure of cancer patient-family caregiver relationship quality (eg, Porter et al¹³). Similarly, we changed “spouse” to “caregiver” and “marriage” to “relationship.”

Stressfulness of completing the post-HCT medical regimen tasks was assessed by an item from the work of Lee and colleagues, dichotomized as stressful vs not.¹⁴

2.4 | Data analysis

Descriptive statistics characterized task adherence (yes/no), division of responsibility (patient vs caregiver vs joint patient-caregiver), and potential correlates of adherence (sociodemographic, clinical, and psychological factors). Chi-squared tests examined associations between task adherence and responsibility. Correlation coefficients examined relationships between task adherence and sociodemographic, clinical, and psychological variables.

3 | RESULTS

3.1 | Participant characteristics

Sociodemographic and clinical characteristics of the 42 participants (21 patient-family caregiver dyads) are shown in Table 1. Most participants (95%) were European American, and most (62%) family caregivers were spouses. Patients were predominantly female (57%); mean age 51 years. Caregivers were mostly female (62%); mean age 53 years. Most patients were diagnosed with acute myelogenous leukemia (71%); most had a matched unrelated donor (71%). Dyads were assessed a mean of 83.4 days post-HCT (range 44–145 days).

3.2 | Adherence and task responsibility

As detailed in Table 2, all dyads reported full adherence to attending clinic appointments, but only approximately two-thirds reported adherence to immunosuppressant medication, other oral medication, or lifestyle self-care behaviors. Adherence to exercise guidelines, bathing daily, using sunblock, or temperature monitoring was lower.

Dyads mostly agreed on task responsibility (90% of the time). All disagreements were such that one member of the dyad stated that a single dyad member had responsibility while the other member stated that both had equal responsibility. There was neither instance in which

each member indicated the other had primary responsibility nor was there any disagreement about the responsibility of the health professional. Division of task responsibility varied substantially across the 16 tasks (Table 2). Responsibility for taking medications was fairly evenly split between the patients being mostly responsible or being a shared responsibility, but all other tasks had more distinct patterns of responsibility. For example, personal tasks such as daily bathing and daily mouth care were nearly exclusively the patient's responsibility, while following diet guidelines and avoiding crowds/sick people were joint responsibilities.

3.3 | Associations between task responsibility and adherence

As shown in Figure 1, levels of adherence differed based on responsibility. For example, among patients mostly responsible for their nonimmunosuppressant medications, 100% were adherent, while among those not mostly responsible (had help from their caregiver), 45% were adherent ($P = .012$). However, patients were more likely to be adherent to the neutropenic diet when the caregiver took shared or full responsibility for this task ($P = .042$).

3.4 | Sociodemographic, clinical, and psychological correlates of adherence

We examined immunosuppressant medication taking, other oral medication taking, a composite variable for line care (flushing line, changing cap, and wrapping port before bathing), and a composite variable for daily lifestyle behaviors (taking temperature, bathing, handwashing, avoiding crowds/sick people, following diet, performing mouth care, exercise, and using sunblock). We computed scores for each composite variable, awarding 1 point for each successful behavior, thus the line care variable score ranged from 0 to 3 and daily lifestyle variable score ranged from 0 to 8.

Better immunosuppressant medication adherence was associated with better relationship quality as reported by the patient ($r = .52$, $P = .015$), and less perceived stressfulness of the medical regimen, as reported by both the patient and the caregiver ($r = -.45$ and $-.57$, with $P = .042$ and $P = .011$, respectively). Better adherence to other medications was associated with the caregivers' perception that the regimen was less stressful ($r = -.46$, $P = .048$). Patient female gender was positively related to adherence to life style behaviors ($r = .53$, $P = .007$). No other factors were significantly associated with adherence, including depression and anxiety symptoms, time since HCT, and time since hospital discharge.

4 | DISCUSSION

Allogeneic HCT patients appear to have difficulty adhering to their prescribed post-HCT medical regimen despite family caregivers' assistance. None of the dyads we assessed was fully adherent to all tasks, and only 71% were fully adherent to the critical task of taking all immunosuppressant doses. Even poorer adherence was found for daily lifestyle tasks (eg, bathing). Only attendance at clinic appointments was successfully completed by all dyads.

Adherence to some tasks was related to which member of the dyad took responsibility for its completion. When patients were mostly responsible for taking their medications as well as flushing their line, those tasks were more likely to be accomplished than when responsibility was shared with the caregiver. However, tasks such as following the diet were more likely to

be accomplished if the caregiver was at least equally responsible, perhaps because it directly affected the caregiver (eg, caregiver was likely also preparing meals for himself or herself). These data suggest that adherence might be improved by selective encouragement for patients to take responsibly for some tasks (eg, taking medications). Perceived regimen stressfulness appeared to be a more important factor than distress (depression and anxiety) in relation to medication taking.

4.1 | Limitations

Although our study's focus on dyadic processes in adherence is novel, the relatively small sample size and cross sectional study design are limitations. Our measurement of adherence was also limited, as we relied on patient and caregiver recall of the past week, which might be subject to recall bias and not representative of the entire treatment interval. In addition, we relied on a single question about task responsibility and sharing rather than exploring this concept in more depth. We also did not measure factors such as the severity of patients' medical symptoms, which may have affected adherence levels or who was responsible for the medical tasks. Further, although all patients and caregivers are provided with education on the need to be adherent to all tasks at our center, it is possible that their beliefs about the importance of any particular task may have affected their adherence level.

4.2 | Clinical implications

Our work adds to the growing body of literature that includes the caregiver in helping medical patients better adhere to their regimens (eg, Coleman et al¹⁵). Given the suboptimal levels of adherence reported here, clinical staff should expressly ask both patients and their caregivers about how they are managing the medical regimen and provide support and problem-solving assistance as warranted. Future research with larger, more diverse patient samples is needed to better understand the factors that help and hinder adherence, as part of the development of effective dyadic interventions to improve adherence in this high risk patient population.

Acknowledgments

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Key points

- Little is known about how well patient-family caregiver dyads adhere to this regimen, how they share responsibility for specific tasks, and the factors involved in successful adherence.
- Although adherence to attending medical appointments was 100%, adherence to all other tasks was not optimal; immunosuppressant medication adherence was 71%.
- Adherence levels for some tasks were influenced by which member of the dyad took responsibility for its accomplishment.
- Strategies to improve adherence should consider dyadic factors including division of task responsibility.

FIGURE 1.

Percentage adherent based on division of task responsibility. Each task has 2 bars: the first bar indicates adherence level (percent adherent to task) for dyads in which the patient was mostly responsible for accomplishing that task; the second bar indicates adherence level for dyads in which either the caregiver was mostly responsible or it was a shared responsibility. Note: 3 tasks were excluded from analysis: attending clinic appointment (because there was 100% adherence); taking IV medications/supplements (because a minority of patients took IV medications); and central venous catheter–dressing changes (because this was usually done by health care professionals) by flush CVC and wrap port

TABLE 1

Background characteristics of participants (N = 42; 21 dyads)

Characteristic, n (%)	Patient n = 21	Caregiver n = 21	Test Statistic	P
Sociodemographic				
Gender, male	9 (43)	8 (38)	Fisher's exact	1.000
Female	12 (57)	13 (62)		
Age (mean; SD)	50.8; 12.6	52.5; 12.6	t(20) = -.410	.687
Range	24–71	23–75		
Ethnic group, European American	20 (95)	20 (95)	Fisher's exact	1.000
African American	1 (5)	1 (5)		
Highest education level, >high school	12 (57)	13 (62)	Fisher's exact	.751
Current marital status, married	17 (81)	21 (100)	Fisher's exact	.107
Patient-caregiver relationship, spousal	13 (62)			
Adult child-parent	4 (19)			
Parent-adult child	4 (19)			
Clinical				
Disease: AML	15 (71)			
Other	6 (29)			
Donor type, matched unrelated	15 (71)			
Sibling	6 (29)			
Days after transplant, mean; SD	83.4; 30.9			
Range	44–145			
Days after hospital discharge, mean; SD	63.8; 32.2			
Range	14–128			
Length of hospitalization, mean; SD	26.4; 6.3			
Range	18–41			

Abbreviations: AML, acute myelogenous leukemia.

TABLE 2

Levels of task adherence and identification of responsibility among patient-family caregiver dyads over the past week (N = 21 dyads)

Task	N(%) adherent	Who was mostly responsible for task accomplishment N (%)		
		Patient	Caregiver	Shared
1. Take immunosuppressant twice/day	15 (71.4)	11 (52.4)	1 (4.8)	9 (42.9)
2. Take other pills daily	16 (71.4)	10 (47.6)	1 (4.8)	10 (47.6)
3. Take IV meds/supplements daily ^a	7 (77.8)	2 (22.2)	1 (11.1)	6 (66.7)
4. Attend clinic appointments	21 (100)	2 (9.5)	5 (23.8)	14 (66.7)
5. Change central venous catheter (CVC) dressing once/week ^{b,d}	20 (100)	2 (10.0)	0	0
6. Flush CVC daily ^b	17 (85)	14 (70.0)	2 (10.0)	4 (20.0)
7. Change CVC cap (every 72 hours) ^{b,e}	16 (80)	9 (45.0)	0	0
8. Bathe daily	8 (38.1)	20 (95.2)	1 (4.8)	0
9. Wrap port before bathing ^b	16 (80)	13 (65.0)	2 (10.0)	5 (25.0)
10. Patient follow hand wash guidelines always	13 (61.9)	16 (76.2)	0	5 (23.8)
11. Avoid crowds/sick people always	15 (71.4)	2 (9.5)	2 (9.5)	17 (81.0)
12. Follow diet guidelines always	13 (61.9)	3 (14.3)	3 (14.3)	15 (71.4)
13. Follow mouth care guidelines (brush twice/day)	13 (61.9)	19 (90.5)	0	2 (9.5)
14. Exercise 30 minutes/day ^c	7 (33.3)	13 (61.9)	0	8 (38.1)
15. Use sunblock always	7 (33.3)	16 (76.2)	0	5 (23.8)
16. Take temperature daily	4 (19.0)	12 (57.1)	1 (4.8)	8 (38.1)

^a9/21 were currently prescribed IV meds.

^b20/21 patients had a line.

^cAny activity equaling 30 minutes combined.

^d18/20 (90.0%) reported task completed by health professional.

^e11/20 (55.0%) reported task completed by health professional.