A Pilot Study of Activity Engagement in the First Six Months After Stem Cell Transplantation

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Purpose/Objectives: To describe the natural pace and pattern of activity resumption in the first six months after stem cell transplantation (SCT).

Design: Longitudinal, descriptive survey.

Setting: Bone marrow transplantation program of a National Cancer Institute–designated comprehensive cancer center in the northeastern United States.

Sample: 18 men and 18 women who underwent either autologous (83%) or allogeneic (17%) transplantation.

Methods: Participants were surveyed 30 days, 100 days, and six months after SCT. Descriptive statistics were followed by exploratory linear mixed modeling with factors of time, gender, and the interaction between time and gender.

Main Research Variables: A modified checklist version of the Activity Card Sort was used to measure activity retention.

Findings: Participants generally were performing 49% of their usual activities 30 days after transplantation, 70% of their premorbid activities 100 days after transplantation, and 77% of their premorbid activities six months after transplantation. Level of activity engagement increased over time, with the greatest changes observed from 30–100 days after SCT. Men retained more of their activities than women in the domains of low physical-demand leisure and social activities.

Conclusions: Rehabilitation screening may be most helpful in the period from 100 days to six months, when activity levels begin to plateau. Activity recovery may differ for men and women; future research should explore how this could affect rehabilitation needs.

Implications for Nursing: Nurses can use structured surveys to explore and promote patients' satisfaction with and ability to engage in daily activities and ensure appropriate referrals to rehabilitation during recovery from SCT.

Stem cell transplantation (SCT) is standard therapy for many hematologic cancers, and more than 17,000 SCTs are performed each year in the United States (Goldman & Ausiello, 2008). Although SCT survivors generally report high global quality of life, their social and physical functioning is lower than that of age-matched peers (Bieri et al., 2008; Kopp et al., 2005; Pidala, Anasetti, & Jim, 2009; Wettergren, Sprangers, Bjorkholm, & Langius-Eklof, 2008). Most survivors experience fatigue during the first year after transplantation (Larsen, Nordstrom, Ljungman, & Gardulf, 2007), which can affect physical functioning, returning to work, and usual activities (Harder et al., 2002). Although most SCT survivors eventually return to school or work and resume their household activities, some survivors are unable to do so (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009).

The ability to resume previous activities and levels of activity engagement is one intuitively plausible indicator of the success of the procedure. Baker, Curbow, and Wingard (1991) found that SCT survivors who were able to retain their valued roles (e.g., worker, home maintainer, friend) had higher quality of life than survivors who reported loss of valued roles. Lee et al. (2001) similarly asked participants to assess the degree to which they were able to return to their previous lifestyles and enjoy their normal activities as a way to measure patient-centered outcomes of SCT. They found that at six months after transplantation, 53% of the autologous transplantation recipients agreed or strongly agreed with the statement "life has returned to normal" and 42% agreed or strongly agreed with the statement "I have been able to enjoy my normal activities" since transplantation. Significantly fewer recipients of allogeneic transplantations endorsed the statements (31% and 21%, respectively). Differences between allogeneic and autogolous transplantation recipients had equalized at 12 months, yet about 33% of both samples did not endorse the statements of recovery at that time point. Lee et al. (2001) concluded that, although their data contained many encouraging reports of recovery, such as few reports of bothersome symptoms, a substantial proportion of participants did not feel that their lives, routines, and activities had returned to normal one year after transplantation.

Although Lee et al. (2001) did not explore differences between men and women in their sample, other studies indicated that the process of functional recovery may be particularly difficult for women. Studies have noted that female survivors report higher rates of depression (DeMarinis, Barsky, Antin, & Chang, 2009) and more fatigue and inferior sleep quality when compared to male SCT survivors (Heinonen et al., 2001a); those factors could affect activity engagement. Other studies have found that female SCT survivors are less likely to return to work (Socie et al., 2001) or are more likely than men to experience a delayed return to work (Kirchhoff, Leisenring, & Syrjala, 2010; Syrjala et al., 2004). Conversely, Andorsky, Loberiza, and Lee (2006) found that women were more likely to endorse statements that life had returned to normal and they had put the illness behind them as compared to men in the sample.

Many studies have explored functional outcomes of SCT, such as disruption of vocational, recreational, and normal activities (Heinonen et al., 2001b; Lee et al., 2001; Syrjala et al., 2004); however, few detailed descriptions of the process of daily activity resumption after SCT are available. For example, in a literature review by Mosher et al. (2009), many researchers reported proportions of survivors who struggle with performance of usual activities or resumption of routine activities, yet they did not give a clear sense of what types of activities are more or less challenging than others. As a result, the current pilot study was designed to target that gap in the literature and to explore the pace and pattern of daily activity resumption after SCT. By beginning to understand the process of activity resumption, researchers may be able to generate hypotheses about people who are at risk for activity limitations and factors that are amenable to nursing rehabilitation interventions that could promote functional recovery in this population. To that end, this analysis focused on the question: What is the natural progression of activity resumption in the first six months after SCT?

Methods

Design and Data Collection

This longitudinal, descriptive, pilot study used paper-and-pencil surveys and a semistructured interview to collect data regarding activity resumption, quality of life, fatigue, and perceived cognitive impairment from patients who had undergone SCT. Participants were asked to complete surveys when consenting to undergo SCT and at 30 days, 100 days, 6 months, 9 months, 12 months, and 18 months after SCT. If participants experienced a relapse of their disease, they were not asked to complete any more surveys. The results of the semistructured interviews are presented elsewhere by Lyons, Root, et al. (2010). This analysis uses the survey data regarding activity resumption from the first six months after SCT; participant attrition after six months as a result of relapse, death, or disinterest yielded a data set too small to be used in these statistical analyses.

Setting and Participants

Participants were recruited from the bone marrow transplantation program at a National Cancer Institute–designated comprehensive cancer center from July 2005 to December 2007. The study was approved by the cancer center's institutional review board. Inclusion criteria were having English as primary language and being older than 18, scheduled to undergo SCT, and

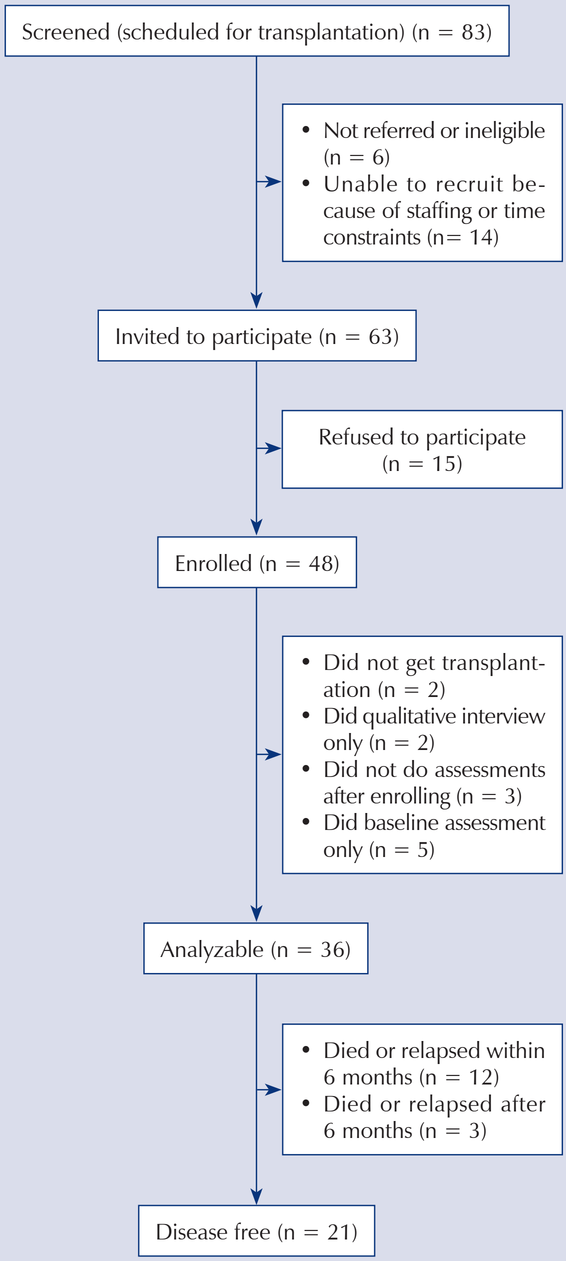

Figure 1. Flow of Recruitment, Enrollment, and Data Collection

able to provide informed consent (as determined by the referring clinician). The nurse coordinators for the bone marrow transplantation program informed patients of the study. Interested patients were approached by the principal investigator, a nurse coordinator, or a research assistant, who provided verbal and written information and obtained informed consent. Each participant signed a document affirming their informed consent.

Measures

Participants provided information regarding age, gender, ethnicity, race, religion, marital status, other members of household, employment status, main occupation, and highest year of education. Chart reviews were conducted at 30 days, 100 days, and six months after transplantation to determine treatment regimen, presence or absence of graft-versus-host disease, and disease status (disease-free versus relapse during data collection).

The **Activity Card Sort (ACS)** (Baum & Edwards, 2001) was developed to measure activity engagement in four domains: instrumental activities (20 items; e.g., driving, paying bills, child care), low physical-demand leisure (28 items; e.g., puzzles, quilting, photography), high physical-demand leisure (17 items; e.g., bicycling, woodworking, hiking), and social activities (15 items; e.g., volunteer work, visiting with friends, traveling). The tool uses a Q-sort methodology (Cordingley, Webb, & Hiller, 1997). The ACS has three different versions for (a) community-dwelling, healthy older adults; (b) older adults in a nursing facility; and (c) people recovering from a medical event. Using a modification of the recovering version of the ACS, the current study's participants placed 80 activities into one of five categories: (a) never done prior to transplantation, (b) do now (as often as before transplantation), (c) do less or differently than before transplantation, (d) not done since transplantation, or (e) new activity since transplantation. Any activities endorsed with the second, third, or fourth categories are counted as activities that were previously done. The instrument yields a total score and four domain scores reflecting the percent of activities retained since transplantation (current activities divided by previously done activities). A score of zero indicates that the respondent is not doing any of his or her pretransplantation activities, nor has he or she added any new activities to the repertoire. A score of 100 indicates that the respondent is performing at his or her pretransplantation level of activity engagement.

Table 1. Sample Demographic and Clinical Characteristics

	Enrolled (N = 48)		Analyzed (N = 36)	
Characteristic	$\bar{X}$	SD	$\bar{X}$	SD
Age (years)	54.2	11.6	53.6	12
Characteristic	n	%	n	%
Gender				
Male	24	50	18	50
Female	24	50	18	50
Race and ethnicity				
Caucasian and non-Hispanic	41	85	36	100
Unknown	7	15	–	–
Marital status				
Never married	1	2	1	3
Married	33	69	26	72
Living with partner	5	10	5	14
Divorced	5	10	3	8
Widowed	1	2	1	3
Unknown	3	6	–	–
Other members of household[a]				
Spouse or partner	36	75	30	83
Children	15	31	13	36
Parents or other relatives	2	4	2	6
None	5	10	4	11
Education				
Some high school	3	6	2	6
High school graduate	11	23	8	22
Some college	13	27	12	33
Bachelor's degree	9	19	8	22
Graduate degree	7	15	6	17
Unknown	5	10	–	–
Disease				
Multiple myeloma	19	40	16	44
Non-Hodgkin lymphoma	17	35	10	28
Leukemia	8	17	7	19
Hodgkin disease	3	6	3	8
Myelodysplastic syndrome	1	2	–	–
Type of transplantation				
Autologous	36	75	30	83
Allogeneic	10	21	6	17
Did not receive transplantation	2	4	–	–

[a] Participants could have endorsed more than one answer.
Note. Because of rounding, not all percentages total 100.

The ACS has been tested for reliability and validity in adults and older adults without illness, as well as in people with multiple sclerosis, cerebral vascular accident, and Alzheimer disease (Baum & Edwards, 2001; Everard, Lach, Fisher, & Baum, 2000; Katz, Karpin, Lak, Furman, & Hartman-Maeir, 2003). The developers reported a one-week test-retest reliability coefficient of r = 0.9 (Baum & Edwards, 2001). Internal consistency of the four domains generally is greater than α = 0.7 (Baum & Edwards, 2008). The theoretic activity domains identified by the developers were confirmed by factor analysis with an older adult sample (Sachs & Josman, 2003). The ACS was designed as a manual card sort; however, Everard et al. (2000) found that a paper-and-pencil version demonstrated adequate concurrent validity as compared to the manual card sort and that the 30-day test-retest reliability for the subscales ranged from 0.83–0.95, with a mean of 0.89. The current authors used a paper-and-pencil modification of the ACS called the ACS(Modified) (ACS[m]); modifications and

Table 2. Mean Activities Reported Prior to Transplantation

	Men (N = 18)		Women (N = 18)				
Domain	$\bar{X}$	SD	$\bar{X}$	SD	t	df	p
Low physical-demand leisure	13.4	3.4	19.6	4.3	–4.9	34	< 0.001
Instrumental	15.7	2	16.8	1.9	–1.7	34	0.093
Social	10.1	3	12.6	1.8	–3.1	34	0.004
High physical-demand leisure	7.3	3.7	7.5	3.9	–0.2	34	0.856
Total activities	46.4	8.6	56.6	9.6	–3.4	34	0.002

psychometrics were described in detail by Lyons, Li, Tosteson, Meehan, and Ahles (2010).

Data Analysis

The current authors first generated descriptive statistics on the number of previously done activities and plotted the ACS(m) total and domain scores for the sample at each time point. With only six people receiving an allogeneic transplantation, statistical power was not adequate to thoroughly explore differences between activity patterns of people based on type of transplantation. The authors explored whether activity retention differs for participants who had remained disease-free during data collection versus those who subsequently relapsed or died; linear mixed models revealed that activity retention did not differ in those groups. Therefore, type of transplantation or relapse status was not included in the final linear mixed models. The authors ran an exploratory analysis to see whether activity patterns were different for patients who remained disease-free versus those who were relapsed or died within the data collection period. In the linear mixed model including relapse, a significant effect of time was observed (F[2, 30.4] = 21.3, $p < 0.001$), but neither relapse status nor the interaction between time and relapse status was significant (F[1, 37] = 0.3, p = 0.62, and F[2, 30.4] = 0.5, p = 0.59, respectively). Therefore, although activity retention changed over time, no difference in activity retention was observed between patients who relapsed versus those who did not on total scores, nor on any activity domains.

The authors were able to compare scores for the 18 men versus the 18 women. After visually plotting the scores, the authors ran a repeated-measures linear mixed model, specifying an unstructured covariance matrix. The dependent variable was the total ACS(m) score, and the model contained three terms: time, gender, and the interaction between time and gender. This allowed the authors to determine whether activity levels change over time, activity levels differ for men versus women, and changes over time differ for men and women (e.g., if women made great gains early on and then leveled off, whereas men made slow progress early on and then more dramatic progress in the last three months). The linear mixed modeling was repeated for each domain of the ACS(m). When the overall models indicated that significant differences existed over time and between genders, the authors conducted linear mixed models first using only 30- and 100-day assessments and then only 100-day and 6-month assessments. This allowed the authors to determine the specific location of the differences (i.e., to identify at what time points one gender was performing more of their previous activities). The models enabled the authors to generate estimated marginal means that are slightly different from the descriptive statistics initially run because the models can adjust for the fact that each participant may not have completed every assessment. Given the small sample and exploratory nature of the study, a liberal a priori alpha level of $p < 0.05$ was set, despite the use of multiple tests. For those who would wish to apply a more conservative interpretation, a Bonferroni correction would indicate that results of $p < 0.001$ be considered statistically significant (i.e., 0.05 divided by the 50 significance tests = 0.001).

Results

Sample Characteristics

Figure 1 depicts recruitment flow and Table 1 presents participant characteristics. Forty-eight patients enrolled in the study (76% of those approached). Participants declined enrollment either because of disinterest or feeling that the survey completion would be too much work. Of the 48 enrolled participants, 36 had SCT and completed at least one activity survey allowing their inclusion in the analysis. All participants were Caucasian and non-Hispanic and generally were married with

Table 3. Proportion of Activities Retained for Entire Sample at Three Time Points After Reinfusion

	30 Days (N = 29)		100 Days (N = 30)		6 Months (N = 22)	
Domain	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Low physical-demand leisure	68	22	79	24	88	13
Instrumental	50	25	76	24	81	19
Social	39	22	67	26	77	18
High physical-demand leisure	30	25	51	32	77	18
Total activities	49	20	70	24	77	15

Note. Seventeen participants provided data at all three assessments.

at least one year of college education. Most had an autologous SCT. Multiple myeloma was the most common disease followed by lymphoma and leukemia. Only one participant experienced graft-versus-host disease during the first six months after transplantation; however, he was too ill to complete any surveys.

Twenty-nine participants were not working for pay during the six months after transplantation, reporting that they were either on medical leave, retired, or unable to find work. Six participants returned to work by 100 days after transplantation. Of them, four were working part-time and two were working full-time. The remaining participant returned to work part-time by six months after transplantation. Five of the participants who had returned to work had office jobs that could be considered sedentary in nature (e.g., clerical or supervisory positions), and two had manual labor jobs.

Activities Reported Prior to Transplantation

Table 2 displays the average number of pretransplantation activities typically done in each domain, broken down by gender. T tests of previous activities reported by participants (i.e., the denominator of the ratio that yields the ACS scores) revealed that women in this sample reported a significantly higher number of previously done activities in terms of total number of activities, low physical-demand leisure activities, and social activities.

Pace and Pattern of Activity Resumption

Total activities: Table 3 presents descriptive statistics for the ACS(m) total and domain scores. Participants generally were doing 49% of their usual activities at 30 days after transplantation, 70% at 100 days after transplantation, and 77% at six months after transplantation. At each time point, participants had retained the greatest proportion of their low physical-demand leisure activities, followed by their instrumental activities, social activities, and finally, high physical-demand activities.

Figure 2 plots the ACS(m) total and domain data, differentiated by gender. Table 4 presents statistics for the linear mixed models. Estimated marginal means from the models are presented to indicate the nature of the significant differences between time points and gender. Regarding the total score, activity levels increased over time. Activity retention at 30 days was significantly less than at 100 days (estimated marginal means were 48% of previous activities versus 69%) and significantly less at 100 days than at six months (69% versus 78%). Men had significantly higher overall activity retention than women in the first 100 days after transplantation (66% versus 52%). When looking at the differences in activity retention between genders, one should recognize that the activity score reflects the percentage of activities retained by each person. Higher scores after transplantation in men compared to women does not necessarily indicate that

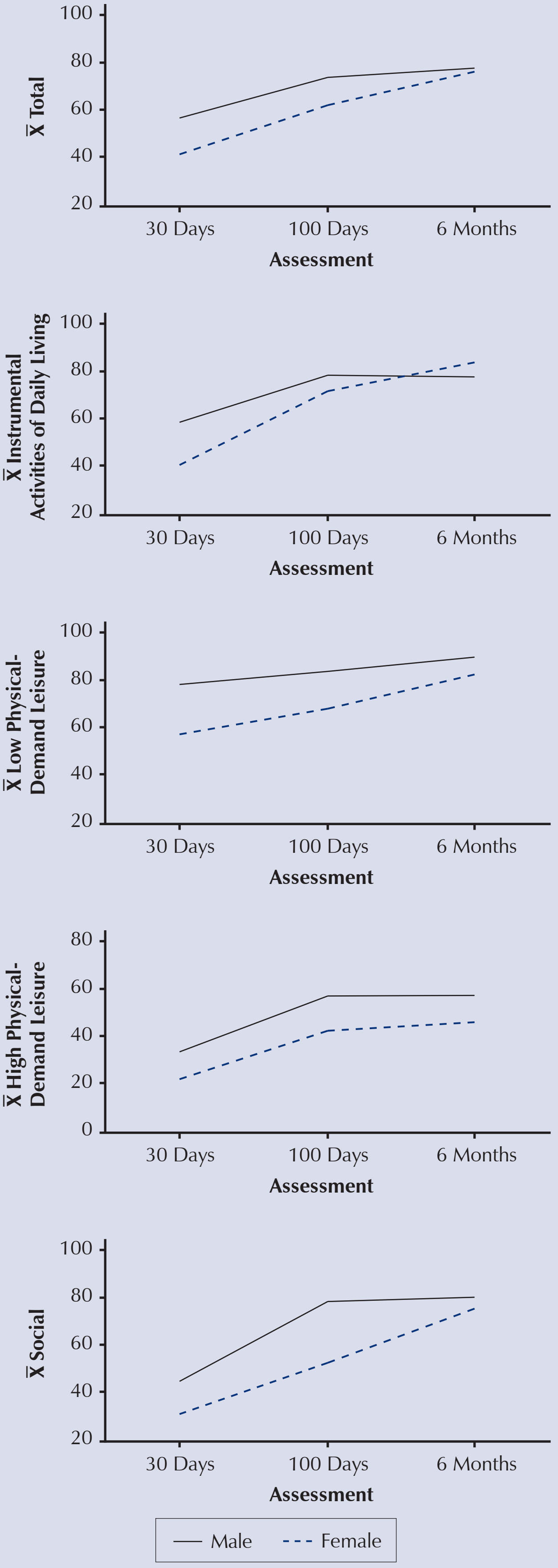

Figure 2. Proportion of Activities Retained Over Time Grouped by Gender

Table 4. Linear Mixed Models Exploring Whether Activity Retention Differs Over Time and Between Genders

	Overall Model		Model Using 30-Day and 100-Day Assessments		Model Using 100-Day and 6-Month Assessments	
Activity Domain	**F**	**p**	**F**	**p**	**F**	**p**
Total activity						
Time	F(2, 27.1) = 32.3	< 0.001	F(24.9) = 24.1	< 0.001	F(26.6) = 7.2	0.01
Gender	F(1, 33.7) = 3.7	0.064	F(32.1) = 4.7	0.04	F(29.4) = 1.4	0.25
Time x gender	F(2, 27.1) = 1.8	0.192	F(24.9) = 0.63	0.436	F(26.6) = 1	0.33
Instrumental activities						
Time	F(2, 24.5) = 19.8	< 0.001	F(22.1) = 27	< 0.001	F(24.5) = 4.8	0.04
Gender	F(1, 29.5) = 1.8	0.186	F(27.4) = 2.9	0.101	F(30) = 0.16	0.7
Time x gender	F(2, 24.5) = 1.6	0.213	F(22.1) = 1	0.32	F(24.5) = 1.96	0.17
Low physical-demand leisure						
Time	F(2, 24) = 16.1	< 0.001	F(22.9) = 4.8	0.04	F(28.4) = 6.6	0.02
Gender	F(1, 30.5) = 9.5	0.004	F(28.1) = 8.5	0.007	F(29.9) = 4.7	0.04
Time x gender	F(2, 24) = 1.6	0.229	F(22.9) = 1	0.323	F(28.4) = 0.2	0.66
High physical-demand leisure						
Time	F(2, 25.1) = 12.8	< 0.001	F(26.1) = 19	< 0.001	F(24.2) = 0.1	0.75
Gender	F(1, 35) = 1.5	0.226	F(34.8) = 1.5	0.234	F(27.9) = 1.4	0.24
Time x gender	F(2, 25.1) = 0.05	0.955	F(26.1) = 0.02	0.877	F(24.2) = 0	0.99
Social activities						
Time	F(2, 25.4) = 39.8	< 0.001	F(30) = 29.8	< 0.001	F(23.5) = 14	0.001
Gender	F(1, 34) = 7.7	0.009	F(34) = 9.9	0.003	F(29) = 5.2	0.03
Time x gender	F(2, 25.4) = 2.1	0.14	F(30) = 0.13	0.721	F(23.5) = 3.8	0.07

men actually were doing more activities than women; the finding simply means that men resumed a higher proportion of their previous activities than women. In summary, participants increased their activity level over time, with the greatest change occurring from 30–100 days. In addition, although men had higher activity retention at 30 days, only weak evidence showed an overall difference between men and women in the sample.

Instrumental activities: In this domain, activity retention at 30 days was significantly less than at 100 days (49% versus 75%) and significantly less at 100 days versus six months (76% versus 82%). Therefore, participants resumed more instrumental activities over time, with no differences between men and women in the sample.

Low physical-demand leisure activities: Scores improved at each time point (30 days versus 100 days: 68% versus 78%; 100 days versus 6 months: 79% versus 88%). Men's scores were significantly higher over the entire course of six months after transplantation (men versus women in first two assessments: 82% versus 64%; men versus women in last two assessments: 90% versus 77%). The finding indicates that participants' activity resumption increased over time and that men resumed more of their low-leisure activities than women.

High physical-demand leisure activities: Activity retention at 30 days was significantly less than at 100 days (29% versus 51%), but no differences existed between 100 days and 6 months or between genders.

Social activities: Participants resumed more social activities over time, with significant differences from 30–100 days (39% versus 66%) and from 100 days to 6 months (66% versus 76%). Men had resumed significantly more of their activities over the entire six months (men versus women in first two assessments: 63% versus 42%; men versus women in last two assessments: 79% versus 63%).

Discussion

The goal of this descriptive pilot study was to explore the pace and pattern of activity resumption after SCT. At all time points, participants had retained the highest proportion of their low physical-demand leisure activities, followed by instrumental, social, and high physical-demand leisure activities. This follows an intuitively plausible pattern and reflects what was described by the participants in the qualitative interviews (Lyons, Root, et al., 2010). Recovery begins with self-care and leisure activities that do not have high-energy demands. As the person recovers from transplantation and isolation precautions are lifted, he or she increases the amount of overall activity, including social activities. Although participants demonstrate improvement in high physical-demand leisure-activity engagement over the first three months, they only were doing about half of their premorbid activities in that domain at six months. Of note, this domain of the

ACS includes some seasonal activities and, therefore, should be interpreted cautiously. Participants may have lacked endurance or interest in doing some of the more physically challenging activities six months after transplantation; however, some may have not done the activity purely because of the time of year (i.e., fewer people choose to hike, camp, or boat during a New England winter).

As expected, the SCT recipients increased their activity levels over time. Activity scores significantly improved at each time point except in the case of high physical-demand leisure, which leveled off after 100 days. However, the gains were steepest in the first 100 days after transplantation in each domain, with less dramatic improvement in time leading up to the six-month assessment. The findings mirror research suggesting that functional status improves over the first six months after transplantation (Larsen et al., 2007), but complete recovery does not occur until well beyond that point (Lee et al., 2001; Syrjala et al., 2004).

By definition, this pilot study was better suited to generate hypotheses than to explain variations in the data. More research is needed to clarify the slower gain of improvement in activity resumption from 100 days to 6 months. Many participants returned to work at 100 days; their vocational demands may have taken energy away from resuming other aspects of their premorbid routine. One-hundred days after transplantation might be a good time to screen SCT survivors for rehabilitation needs and services that would promote greater functional recovery; however, screening or research also might demonstrate that survivors are satisfied with the changes in their activity engagement. The ACS(m) essentially asks respondents to compare their current activity level with previous levels, yet an empiric question is whether all survivors want to return to their previous activity level.

The ACS(m) offers a more precise measurement than has previously been used to explore how current activity level compares with premorbid activity levels. Other SCT survivorship researchers have used tools such as the SF-36® that compare a sample to population norms (Byar, Eilers, & Nuss, 2005) or have asked individuals the degree to which they are "back to normal" (Lee et al., 2001). The former measure gives a helpful comparison to people who have not undergone transplantation. The latter is a gross estimate of how the transplantation process has affected an individual, yet it fails to discern what "back to normal" means and whether that assessment reflects a response shift to a new normal (Tierney, Facione, Padilla, & Dodd, 2007) (i.e., an assessment of how active one is in relation to what the person thinks is reasonable and acceptable given having undergone SCT). The ACS(m) can offer a more individualized and detailed measurement of recovery, particularly when coupled with follow-up questions that can explore satisfaction with activity levels. For example, one could ask, "Of the activities you categorized as 'not done since transplantation,' are there ones that you would like to do again in the coming month?"

The results indicated that men and women differed in their activity recovery in the domains of low-leisure and social activities. Men had resumed a greater proportion of their premorbid activities in the domains of low physical-demand leisure and social activities, but women had a significantly higher number of premorbid activities overall and within those domains. Therefore, although women retained fewer of their low-leisure and social activities at 30 and 100 days, their baseline level of activity was higher in those domains; conversely, men were doing more of their social and low-leisure activities after transplantation but had fewer activities in their premorbid repertoire. Again, note that participants' satisfaction with current activity levels was not assessed in the current study. Future research should explicitly solicit that information from participants to contextualize the quantitative findings. However, the data do raise interesting hypotheses. Does lower activity retention translate into greater disability for female SCT survivors? Do women need to make more frequent or more conscious choices regarding which activities they resume and at what time after transplantation? If SCT induces menopause in women, does the symptom burden associated with menopause affect activity levels? How does activity retention relate to quality of life? One could hypothesize that women are frustrated by an inability to do what they had done previously or, alternatively, that they are enjoying the opportunity to selectively engage in fewer activities. Exploring those issues with the ACS(m) and supplementary questions regarding satisfaction with recovery and needs for rehabilitation could aid in the development of nursing rehabilitation interventions for this population. An additional variable to consider in future studies is cognitive status. Many chemotherapy recipients express frustration with memory and concentration following treatment, and those perceived deficits may influence activity engagement.

Limitations

The current study's findings should be interpreted cautiously in light of its inherent design limitations, which are common in the SCT literature, as indicated in a review article by Mosher et al. (2009). The study used a small, heterogenous convenience sample, which limited statistical power and generalizability. In particular, the gender effects were below the a priori alpha level of $p < 0.05$, but they did not fall below a Bonferroni-corrected alpha level of $p < 0.001$. The sample also included six participants who had an allogeneic transplantation. They were included in the analysis because exploratory linear mixed models did not suggest a difference between participants based on type of transplantation; however, trends in the data for interactions suggested that people with allogeneic transplantations have a slower initial recovery, which mirrors other research (Andorsky et al., 2006; Lee et al., 2001). Future studies using the ACS(m) with larger samples could pursue potential differences in activity resumption based on type of transplantation and gender. In addition, the results may have been biased by attrition. Participants most often missed assessments because they were feeling unwell. However, participants missed assessments because they were traveling or for unknown reasons; therefore, one should not assume that the surveys were completed only by participants in the best of health. A final limitation is the risk for making type I errors, given that multiple significance tests were run. The authors consider the risk justifiable because the study was of a hypothesis-generating nature as opposed to a hypothesis-testing nature. Despite the limitations, this pilot study begins to fill a gap in the knowledge by increasing understanding of the pace and pattern of recovery within specific domains of daily activity. More research is needed with larger samples that can use an a priori design to test hypotheses about factors such as gender and type of transplantation that can explain the variance in activity resumption among participants.

Implications for Nursing Practice

Sherman, Cooke, and Grant (2005) presented a content analysis of the discussions that arose during support group meetings for SCT survivors. Participants in their groups noted many post-treatment difficulties, including challenges that they faced in trying to return to their pretransplantation level of functioning, their careers, and their social lives. Participants not knowing the extent to which they would recover their pretransplantation level of functioning was one of the most distressing issues raised in the support groups. Survivors also reported experiencing shifting priorities and perspectives during recovery. They acknowledged wanting to change some of their previous behaviors and roles after having lived through this life-changing process. Sherman et al. (2005) asserted that support groups can aid recovery after SCT, allowing that other nursing interventions also need to be developed.

The current study affirms that activity resumption is a slow process after SCT. On average, survivors were doing about 75% of what they deemed to be their usual activities at six months after transplantation. The ACS(m) can be used as a clinical tool to begin a conversation about how survivors experience their daily activities. The tool's categorization of activities leads naturally into a discussion as to which activities survivors are happy to be doing more or less of, which activities they have not yet attempted, and which activities bring them satisfaction and induce a sense of health and well-being. Such a discussion gives nurses the opportunity to explore sources of dissatisfaction and barriers to activity resumption. Barriers could include symptoms (e.g., fatigue), psychological worries (e.g., anxiety, depression), physical impairments (e.g., reduced mobility), or environmental or social challenges (e.g., family members feeling overprotective and fearful of patients' exertion). Once barriers are identified, nurses can provide the services to address them or can facilitate referral to ancillary services, such as rehabilitation or social services. Nurses are well suited to promote functional recovery after SCT and to help survivors surmount the many challenges they face as they rebuild their lives and lifestyles.

Conclusion

The goal of this pilot study was to describe the pace and pattern of activity resumption after SCT to generate hypotheses about rehabilitation needs during recovery. Mosher et al. (2009) reviewed the literature and reported that, although most SCT survivors resume their normal activities, a sizable proportion struggle with functional limitations. The pilot data suggest that a plausible time period for screening on rehabilitation needs would be from 100 days to 6 months after transplantation and that survivors' social and high-demand physical leisure activities may be the slowest to return. The data also suggest that activity recovery differs for men versus women and that premorbid activity levels should be considered when assessing rehabilitation needs. Future research and clinical screening is needed to explore those issues with survivors to assess their need for and interest in supportive services to help them maximize their functional recovery. Use of the ACS(m) and semistructured interviewing provides a strong methodology for pursuing this line of inquiry and developing an evidence-based approach to rehabilitation intervention.

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References

Andorsky, D.J., Loberiza, F.R., & Lee, S.J. (2006). Pre-transplantation physical and mental functioning is strongly associated with self-reported recovery from stem cell transplantation. *Bone Marrow Transplantation, 37*, 889–895. doi: 10.1038/sj.bmt.1705347

Baker, F., Curbow, B., & Wingard, J.R. (1991). Role retention and quality of life of bone marrow transplant survivors. *Social Science and Medicine, 32*, 697–704.

Baum, C.M., & Edwards, D. (2001). *Activity Card Sort*. St. Louis, MO: Washington University School of Medicine.

Baum, C.M., & Edwards, D. (2008). *Activity Card Sort* (2nd ed.). Bethesda, MD: American Occupational Therapy Association Press.

Bieri, S., Roosnek, E., Helg, C., Verholen, F., Robert, D., Chapuis, B., . . . Chalandon, Y. (2008). Quality of life and social integration after allogeneic hematopoietic SCT. *Bone Marrow Transplantation, 42*, 819–827. doi: 10.1038/bmt.2008.253

Byar, K.L., Eilers, J.E., & Nuss, S.L. (2005). Quality of life 5 or more years post-autologous hematopoietic stem cell transplant. *Cancer Nursing, 28*, 148–157.

Cordingley, L., Webb, C., & Hiller, V. (1997). Q methodology. *Nurse Researcher, 4(3)*, 31–45.

DeMarinis, V., Barsky, A.J., Antin, J.H., & Chang, G. (2009). Health psychology and distress after haematopoietic stem cell transplantation. *European Journal of Cancer Care, 18*(1), 57–63. doi: 10.1111/j.1365-2354.2008.00931.x

Everard, K.M., Lach, H.W., Fisher, E.B., & Baum, M.C. (2000). Relationship of activity and social support to the functional health of older adults. *Journal of Gerontology: Psychological and Social Sciences, 55*, 208–212.

Goldman, L., & Ausiello, D. (Eds.). (2008). *Cecil medicine*. Philadelphia, PA: Saunders Elsevier.

Harder, H., Cornelissen, J.J., Van Gool, A.R., Duivenvoorden, H.J., Eijkenboom, W.M., & van den Bent, M.J. (2002). Cognitive functioning and quality of life in long-term adult survivors of bone marrow transplantation. *Cancer, 95*, 183–192. doi: 10.1002/cncr.10627

Heinonen, H., Volin, L., Uutela, A., Zevon, M., Barrick, C., & Ruutu, T. (2001a). Gender-associated differences in the quality of life after allogeneic BMT. *Bone Marrow Transplantation, 28*, 503–509. doi: 10.1038/sj.bmt.1703158

Heinonen, H., Volin, L., Uutela, A., Zevon, M., Barrick, C., & Ruutu, T. (2001b). Quality of life and factors related to perceived satisfaction with quality of life after allogeneic bone marrow transplantation. *Annals of Hematology, 80*, 137–143.

Katz, N., Karpin, H., Lak, A., Furman, T., & Hartman-Maeir, A. (2003). Participation in occupational performance: Reliability and validity of the Activity Card Sort. *OTJR: Occupation, Participation, and Health, 23*, 10–17.

Kirchhoff, A.C., Leisenring, W., & Syrjala, K.L. (2010). Prospective predictors of return to work in the 5 years after hematopoietic cell transplantation. *Journal of Cancer Survivorship, 4*(1), 33–44. doi: 10.1007/s11764-009-0105-2

Kopp, M., Holzner, B., Meraner, V., Sperner-Unterweger, B., Kemmler, G., Nguyen-Van-Tam, D.P., & Nachbaur, D. (2005). Quality of life in adult hematopoietic cell transplant patients at least 5 yr after treatment: A comparison with healthy controls. *European Journal of Haematology, 74*, 304–308. doi: 10.1111/j.1600-0609.2004.00402.x

Larsen, J., Nordstrom, G., Ljungman, P., & Gardulf, A. (2007). Factors associated with poor general health after stem-cell transplantation. *Supportive Care in Cancer, 15*, 849–857. doi: 10.1007/s00520-006-0200-0

Lee, S.J., Fairclough, D., Parsons, S.K., Soiffer, R.J., Fisher, D.C., Schlossman, R.L., . . . Weeks, J.C. (2001). Recovery after stem-cell transplantation for hematologic diseases. *Journal of Clinical Oncology, 19*, 242–252.

Lyons, K.D., Li, Z., Tosteson, T.D., Meehan, K., & Ahles, T.A. (2010). Consistency and construct validity of the Activity Card Sort (modified) in measuring activity resumption after stem cell transplantation. *American Journal of Occupational Therapy, 64*, 562–569. doi: 10.5014/ajot.2010.09033

Lyons, K.D., Root, L.D., Kimtis, E., Schaal, A.D., Stearns, D.M., Williams, I.C., . . . Ahles, T.A. (2010). Activity resumption after stem cell transplantation. *OTJR: Occupation, Participation and Health, 30*, 20–28. doi: 10.3928/15394492-20091214-04

Mosher, C.E., Redd, W.H., Rini, C.M., Burkhalter, J.E., & DuHamel, K.N. (2009). Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: A review of the literature. *Psycho-Oncology, 18*, 113–127. doi: 10.1002/pon.1399

Pidala, J., Anasetti, C., & Jim, H. (2009). Quality of life after allogeneic hematopoietic cell transplantation. *Blood, 114*, 7–19. doi: 10.1182/blood-2008-10-182592

Sachs, D., & Josman, N. (2003). The Activity Card Sort: A factor analysis. *OTJR: Occupation, Participation and Health, 23*, 165–176.

Sherman, R.S., Cooke, E., & Grant, M. (2005). Dialogue among survivors of hematopoietic cell transplantation: Support-group themes. *Journal of Psychosocial Oncology, 23*, 1–24. doi: 10.1300/J077v23n01_01

Socie, G., Mary, J.Y., Esperou, H., Robert, D.V., Aractingi, S., Ribaud, P., . . . Vexiau, P. (2001). Health and functional status of adult recipients 1 year after allogeneic haematopoietic stem cell transplantation. *British Journal of Haematology, 113*, 194–201.

Syrjala, K.L., Langer, S.L., Abrams, J.R., Storer, B., Sanders, J.E., Flowers, M.E.D., & Martin, P.J. (2004). Recovery and long-term function after hematopoietic cell transplantation for leukemia or lymphoma. *JAMA, 291*, 2335–2343. doi: 10.1001/jama.291.19.2335 291/19/2335

Tierney, K., Facione, N., Padilla, G., & Dodd, M. (2007). Response shift—A theoretical exploration of quality of life following hematopoietic cell transplantation. *Cancer Nursing, 30*, 125–138.

Wettergren, L., Sprangers, M., Bjorkholm, M., & Langius-Eklof, A. (2008). Quality of life before and one year following stem cell transplantation using an individualized and a standardized instrument. *Psycho-Oncology, 17*, 338–346. doi: 10.1002/pon.1240