CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Patient's perspectives on what life is list post-HCT: Quality of Life assessments

Agenda

1) Patient Reported Outcomes (PROs): Assessing patient's quality of life

2) What we have learned thus far about post-HCT through PROs:

- **Pre-HCT QOL**
- **Age**
- **Post-transplant cyclophosphamide (PTCy)**
- **Mismatched unrelated donors**
- **Financial well-being**

Mr. Brewers, a 62-year-old hardware store owner, has AML in first clinical remission. His physician referred him for alloHCT consultation. Mr. Brewers and his wife prepare a list of questions to ask the transplant team, including How likely is it that Mr. Brewers will be cured? **How long will it take to feel like himself again? Will he be able to manage his hardware business after the transplant, including stocking shelves and doing the accounting? Will transplant be expensive?** What challenges will Mrs. Brewers face, and how can she best help her husband?

Mr. and Mrs. Brewers are asking not only about the curative potential of HCT **but also about post-HCT physical and cognitive functioning, quality of life, financial security, and psychosocial well-being for him and his caregiver spouse**.

Burns, Linda J., Beatrice Abbetti, Stacie D. Arnold, Jeffrey Bender, Susan Doughtie, Areej El-Jawahiri, Gloria Gee et al. "Engaging patients in setting a patient-centered outcomes research agenda in hematopoietic cell transplantation." *Biology of Blood and Marrow Transplantation* 24, no. 6 (2018): 1111-1118.

Mr. Brewers, a 62-year-old hardware store owner, has AML in first clinical remission. His physician referred him for alloHCT consultation. Mr. Brewers and his wife prepare a list of questions to ask the transplant team, including How likely is it that Mr. Brewers will be cured? **How long will it take to feel like himself again? Will he be able to manage his hardware business after the transplant, including stocking shelves and doing the accounting? Will transplant be expensive?** What challenges will Mrs. Brewers face, and how can she best help her husband?

Mr. and Mrs. Brewers are asking not only about the curative potential of HCT **but also about post-HCT physical and cognitive functioning, quality of life, financial security, and psychosocial well-being for him and his caregiver spouse**.

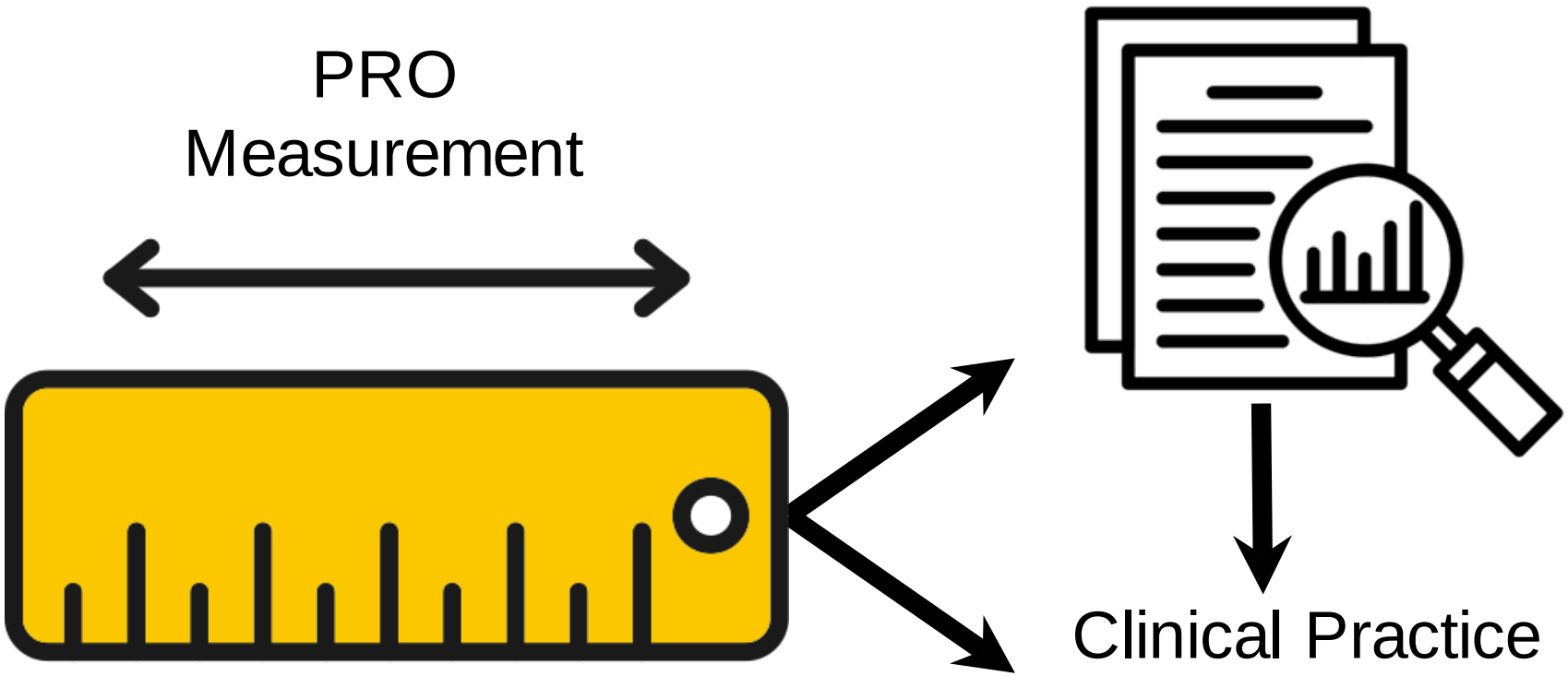
How can we answer these questions, focusing on patient's perspective?

Burns, Linda J., Beatrice Abbetti, Stacie D. Arnold, Jeffrey Bender, Susan Doughtie, Areej El-Jawahiri, Gloria Gee et al. "Engaging patients in setting a patient-centered outcomes research agenda in hematopoietic cell transplantation." *Biology of Blood and Marrow Transplantation* 24, no. 6 (2018): 1111-1118.

QOL using PROs

Research

PRO
Measurement

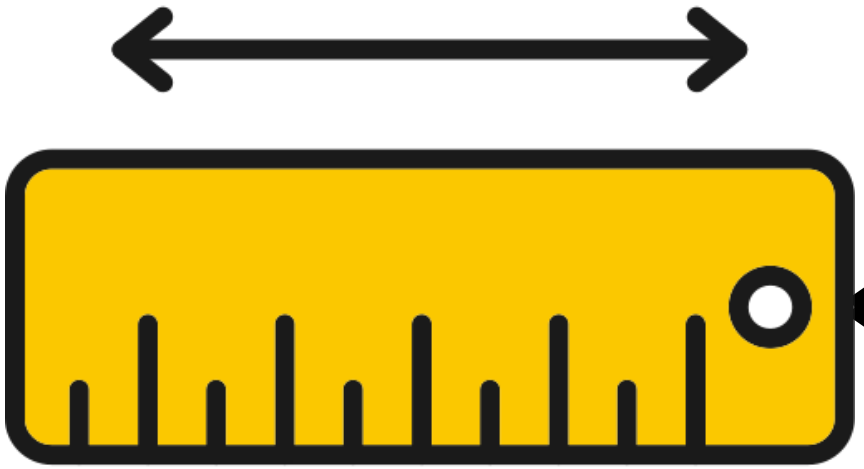


Clinical Practice

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

QOL using PROs

PRO Measurement



Research

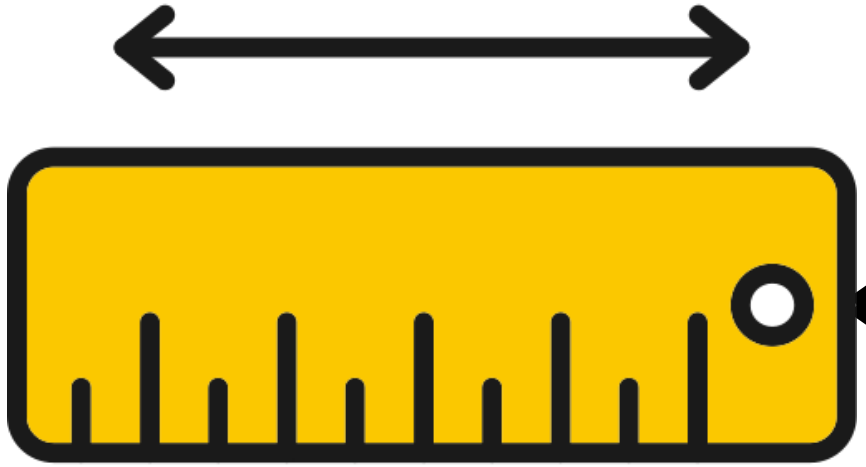
Clinical Practice

"Any report of the status of patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else." – FDA, 2009

CIBMTR
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

QOL using PROs

PRO Measurement



Research

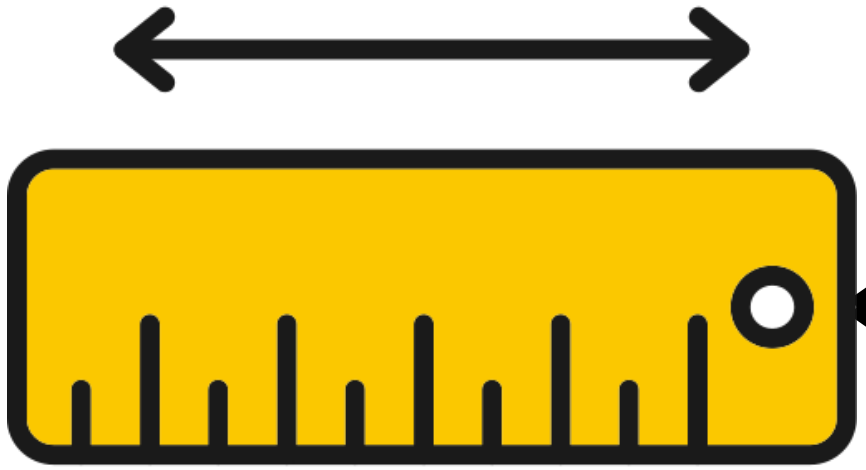
- ✓ Understand burden of disease and quality of life after treatment
- ✓ Understand treatment impacts beyond clinical endpoints

Clinical Practice

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

QOL using PROs

PRO Measurement



Research

Clinical Practice

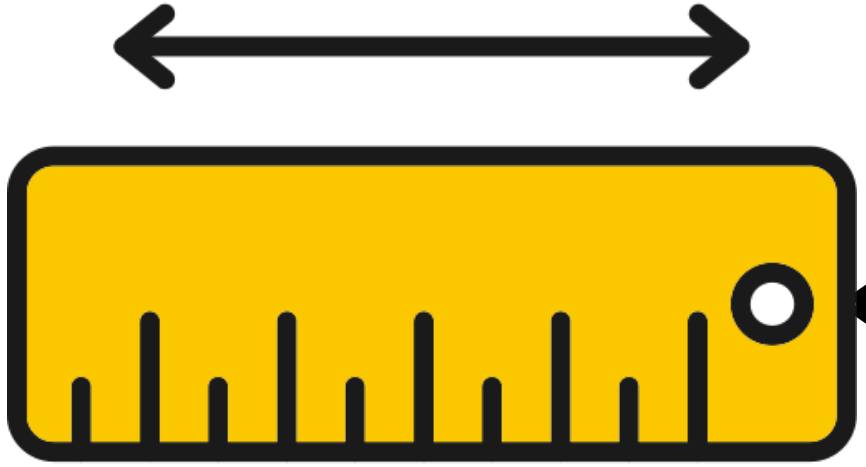
- ✓ Improve patient satisfaction
- ✓ Improve patient-provider communication
- ✓ Improve survival/QoL

Fayers & Machin 2016; Shi et al. 2016; Cleeland et al. 2011; Basch 2017; Basch et al. 2016

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

QOL using PROs

PRO Measurement



Clinical Practice

- ✓ Improve patient satisfaction
- ✓ Improve patient-provider communication
- ✓ Improve survival/QoL

Fayers & Machin 2016; Shi et al. 2016; Cleeland et al. 2011; Basch 2017; Basch et al. 2016

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Promises and Pitfalls to PROs

Promises

- **Understand burden of disease, QOL**
- Better indicator of some symptoms
- Improves patient/provider communication, patient satisfaction
- Remotely monitor patient symptoms
- **Able to compare across patient populations**

Pitfalls

- Too many different measures, difficult to compare
- Missing data
- **Likely biased (patients well enough and alive to complete PRO)**
- **Potential patient burden**
- **Require resources**

Promises

- Understand burden of disease, QOL
- Better indicator of some symptoms
- Improves patient/provider communication, patient satisfaction
- Remotely monitor patient symptoms
- Able to compare across patient populations

Pitfalls

- Too many different measures, difficult to compare
- Missing data
- Likely biased (patients well enough and alive to complete PRO)
- Potential patient burden
- Require resources

Despite the Pitfalls of PROs…

Table 2. Survey responses by stakeholder group regarding patient reported outcome (PRO) data collection after hematopoietic stem cell transplantation and cell therapy.

	All respondents ($n = 813$)	HCPs ($n = 351$)	Patients ($n = 278$)	*P* value
Importance of PRO data collection				0.14
Extremely/Quite	777 (95.7%)	330 (94.3%)	269 (96.8%)	
Neutral/Not so/Not at all	35 (4.3%)	20 (5.7%)	9 (3.2%)	
Missing	1	1	0	

Schoemans, Hélène, Linda J. Burns, Sarah J. Liptrott, John Murray, Michelle Kenyon, Anna Barata, Natacha Bolaños et al. "Patient engagement in hematopoietic stem cell transplantation and cell therapy: a survey by the EBMT patient engagement task force & transplantation complications working party." *Bone marrow transplantation* 59, no. 9 (2024): 1286-1294.

Biology of Blood and Marrow Transplantation
Volume 24, Issue 6, June 2018, Pages 1111-1118

Report

Engaging Patients in Setting a Patient-Centered Outcomes Research Agenda in Hematopoietic Cell Transplantation

Linda J. Burns [1], Beatrice Abbetti [2], Stacie D. Arnold [3], Jeffrey Bender [4], Susan Doughtie [5], Areej El-Jawahiri [6], Gloria Gee [4], Theresa Hahn [7], Mary M. Horowitz [8], Shirley Johnson [7], Mark Juckett [9], Lakshmanan Krishnamurit [10], Susan Kullberg [11], C. Fred LeMaistre [12], Alison Loren [13], Navneet S. Majhail [14], Elizabeth A. Murphy [1], Doug Rizzo [8], Alva Roche-Green [15], Wael Saber [8]… Ellen M. Denzen [1]

Physical Health and Fatigue	• Adopt the PROMIS measures of Fatigue and Physical Function across prospective studies • Adopt assessment time points of pre-HCT, day +100; 1, 2, and 5 years post-HCT; and beyond (frequency to be determined)

PRO Reviews

Transplantation and Cellular Therapy
Volume 27, Issue 5, May 2021, Pages 390.e1-390.e7

Cellular Therapy

Patient-Reported Outcomes for Cancer Patients with Hematological Malignancies Undergoing Chimeric Antigen Receptor T Cell Therapy: A Systematic Review

Mona Kamal [1], Jacinth Joseph [2], Uri Greenbaum [2], Rachel Hicklen [3], Partow Kebriaei [2], Samer A. Srour [2 †], Xin Shelly Wang [1 †]

Bone Marrow Transplantation (2016) **51,** 1173–1179

www.nature.com/bmt

REVIEW

Can we agree on patient-reported outcome measures for assessing hematopoietic cell transplantation patients? A study from the CIBMTR and BMT CTN

BE Shaw[1], SJ Lee[2], MM Horowitz[1], WA Wood[3], JD Rizzo[1] and KE Flynn[4]

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

› Biol Blood Marrow Transplant. 2019 Jan;25(1):e5-e16. doi: 10.1016/j.bbmt.2018.09.030. Epub 2018 Oct 8.

Positive Psychological Constructs and Health Outcomes in Hematopoietic Stem Cell Transplantation Patients: A Systematic Review

Hermioni L Amonoo [1], Margot E Barclay [2], Areej El-Jawahri [3], Lara N Traeger [2], Stephanie J Lee [4], Jeff C Huffman [2]

Affiliations + expand

PMID: 30308327 DOI: 10.1016/j.bbmt.2018.09.030

Sign in

Biology of Blood and Marrow Transplantation
Volume 23, Issue 4, April 2017, Pages 538-551

Reports

National Institutes of Health Hematopoietic Cell Transplantation Late Effects Initiative: The Patient-Centered Outcomes Working Group Report

Margaret Bevans [1], Areej El-Jawahri [2], D. Kathryn Tierney [3], Lori Wiener [4], William A. Wood [5], Flora Hoodin [6], Erin E. Kent [7], Paul B. Jacobsen [8], Stephanie J. Lee [9], Matthew M. Hsieh [10], Ellen M. Denzen [11], Karen L. Syrjala [9]

› Qual Life Res. 2023 Apr;32(4):939-964. doi: 10.1007/s11136-022-03258-0. Epub 2022 Oct 6.

Patient-reported cognitive function among hematopoietic stem cell transplant and cellular therapy patients: a scoping review

Rachel Cusatis [1 2], Joanna Balza [3], Zachary Uttke [4], Vishwajit Kode [5], Elizabeth Suelzer [6], Bronwen E Shaw [7], Kathryn E Flynn [7 5]

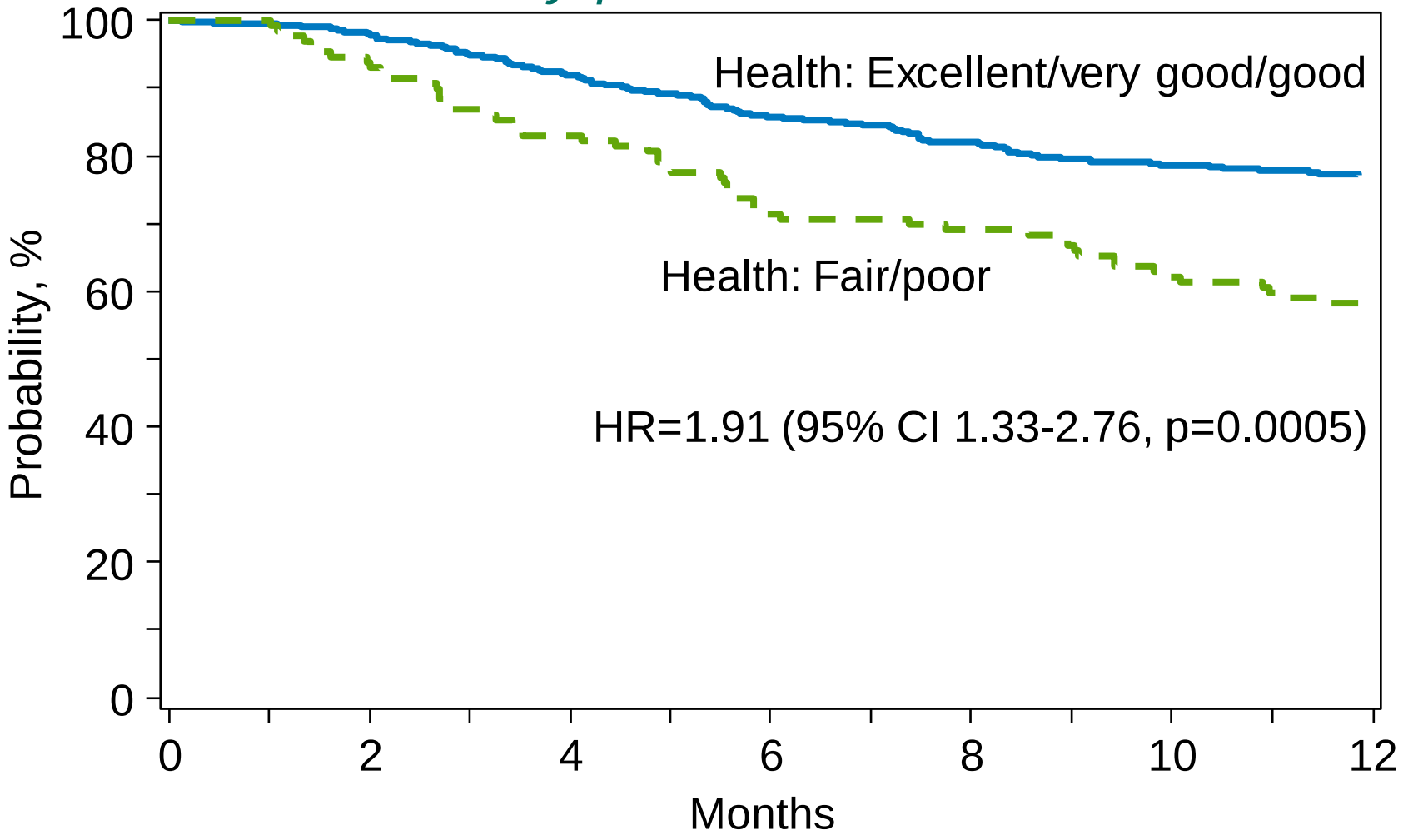
Affiliations + expand

PMID: 36203005 PMCID: PMC10259487 DOI: 10.1007/s11136-022-03258-0

Pre-HCT QOL & post-HCT QOL

Pre-HCT QOL predicting Outcomes

Overall Survival by pre-HCT General Health Status



Shaw, Bronwen E., Kathryn E. Flynn, Naya He, Rachel Cusatis, Anita D'Souza, Betty K. Hamilton, Mary M. Horowitz et al. "Incorporating patient-reported outcome data into a predictive calculator for allogeneic hematopoietic cell transplantation recipients." *Cancer* 130, no. 10 (2024): 1826-1835.

QOL & Age post-HCT

QOL & Age post-HCT

Received: 19 July 2022 | Revised: 3 October 2022 | Accepted: 12 October 2022

DOI: 10.1002/ajh.26768

RESEARCH ARTICLE

Health-related quality of life in reduced-intensity hematopoietic cell transplantation based on donor availability in patients aged 50–75 with advanced myelodysplastic syndrome: BMT CTN 1102

Rachel Cusatis[1] | Michael J. Martens[1,2] | Ryotaro Nakamura[3] | Corey S. Cutler[4] | Wael Saber[1] | Stephanie J. Lee[1,5] | Brent R. Logan[1,2] | Bronwen E. Shaw[1] | Alyssa Gregory[6] | Anita D'Souza[1] | Betty K. Hamilton[7] | Mary M. Horowitz[1] | Kathryn E. Flynn[1]

[1]CIBMTR® (Center for International Blood and Marrow Transplant Research), Department of Medicine, Medical College of Wisconsin, Milwaukee, Wisconsin, USA

[2]Division of Biostatistics, Institute for Health and Equity, Medical College of Wisconsin, Milwaukee, Wisconsin, USA

[3]Department of Hematology & Hematopoietic Cell Transplantation, City of Hope, Duarte, California, USA

[4]Division of Stem Cell Transplantation and Cellular Therapy, Dana-Farber Cancer Institute, Boston, Massachusetts, USA

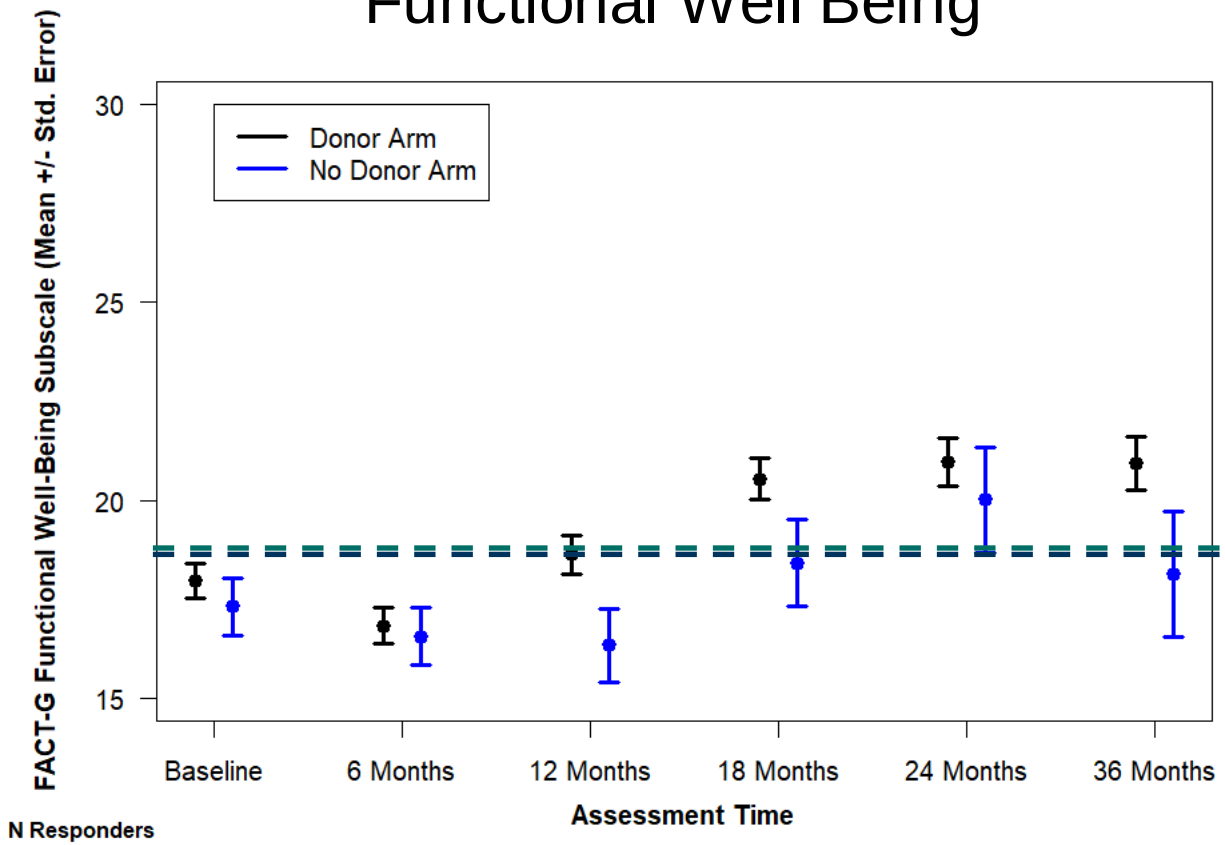
[5]Fred Hutchinson Cancer Center, Seattle, Washington, USA

[6]Emmes Company, Rockville, Maryland, USA

[7]Blood & Marrow Transplant Program, Cleveland Clinic Taussig Cancer Institute, Cleveland, Ohio, USA

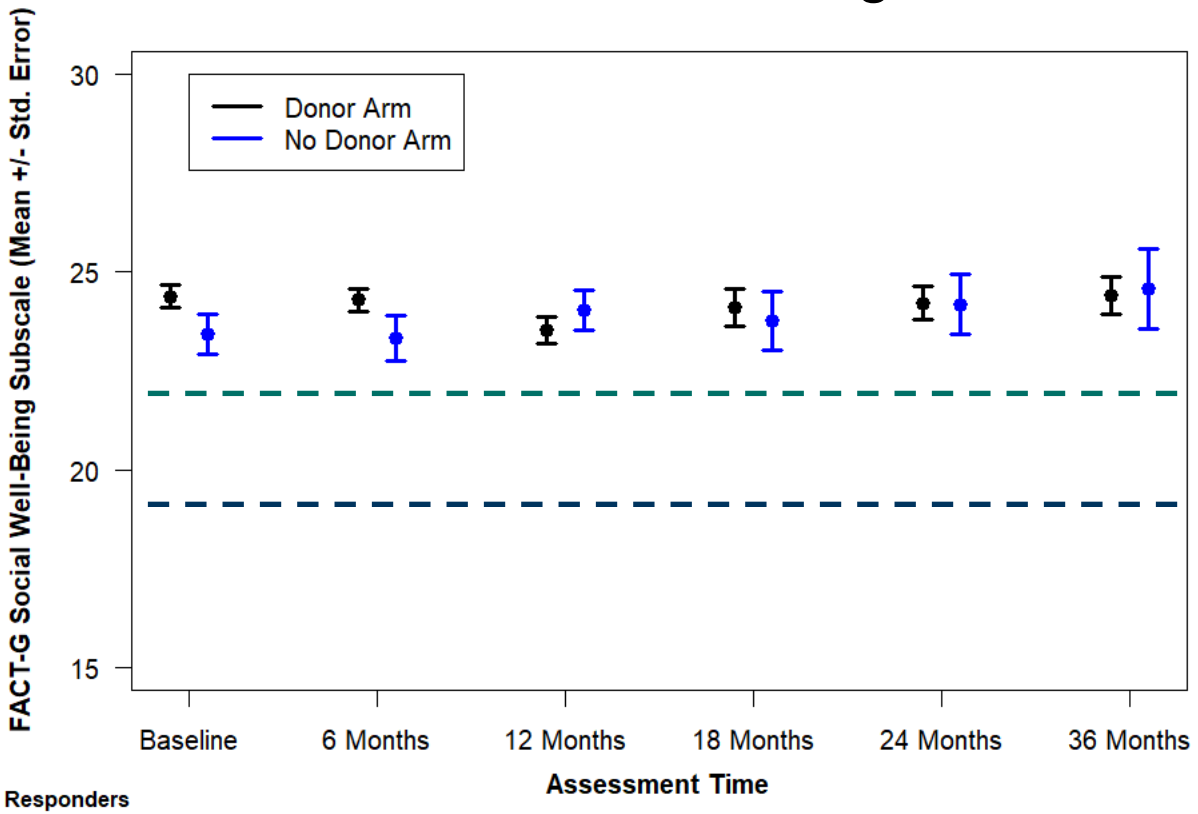
QOL & Age post-HCT

Functional Well Being



N Responders	Baseline	6 Months	12 Months	18 Months	24 Months	36 Months
Donor Arm	204	174	135	107	93	78
No Donor Arm	85	69	45	36	27	19

Social Well Being



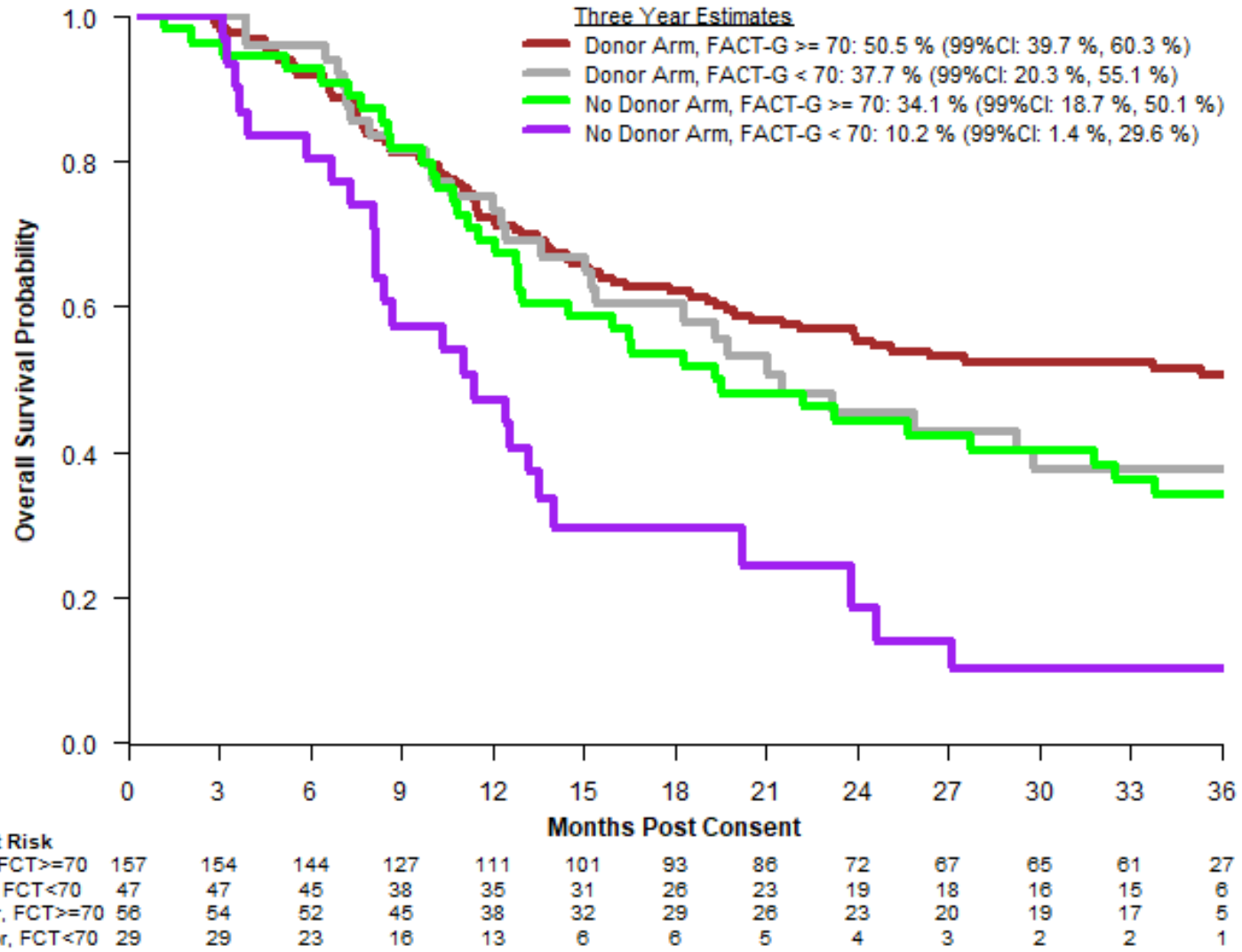
N Responders	Baseline	6 Months	12 Months	18 Months	24 Months	36 Months
Donor Arm	205	174	135	107	93	78
No Donor Arm	85	70	46	35	27	18

CIBMTR
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Cusatis, Rachel, Michael J. Martens, Ryotaro Nakamura, Corey S. Cutler, Wael Saber, Stephanie J. Lee, Brent R. Logan et al. "Health-related quality of life in reduced-intensity hematopoietic cell transplantation based on donor availability in patients aged 50–75 with advanced myelodysplastic syndrome: BMT CTN 1102." *American journal of hematology* 98, no. 2 (2023): 229-250.

QOL & Age post-HCT

QOL Associations with OS – FACT-G



CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

QOL & Age post-HCT

Quality of life, physical functioning, & psychological distress in older adults undergoing HCT

Adults, including older adults, may benefit from augmented supportive care during HCT

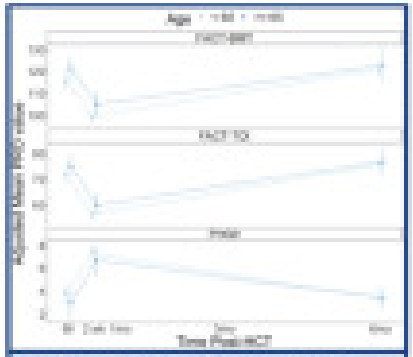
Aim: describe trajectory of QOL, physical functioning and psychological distress of older adults post HCT

Methods: secondary data analysis

Older age: ≥ 65

At 2 weeks, older adults experience significant decrement in QOL and physical functioning and increase in psychological distress during HCT

Older adults with baseline psychological distress or impaired performance status at higher risk of lower pre-HCT quality of life



No difference in trajectory of QOL, physical functioning, and psychological distress between older and younger adults

ASTCT Transplantation and Cellular Therapy

Newcomb et al, 2023

@rnewcomb3

ELSEVIER

Transplantation and Cellular Therapy

Volume 29, Issue 6, June 2023, Pages 387.e1-387.e7

Full Length Article

Supportive Care

Quality of Life, Physical Functioning, and Psychological Distress of Older Adults Undergoing Hematopoietic Stem Cell Transplantation

Richard Newcomb [1], P. Connor Johnson [1], Katherine Cronin [1], Joanna J. Choe [1], Katherine Holmbeck [1], Anisa Nabily [1], Porsha Lark [1], Dustin J. Rabideau [2 3], Zachariah DeFilipp [1], Yi-Bin Chen [1], Areej El-Jawahri [1]

Show more

Add to Mendeley Share Cite

https://doi.org/10.1016/j.jtct.2023.03.017

Get rights and content

QOL & Age post-HCT

- Young adults (YA; 18-39) had worse mental QOL and more cancer-related distress compared to older adults
- YA had slightly better physical QOL
- YA had lower levels of health self-efficacy

ELSEVIER

Transplantation and Cellular Therapy

Go to Transplantation and Cellular Therapy on ScienceDirect

Volume 28, Issue 10, October 2022, Pages 701.e1-701.e7

Full Length Article

Survivorship

Health-Related Quality of Life in Young Adult Survivors of Hematopoietic Cell Transplantation

Seth J. Rotz [1 2], Jean C. Yi [3], Betty K. Hamilton [2], Wei Wei [4], Jaime M. Preussler [5], Jan Cerny [6], Abhinav Deol [7], Heather Jim [8], Nandita Khera [9], Theresa Hahn [10], Shahrukh K. Hashmi [11], Shernan Holtan [12], Samantha M. Jaglowski [13], Alison W. Loren [14], Joseph McGuirk [15], Jana Reynolds [16], Wael Saber [17], Bipin N. Savani [18], Patrick Stiff [19], Joseph Uberti [7]...Karen L. Syrjala [3]

Summary: QOL & Age post-HCT

- Receiving HCT among older adults with MDS did not come at the detriment of QOL
- Older patients experienced similar QOL trajectories to younger patients, generally returning to baseline levels
- Younger patients may experience worse mental QOL post-HCT and more cancer-related distress compared to older patients

QOL & PTCy post-HCT

QOL & PTCy post-HCT

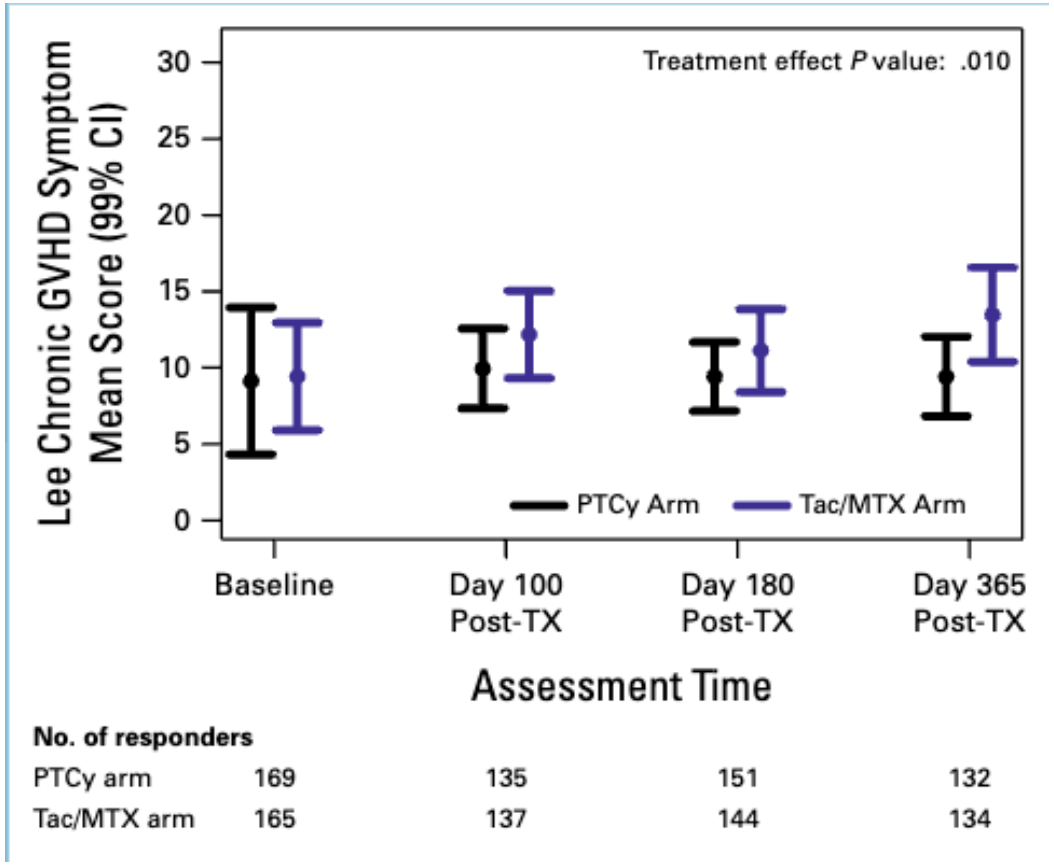
Clinical Trial Updates

Improved Patient-Reported Outcomes With Post-Transplant Cyclophosphamide: A Quality-of-Life Evaluation and 2-Year Outcomes of BMT CTN 1703

Shernan G. Holtan, MD[1]; Javier Bolaños-Meade, MD[2]; Monzr M. Al Malki, MD[3]; Juan Wu, PhD[4]; Carrie L. Kitko, MD[5]; Ran Reshef, MD[6]; Andrew R. Rezvani, MD[7]; Brian C. Shaffer, MD[8,9]; Melhem M. Solh, MD[10]; Janny M. Yao, PharmD[11]; Lyndsey Runaas, MD[12]; Hany Elmariah, MD[13]; Karilyn T. Larkin, MD[14]; Najla El Jurdi, MD[15]; Mahasweta Gooptu, MD[16]; Alison W. Loren, MD[17]; Aric C. Hall, MD[18]; Amin M. Alousi, MD[19]; Omer Jamy, MD[20]; William Clark, MD[21]; Leslie Kean, MD, PhD[22]; Ami S. Bhatt, MD[23]; Miguel-Angel Perales, MD[8,9]; Kristy Applegate, MBA[4]; Yvonne Adeduni Efebera, MD, MPH[24]; Eric Leifer, PhD[25]; Richard J. Jones, MD[2]; Mary M. Horowitz, MD[26,27]; Deborah Mattila, MD[28]; Wael Saber, MD[27]; Mehdi Hamadani, MD[27]; and Michael J. Martens, PhD[26,29]

DOI https://doi.org/10.1200/JCO.24.00921

Holtan, Shernan G., Javier Bolaños-Meade, Monzr M. Al Malki, Juan Wu, Carrie L. Kitko, Ran Reshef, Andrew R. Rezvani et al. "Improved patient-reported outcomes with post-transplant cyclophosphamide: a quality-of-life evaluation and 2-year outcomes of BMT CTN 1703." *Journal of Clinical Oncology* 43, no. 8 (2025): 912-918.



QOL & PTCy post-HCT

blood®

Volume 146, Supplement 1, 3 November 2025, Page 6042

Poster

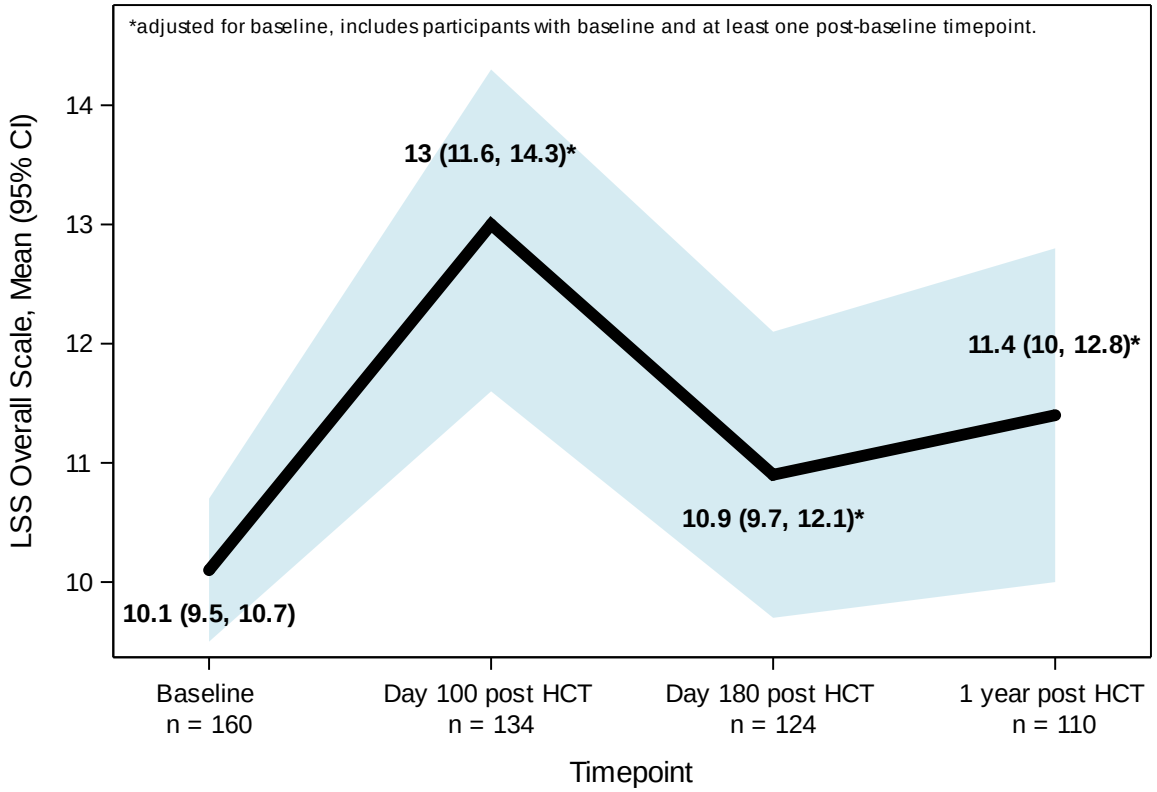
723. Allogeneic Transplantation: Long-term Follow-up, Complications, and Disease Recurrence

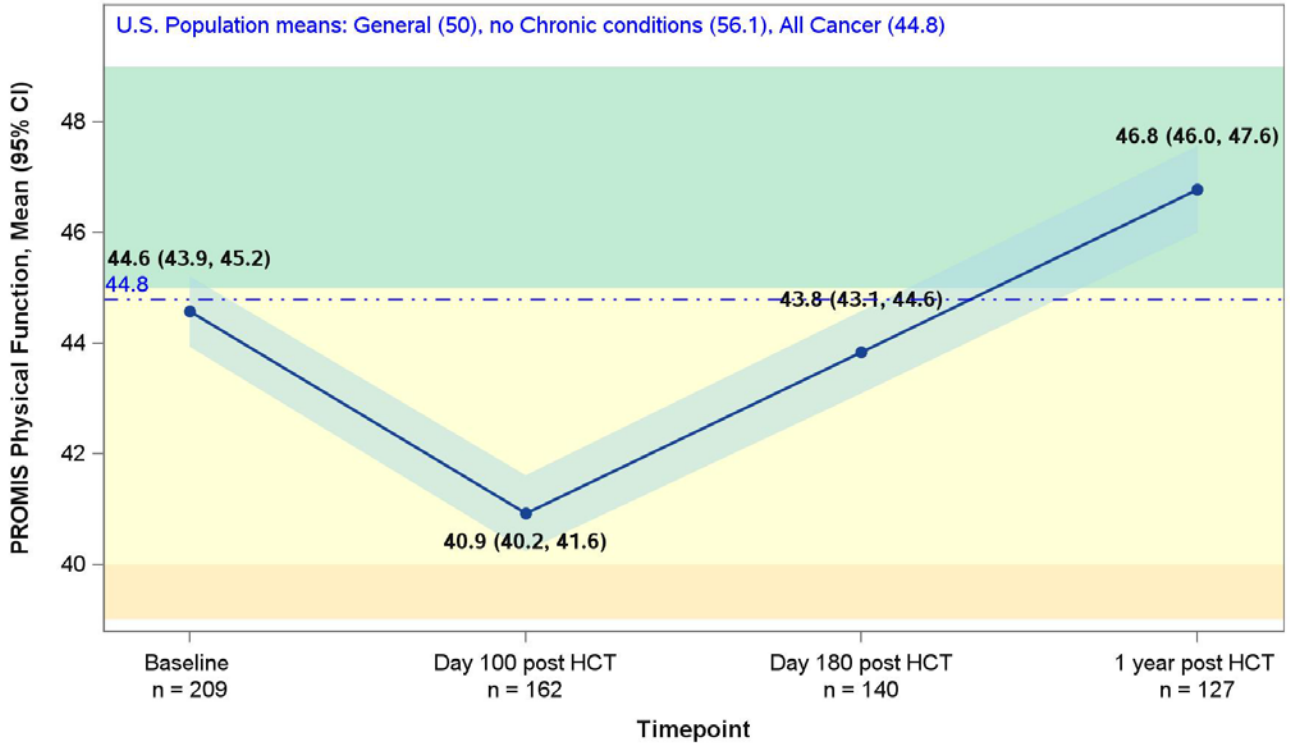
Living the recovery: One-year qol outcomes for patients receiving ptcy gvhd prophylaxis on the access clinical trial

Rachel Cusatis [1], Jianqun Kou [2], Juan (Maggie) Wu [2], Caitrin Bupp [2], Deborah Mattila [2], Sarah Smith [2], Kathryn Flynn [1], Jeffery Auletta [2], Steven Devine [2], Brent Logan [1 3], Bronwen Shaw [1]

Cusatis, Rachel, Jianqun Kou, Juan Maggie Wu, Caitrin Bupp, Deborah Mattila, Sarah Smith, Kathryn Flynn et al. "Living the recovery: One-year qol outcomes for patients receiving ptcy gvhd prophylaxis on the access clinical trial." *Blood* 146 (2025): 6042.

QOL & PTCy post-HCT





Summary: QOL & PTCy post-HCT

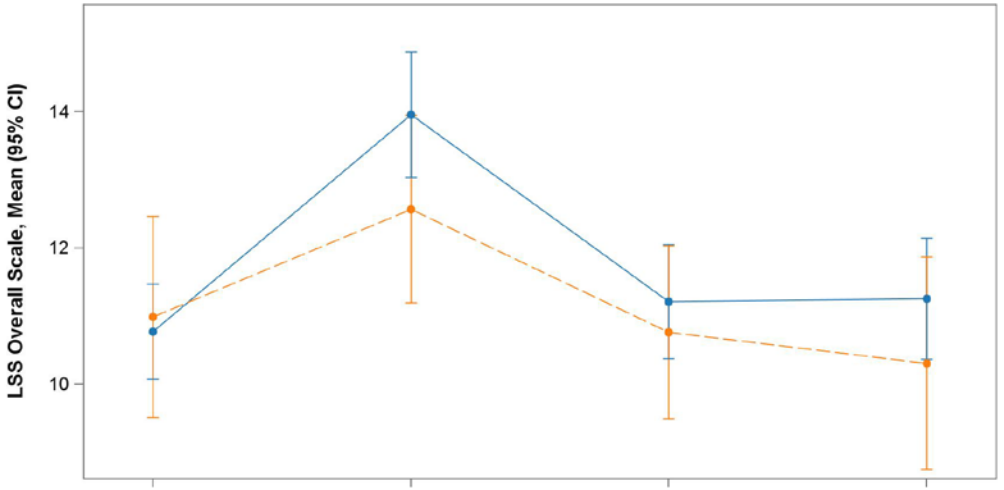
- Patients receiving PTCy had significantly better QOL at 1-year post-HCT compared to Tac/MTX

- Patients receiving PTCy returned to baseline QOL, which was similar to general US population norms

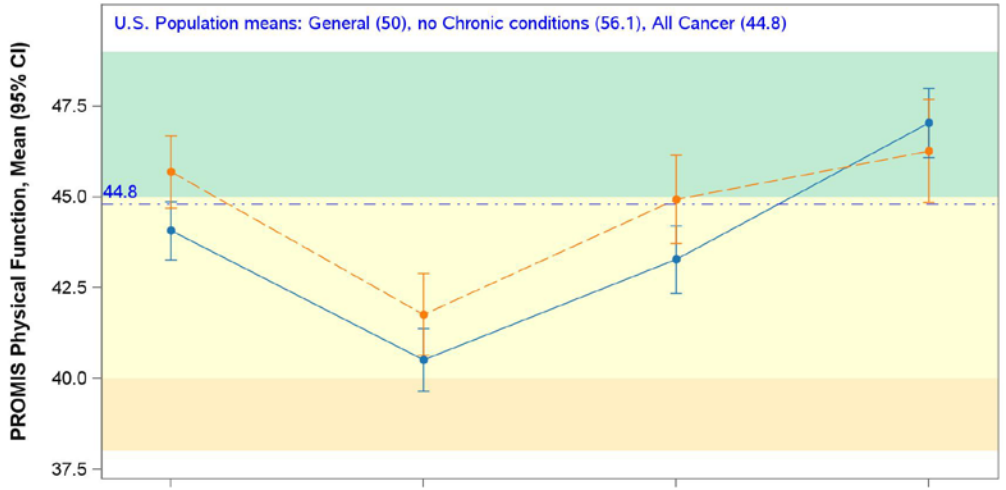
QOL & HLA Mismatch post-HCT

QOL & HLA mismatch post-HCT

- The ACCESS trial (NCT04904588) was designed to test a strategy which broadens access to HCT by enrolling patients lacking matched donors using post-transplant cyclophosphamide (PTCy) based GVHD



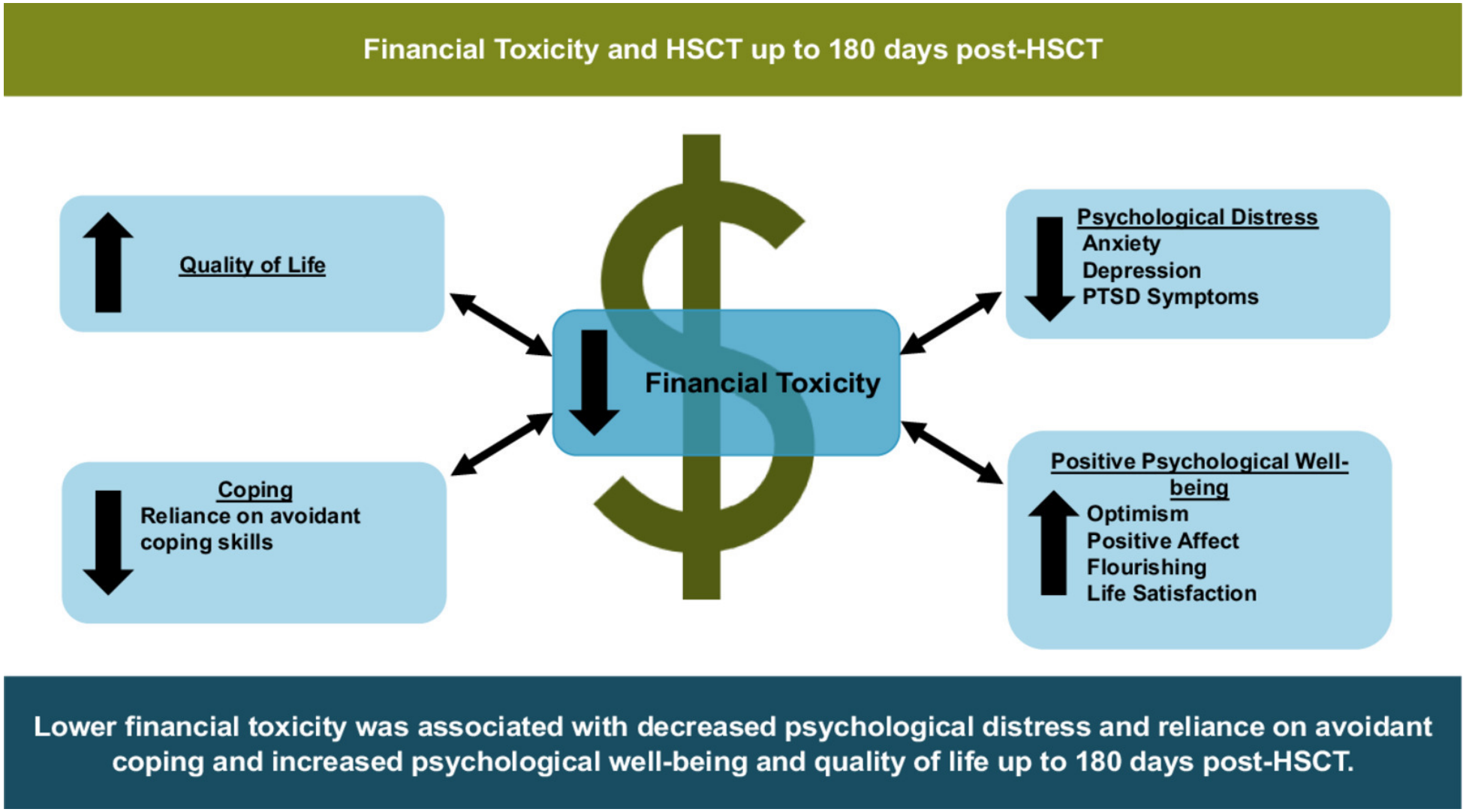
	Baseline	Day 100 post HCT	Day 180 post HCT	1 year post HCT
Count				
7/8	139	106	94	86
<7/8	64	51	47	40
Mean (95% CI)				
7/8	10.8 (10.1, 11.5)	14.0 (13.0, 14.9)	11.2 (10.4, 12.1)	11.3 (10.4, 12.1)
<7/8	11.0 (9.5, 12.5)	12.6 (11.2, 13.9)	10.8 (9.5, 12.0)	10.3 (8.7, 11.9)



	Baseline	Day 100 post HCT	Day 180 post HCT	1 year post HCT
Count				
7/8	144	110	93	86
<7/8	65	52	47	41
Mean (95% CI)				
7/8	44.1 (43.3, 44.9)	40.5 (39.7, 41.4)	43.3 (42.3, 44.2)	47.0 (46.1, 48.0)
<7/8	45.7 (44.7, 46.7)	41.8 (40.6, 42.9)	44.9 (43.7, 46.2)	46.3 (44.9, 47.7)

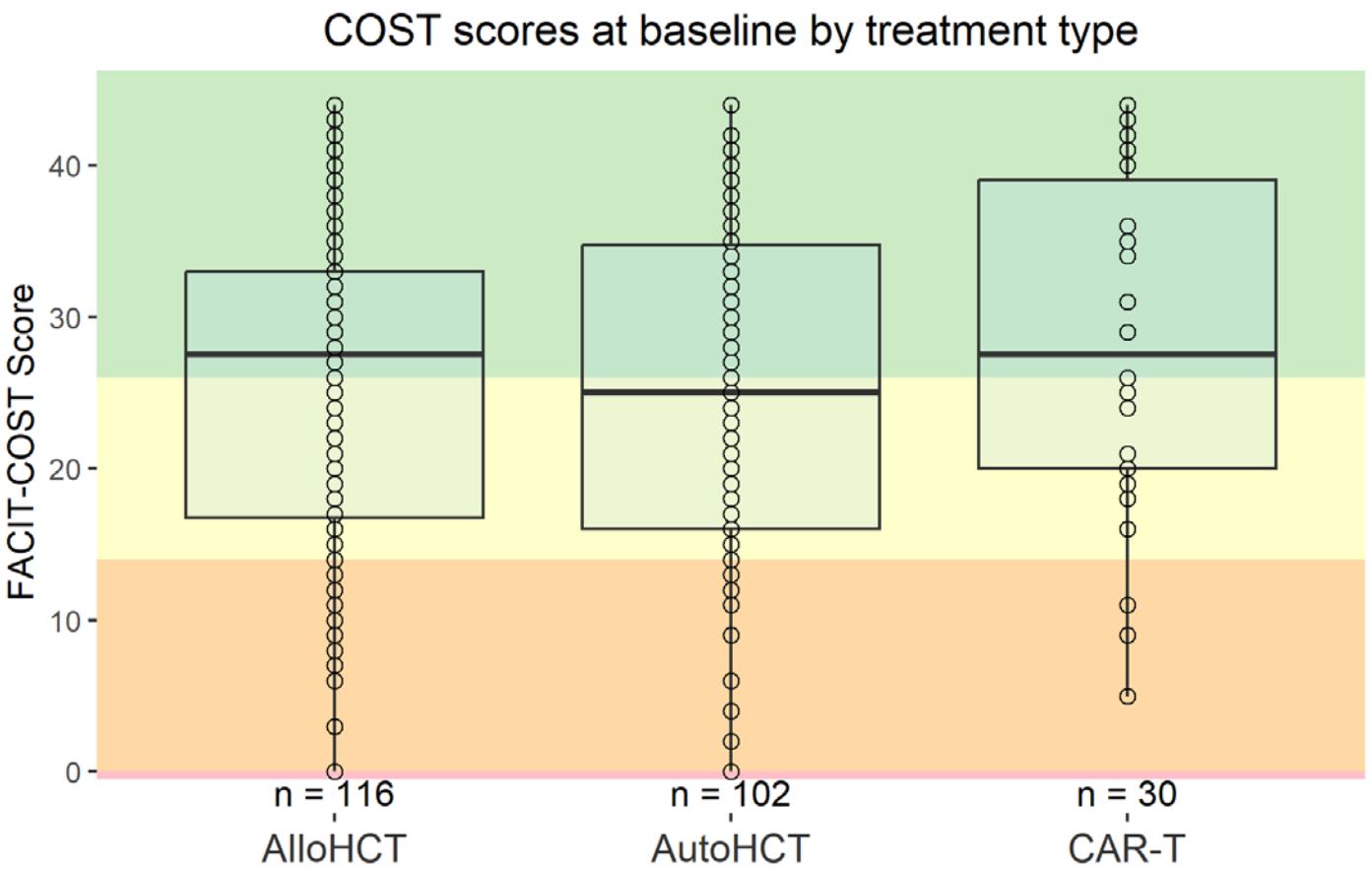
QOL & Financial Well-being post-HCT

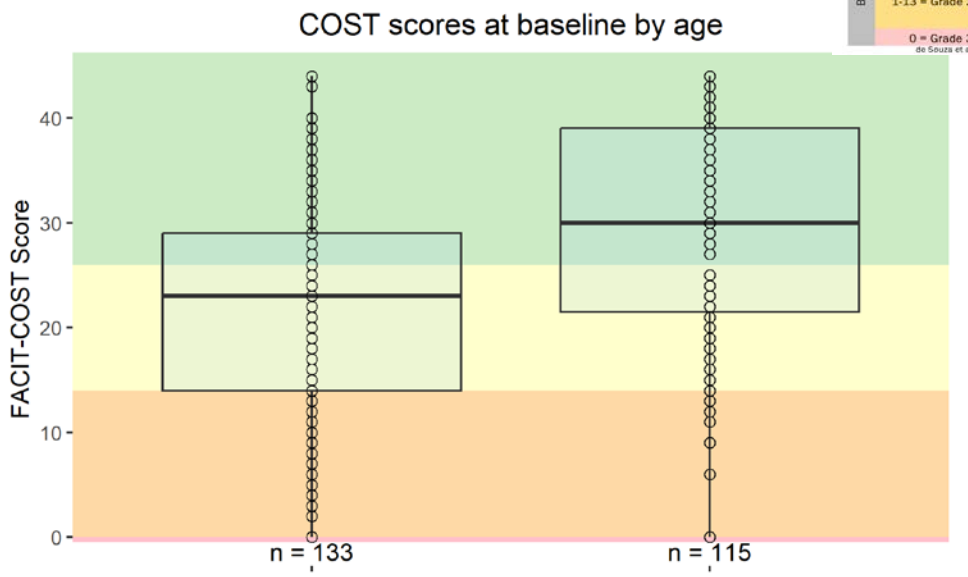
QOL & Financial Toxicity post-HCT

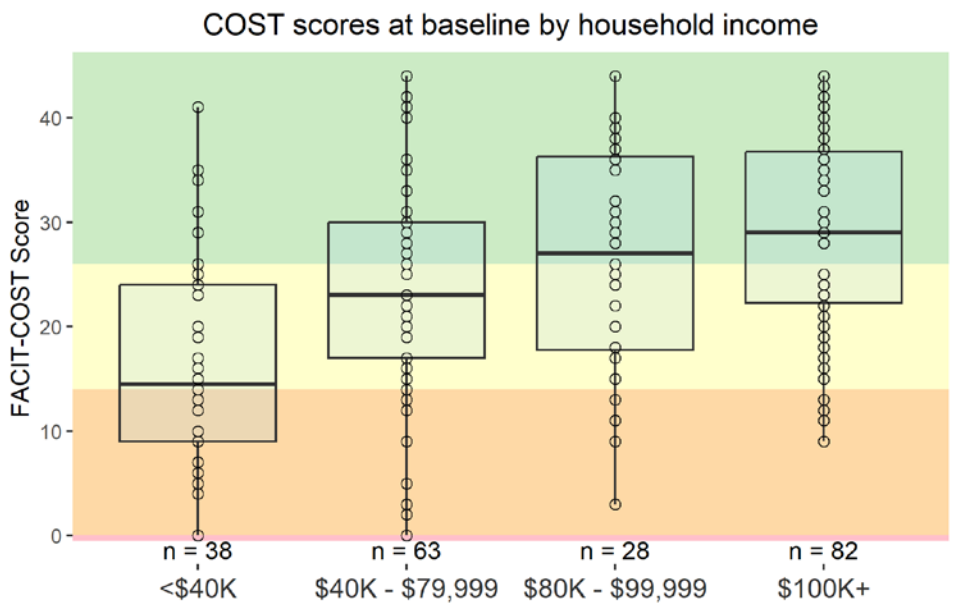


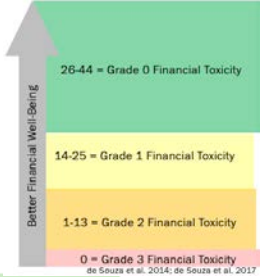
Schaefer DA, Longley RM, Wolfe ED, Keane EP, Larizza IS, Boardman AC, Rosenberg J, Mate-Kole M, Waldman LP, Majhail N, Lee SJ, Khera N, Amonoo HL. Financial Toxicity, Psychological Well-Being, and Quality of Life in Hematopoietic Stem Cell Transplantation. Transplant Cell Ther. 2025 Nov;31(11):936.e1-936.e10. doi: 10.1016/j.jtct.2025.08.012. Epub 2025 Aug 18. PMID: 40829691.

QOL & Financial Toxicity post-HCT









Cusatis, Rachel, Jianqun Kou, Caitrin Bupp, Michelle Kuxhausen, Deborah Matilla, Idayat M. Akinola, Miranda Kapfhammer et al. "Patient Reported Financial Toxicity Pre-Infusion for Adult Transplantation and Cellular Therapy Recipients: Results from CIBMTR PRO Data Collection." *Transplantation and Cellular Therapy, Official Publication of the American Society for Transplantation and Cellular Therapy* 31, no. 2 (2025): S369-S370.

CIBMTR
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Summary: QOL & Financial Toxicity post-HCT

- Patients experience financial toxicity pre & post-HCT
- Financial toxicity is associated with significantly worse QOL, worse coping, and increased psychological distress among HCT patients
- Financial toxicity impacts some patients more than others, particularly younger, racial/ethnic minorities, and lower income patients

Answering Mr. & Mrs. Brewer

How long will it take to feel like himself again?

We see patients returning to baseline physical, cognitive, and social functioning by 1-year post-HCT, in some cases as early as D180.

Will he be able to manage his hardware business after the transplant, including stocking shelves and doing the accounting?

If you are well enough and able to stock those shelves and do your accounting now, that is a good indication you may be able to return to those shelves and books by 1-year post-HCT.

Will transplant be expensive?

Yes, but that expense impacts people and families differently, often dependent on income, health insurance, and other factors. *And we have financial navigators available to help*.

Burns, Linda J., Beatrice Abbetti, Stacie D. Arnold, Jeffrey Bender, Susan Doughtie, Areej El-Jawahiri, Gloria Gee et al. "Engaging patients in setting a patient-centered outcomes research agenda in hematopoietic cell transplantation." *Biology of Blood and Marrow Transplantation* 24, no. 6 (2018): 1111-1118.

Acknowledgments

- Thank you to…
  - Patients who consent to observational and prospective research
  - Transplant centers who support the mission of the CIBMTR by providing data

- CIBMTR Funding:

Questions?

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

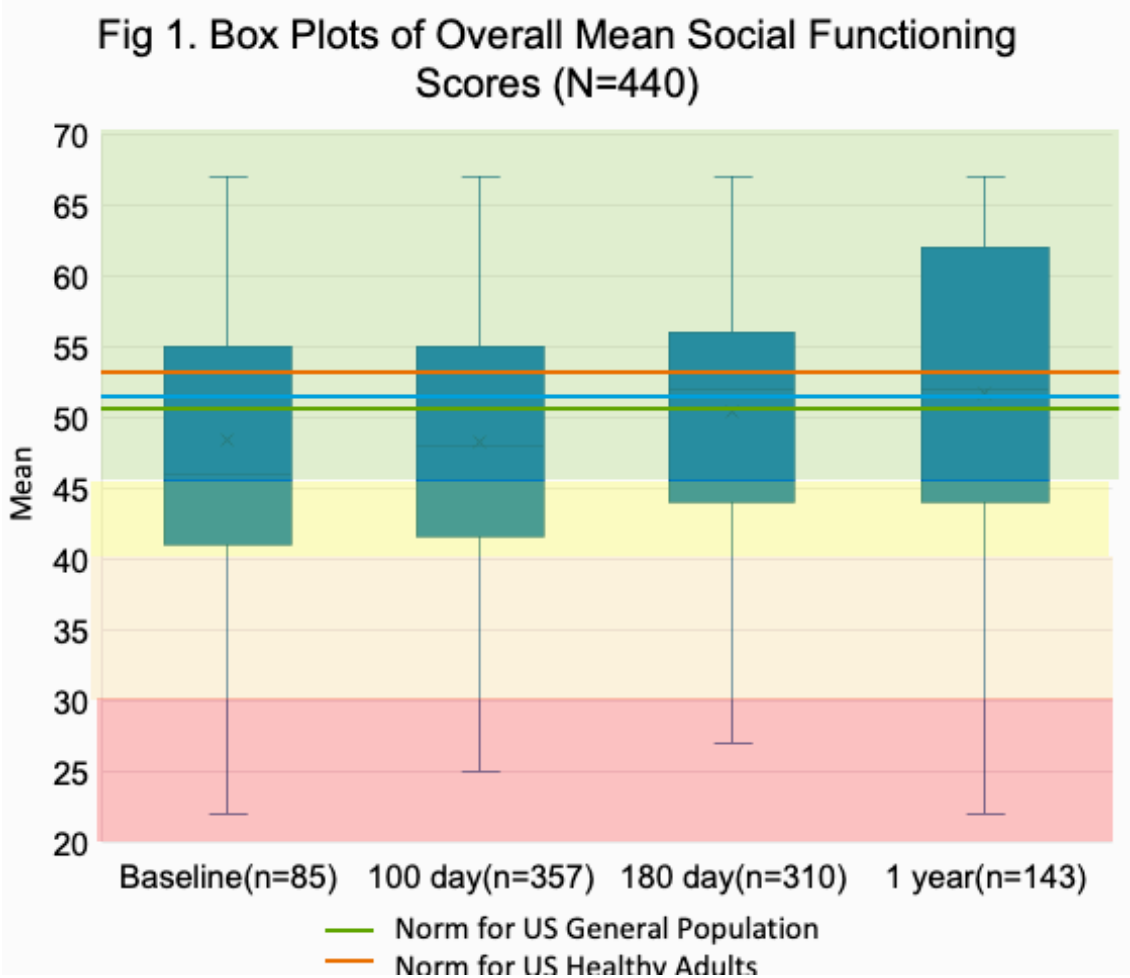
Thank you

rcusatis@mcw.edu

Extra Slides

CIBMTR's PRO Collection

- Compare HCT patients to general population and cancer norms
- Social functioning on average is lowest at D100 and returns to baseline levels at 1 year



CIBMTR
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Cusatis R, Ndifon E, Mattila D, Berman L, Akinola I*, Kapfhammer M, Jacox C, Luetke C, Hamilton BK, Muffly L, Negrin RS, Shaughnessy P, Shaw BE, Flynn KE, Social Functioning after Transplantation and Cellular Therapy: Initial Patient-Reported Outcomes Results from the CIBMTR. Poster Presentation, Tandem Transplantation and Cellular Therapy Meeting from ASTCT & CIBMTR, Orlando, FL, 02/15/2023 – 02/18/2023

CIBMTR's PRO Collection

- Compare clinical trial patient characteristics to general HCT in US

- *Compared to patients enrolled on the PRO protocol, ACCESS trial participants were of significantly:*
  - *lower educational attainment (26% v. 7%)*
  - *lower personal income (21% v. 37%)*
  - *closer distance to transplant centers (28 miles v. 48miles)*

CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Yusuf, RA, Ndifon E, Silverman T, Bankole L, Mattila D, Olson J, Kuxhausen M, Bupp C, Devine SM, Auletta JJ, Shaw BE, Cusatis, R, Social Determinants fo health, Disease and Traetment Related Characteristics of Access Clinical Trial Participants. Poster Presentation, Tandem Transplantation and Cellular Therapy Meeting from ASTCT & CIBMTR, San Antonio, TX, 02/21/2024 – 02/24/2024

http://nihpromis.org/

PROMIS®

Dynamic Tools to Measure Health Outcomes from the Patient Perspective

About PROMIS® | Measures | Science | Software | What's New | Related Resources | PROMIS® For You | Search

Patient Reported Outcomes Measurement Information System (PROMIS), funded by the National Institutes of Health (NIH), is a system of highly reliable, valid, flexible, precise, and responsive assessment tools that measure patient–reported health status.

Researchers

Provides efficient, reliable, and valid assessments of adult and child (pediatric) self–reported health

- PROMIS Instruments Selected References
- PROMIS In Research

Clinicians

Provides data about the effect of therapy that cannot be found in traditional clinical measures

- PROMIS for Clinicians
- Select Publications
- Computer Adaptive Test (CAT) Demonstration

Patients

Measures what you are able to do and how you feel

- More on PROMIS
- What Patient Reported Outcomes (PROs) are
- PROMIS Measures

Contact PROMIS | Policies | Accessibility | FAQs | Glossary | File Formats | Site Map | PROMIS Researcher Login

USA.gov

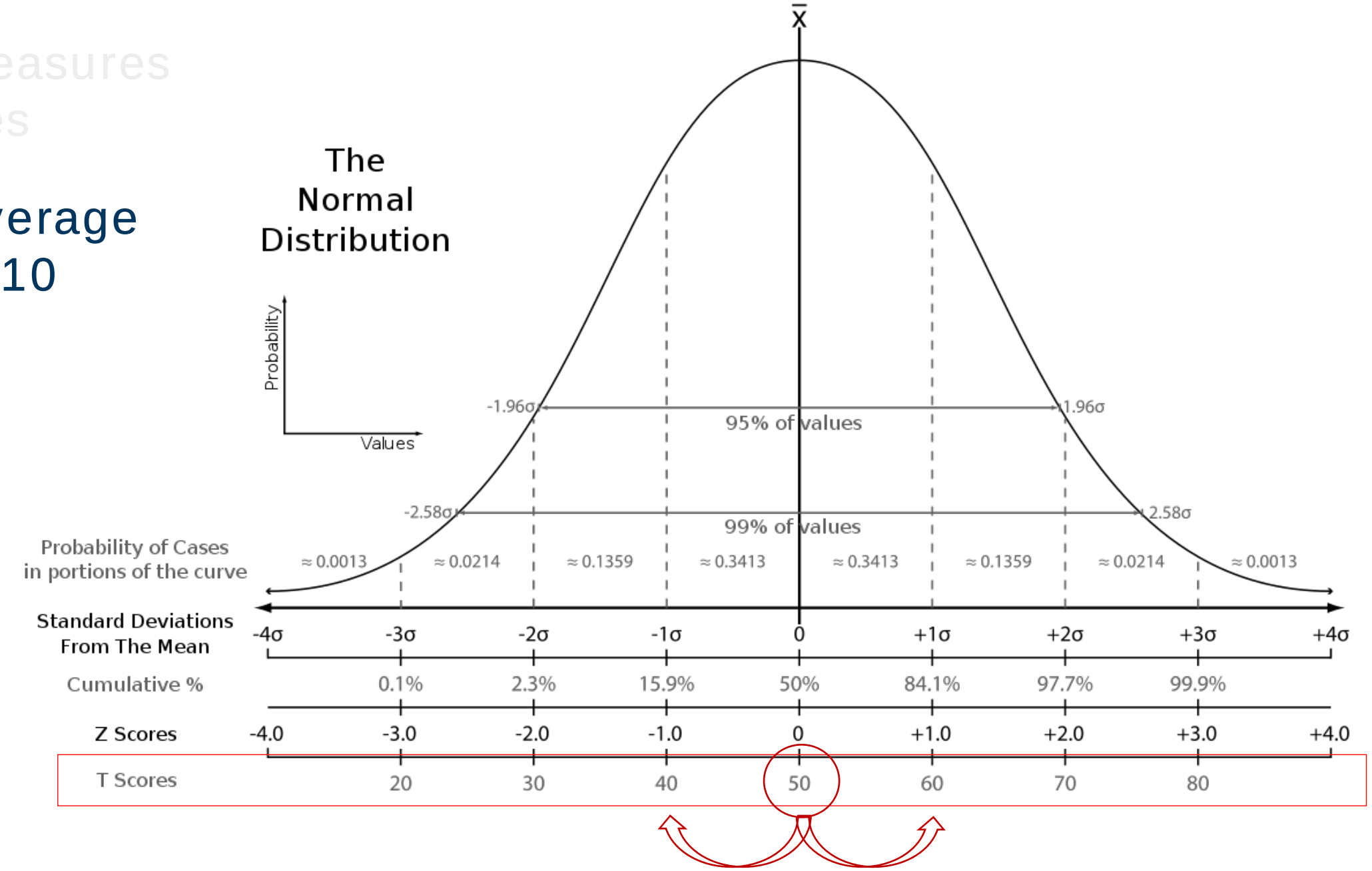
CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP

Why PROMIS was Created

- Publicly available, high-quality measures
- Adults and children
- Based on qualitative and modern psychometric methods
  - Allows more confidence in measurement across diverse populations
- Generic item banks set on a standard metric
  - Compare patient outcomes across disease states
  - Compare outcomes for patients with multiple conditions
  - Compare to other measures
- Reduce patient burden

PROMIS measures use T-scores

50 is US average with SD of 10



Higher Scores = Better Well-Being

Physical Function

Cognitive Function

Ability to Participate in Social Roles

Sexual Function

Higher Scores = Worse Well-Being

Depression

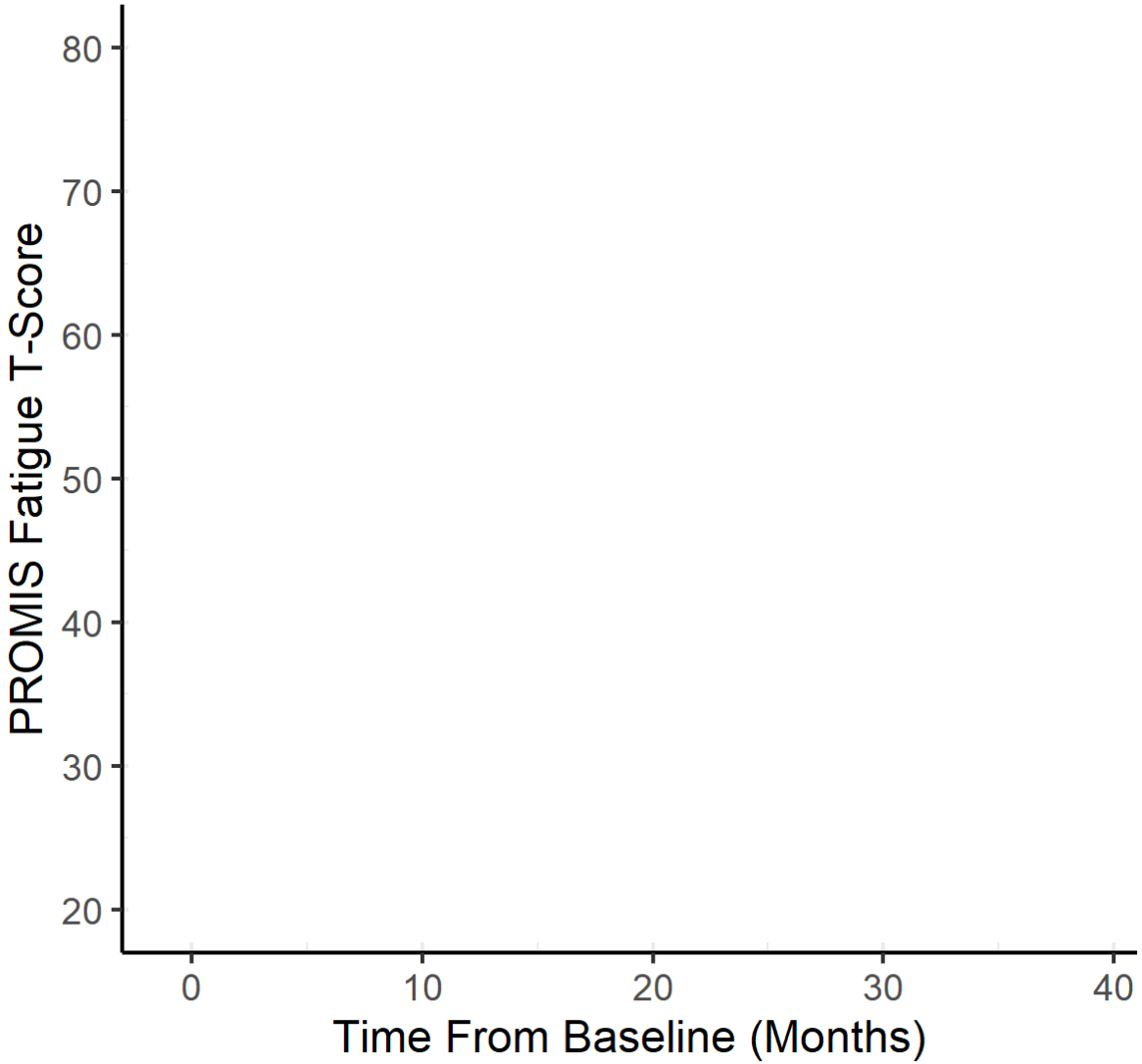
Anxiety

Pain Interference

Sleep Disturbance

Fatigue

PROMIS Domains



CIBMTR®
A RESEARCH COLLABORATION BETWEEN THE MEDICAL COLLEGE OF WISCONSIN AND NMDP