INTRODUCTION

- Federally-funded Hemophilia Treatment Centers (HTCs) are increasingly called to demonstrate how they achieve national public health benchmarks in health promotion, quality of life, and health literacy to improve outcomes and costs.

- The Hemophilia Utilization Group Study (HUGS) is one of the longest prospective longitudinal US cohort hemophilia studies. The 20-year-old study monitors quality, costs, outcomes and access among children, their caregivers and adults with hemophilia (FVIII) and B (FIX) who receive care at HTCs. Originally a study of five California HTCs, HUGS now collects data from 32 geographically diverse HTCs serving eleven states through the US.

- Healthy People 2020 (HP 2020) is a US federal government effort that articulates science-based, 10-year objectives to stimulate health improvements for all American individuals and communities. US HTCs are required to conduct activities to achieve HP 2020 objectives.

OBJECTIVES

- Present HUGS major contributions to monitoring hemophilia-related achievement of selected US health priorities outlined in the National Action Plan to Increase Health Literacy and Healthy People 2020, such as blood disorders and safety, chronic pain, adolescent health; physical activity; disability; health literacy, absenteeism, and access to care;

- Illustrate the impact of HUGS to patient self-reported outcomes, health-related quality of life (HRQoL); barriers to care, joint range of motion limitation and burden of illness;

- Highlight HUGS contributions to understanding variation in the determinants of and indirect costs of hemophilia care; clinical service utilization; and the impact of insurance coverage on access to care;

- Demonstrate HUGS contributions to monitoring changes in access, quality, insurance-related costs and employment.

METHODOLOGY: 20 YEARS OF HUGS RESEARCH PUBLICATIONS AND FINDINGS DOCUMENT COST, QUALITY, AND OUTCOMES

HUGS FINDINGS ON COSTS AND RELATED HEALTHY PEOPLE 2020 OBJECTIVES

HUGS 1998: The mean annual cost of hemophilia care among a sample of 336 California residents with FVIII treated at HTCs was calculated to be $139,102.00. Clinical and demographic characteristics significantly associated with these costs included severity, inhibitor status and severity, status, age, and insurance type.

HUGS 2003: Total health care costs found to be positively correlated with comorbid medical conditions such as HIV and joint arthropathy. Managed care contracts places physicians at financial risk for the care of patients, incentivizing providers to focus on short-term outcomes with the potential cost of diminished health status in the long term. Risk adjustment for complications should be considered by policy makers in the financing of hemophilia treatment.

HUGS 2009: Among 198 children and adults with severe FVIII, those using prophylaxis were less likely to have an emergency room visit if they used prophylaxis (p<0.03). Those using prophylaxis reported less severe joint pain and motion limitation than those who were not. Patients were more likely to use prophylaxis if they or their parents had full or part-time employment, more than 12 years of education or annual income greater than $20,000.


HUGS 2011: 20% of adult FVIII patients or parents of affected children stayed in a less desirable job in order to maintain comprehensive care, affecting 40% of adults with FVIII; 27% of 329 adults and children reported difficulty finding adequate insurance coverage; 40% reported not having full coverage for hemophilia-related medical care. 90% of those reporting insurance difficulties were adults with hemophilia. Of 329 adults and children, 40% reported not having full coverage for prescription drugs.

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HUGS 2012: Mean annual indirect costs for mild to severe FIX among parents and adults range from $47 to $10,734 and $132 to $1,308, respectively. All levels of severity showed a large range of annual indirect costs. Lost wages from missed work and working part time being unemployed due to FIX are the major drivers of total indirect costs of hemophilia.

HUGS 2012: Objective to Increase Employment in Persons with Disabilities (DH 16) – Increase the % of persons with disabilities who are employed to 21.1%

HUGS 2013: The unemployment rate among 444 persons with FVIII & FIX was 21% for adults and 16% for the parents of children with hemophilia estimated at 3.63 million dollars annually. The unemployment rate was significantly higher among those with F VIII compared to F IX. 46% of parents or parents of affected children worked full-time; 20% worked part time and 32% were unemployed. 64% of the unemployed reported being able to work. HP 2020 Objective to Reduce Unemployment in Persons with Disabilities (DH 18) – Reduce unemployment among persons with disabilities to 13.1%

HUGS offers clinicians and researchers opportunities to characterize longitudinal and prospective trends in quality, outcomes and costs. HUGS cohort data, and its commitment to disease-agnostic measures, can help describe determinants and variations of access to new therapies and practice innovations.

HUGS data provides unique information on clinician and patient-reported outcomes, HRQoL and costs to patients, providers and policy-makers, all of whom face the challenges of a rapidly changing and dynamic health care environment. HUGS contributions to the research literature provide an excellent resource for monitoring achievement of more than ten Healthy People 2020 objectives among patients obtaining care at Hemophilia Treatment Centers.

CONCLUSION

- Present HUGS major contributions to monitoring hemophilia-related achievement of selected US health priorities outlined in the National Action Plan to Increase Health Literacy and Healthy People 2020, such as blood disorders and safety, chronic pain, adolescent health; physical activity; disability; health literacy, absenteeism, and access to care;

- Illustrate the impact of HUGS to patient self-reported outcomes, health-related quality of life (HRQoL); barriers to care, joint range of motion limitation and burden of illness;

- Highlight HUGS contributions to understanding variation in the determinants of and indirect costs of hemophilia care; clinical service utilization; and the impact of insurance coverage on access to care;

- Demonstrate HUGS contributions to monitoring changes in access, quality, insurance-related costs and employment.

REFERENCES

15. HUGS 2011: For 164 children ages 2-14 with hemophilia A, quality of life scores were similar to the healthy US population: 85.9
16. HUGS 2012: For 165 children ages 2-14 with hemophilia A, quality of life scores were similar to the healthy US population: 85.9
17. HUGS 2013: In 82 adults with FIX ages 15-64, 68% achieved the recommended PA level. Youngest adults (18-24 yrs.)
18. HUGS 2014: In 156 adults with FVIII, 9.2% reported no pain, 22.1% reported pain with joint bleed, 30.0% reported some pain, 24.4% reported moderate pain and 21.4% reported pain all the time.
19. HUGS 2015: In the last decade, the % unable to or who are limited in work has decreased from 50% to 20% in women and from 70% to 25% in men.
20. HUGS 2016: Objective on Disability & Health (DH 15, 16, 18) – Reduce proportion reporting serious psychological distress.
21. HUGS 2017: For 39 children with FIX, 12% with mild and 5% with severe disability.
22. HUGS 2018: Objective on Adolescent Health (AH 5.6) – Reduce school absenteeism among adolescents due to illness or injury. National baseline for excessive absenteeism = 5% of all US children age 12-17 miss >10 days in past 12 months.
23. HUGS 2019: Excessive absenteeism: 12% of 91 children ages 5-17 with FVIII. For 39 children with FIX, 12% with mild and 5% with severe disability.
24. HUGS 2020: Objective on Physical Activity for Adults and Children (PA 2.3) – Increase proportion of adults who engage in aerobic PA of at least moderate intensity; increase proportion of adolescents who meet US guidelines for aerobic PA.
25. HUGS 2021: In 82 adults with FIX ages 15-64, 68% achieved the recommended PA level. Youngest adults (18-24 yrs.) engaged in the most minutes/week, dropping among those ages 25-34, up among those ages 35-44, then dropping in those older than 44 yrs.
26. HUGS 2022: In 53 children with FIX ages 5-14, 79% engaged in PA at least 4 days/week, on par with US adolescent population.
27. As activity increases, so does HRQoL among adults with FIX deficiency (SF-36 Physical component score).
28. Objective on Disability & Health (DH 15, 16, 18) – Reduce proportion reporting serious psychological distress.
29. HUGS 2011: For 164 children ages 2-14 with hemophilia A, quality of life scores were similar to the healthy US population: 85.9 total mean Pediatric score vs. 82.7 Healthy Children. Each additional bleeding episode, school absence, and emergency department visit during a 2-year period among 124 children with hemophilia A impacted mental health scores more than physical health scores.
30. HUGS 2012: For 157 adults ages 18-64 with FVIII, quality of life scores for mental health were similar to the general US population. Work absences among those employed full-time negatively impacted physical health scores more than mental health scores, but each additional missed day lowered mental health scores on the SF-12.
31. National Action Plan to Increase Health Literacy Baseline – 21% of US English-speaking adults have proficient health literacy skills.
32. HUGS 2010: 96% of children and 97% of adults with FIX deficiency gave the average number of correct responses for reading comprehension. 87.5% of children and adults obtained the mean number of correct answers for numeracy.