

# Perceived Ideal Roles of Hemophilia Treatment Center Social Workers in the United States and Barriers to those Roles

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## Background

Social Workers (SWs) play an important role in the multidisciplinary teams at the approximately 141 Hemophilia Treatment Centers (HTCs) across the United States. Little research has been done to identify:

- the roles that HTC SWs primarily perform (referred to as “actual roles”),
- the roles that HTC SWs feel are the most important for adult and pediatric patients and their families (referred to as perceived “ideal roles”).

## Objectives

- To identify the perceived “ideal roles” that HTC SWs feel are the most important for adult and pediatric patients and their families.
- To define the “actual roles” the HTC SWs are currently undertaking in their positions across the US.
- To determine associations between and barriers to the ideal roles that SWs feel should be practiced and those that are actually practiced.

## Methods

- An online survey, utilizing Survey Monkey, was created and emailed to 147 SWs at HTCs in the United States during December, 2015.
- Data on actual role responsibilities, perceived ideal roles and barriers to ideal roles were collected and summarized.
- Associations between demographics (age, sex, years of experience) and both ideal and actual roles were analyzed with chi-square tests.

## Role Definitions

For the purpose of this survey, HTC SW roles were defined as:

**Counseling:** Includes psychosocial assessments, individual, family, group, mental health, crisis, important grief and supportive counseling and support groups.

**Grants/ Research:** Work that involves managing MCHB and CDC grant projects, writing grants, grant reporting, creating budgets, conducting research and writing articles.

**Case management (excluding financial and insurance):** Includes information and referral services, discharge planning, patient and family education, networking and resource sharing, and documentation (medical records, electronic records, inter-and intra-agency communication, case notes, etc.) related to medical and health care needs.

**Financial and Insurance:** Includes all aspects of assisting patients and families in accessing, applying for, advocating for and communicating with various sources of insurance and benefits, such as health insurance providers, Medicare, Medicaid, Social Security programs, etc.

**Outreach/Programs:** Includes work generally done outside your institution such as community education, home and school visits, speaking engagements and presentations, program development, advocacy, lobbying, fundraising and working with chapters, creating/publishing newsletters, websites and other social media.

**Administrative:** Includes duties involved in a PHS/340B Hemophilia Factor Program, data and oversight of ATHN Clinical Manager, registries, management (such as serving as the HTC Coordinator or supervisor), working groups (such as the SWWG, ATHN), and committees.

## Results

Figure 1. Ideal vs. Actual Roles Pediatric Patients

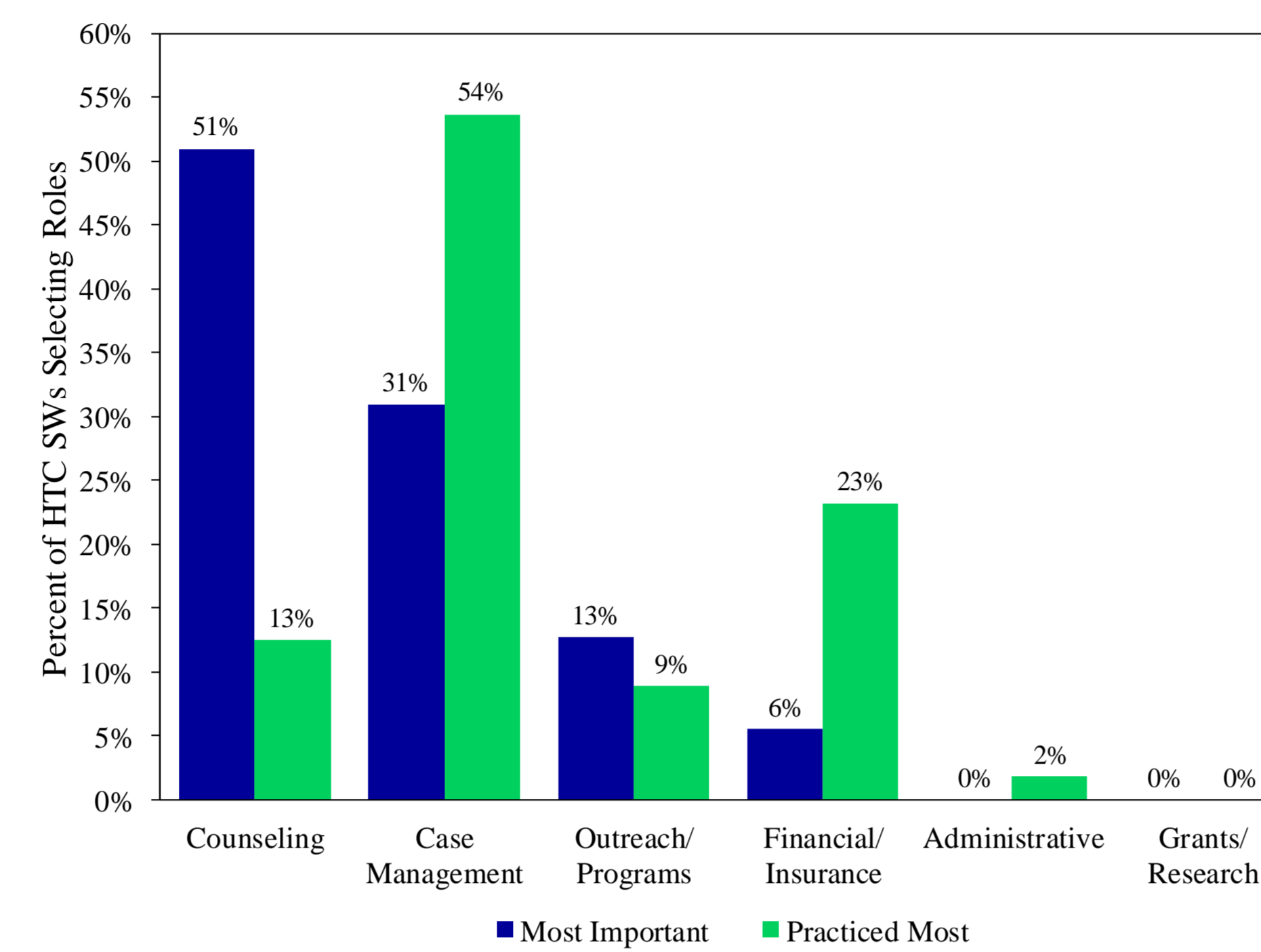


Figure 2. Ideal vs. Actual Roles Adult Patients

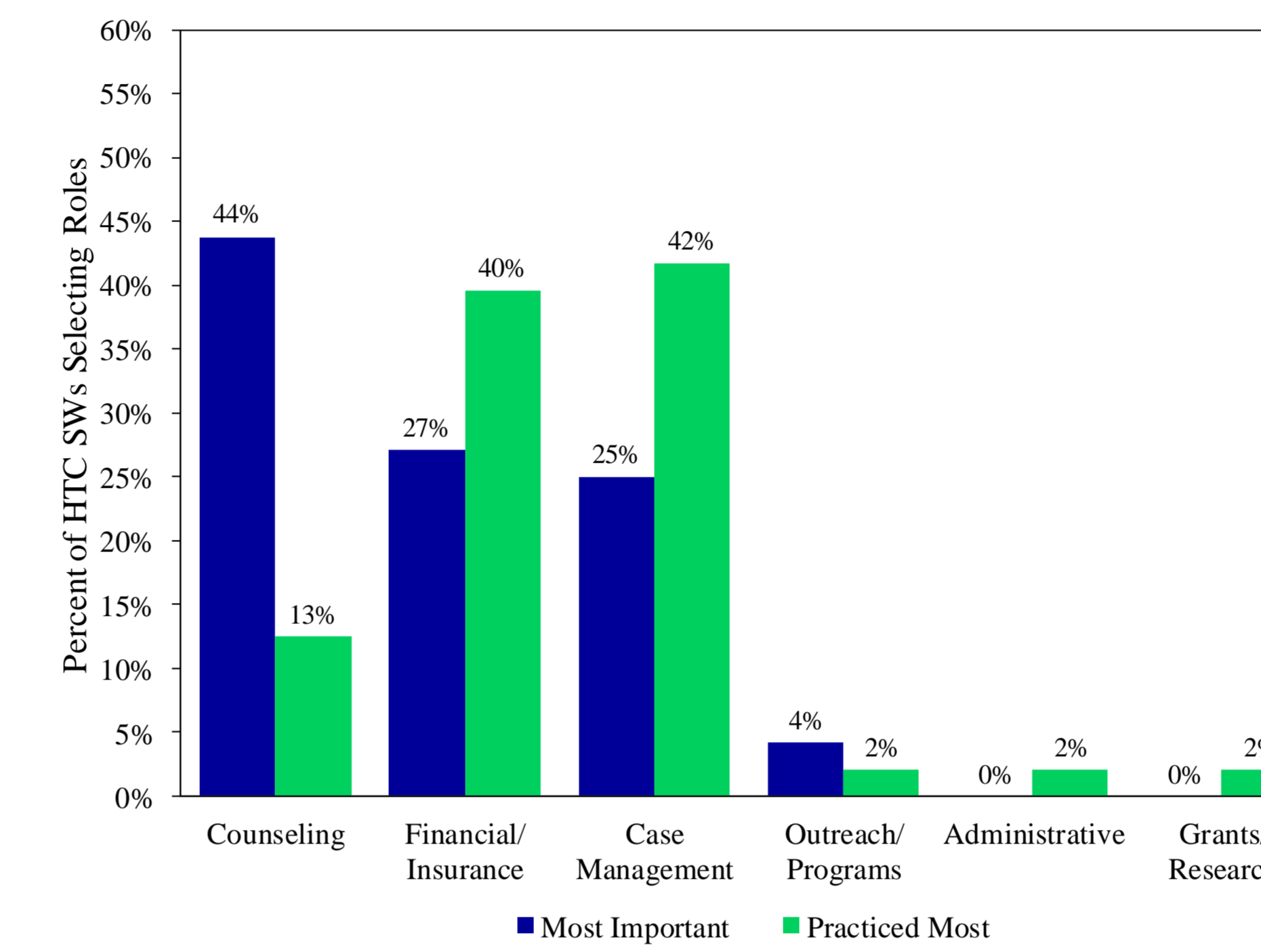


Figure 3. Ideal vs. Actual Roles Families

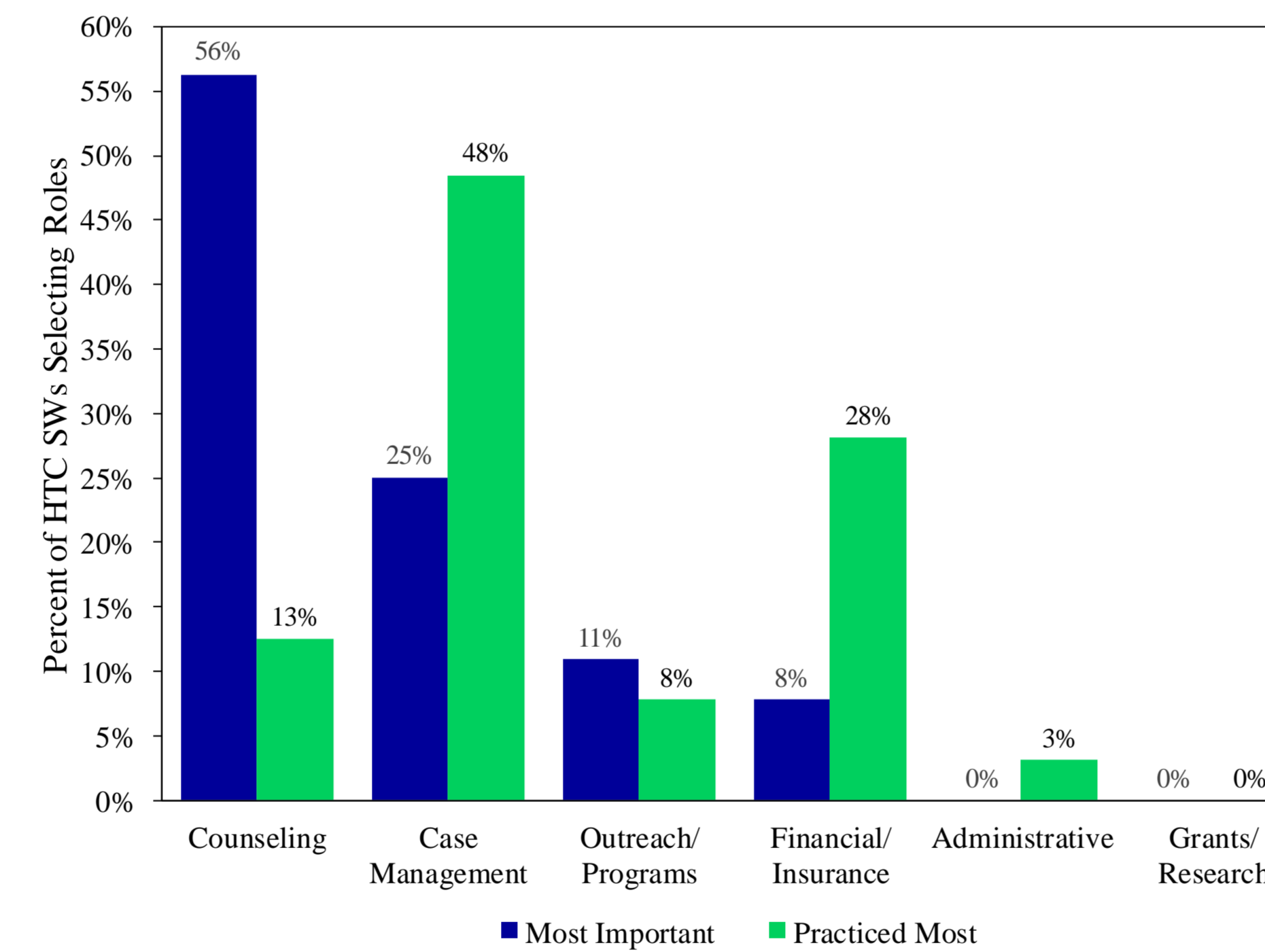


Figure 4. Overall Percent of SWs Ranking Role as Most Important

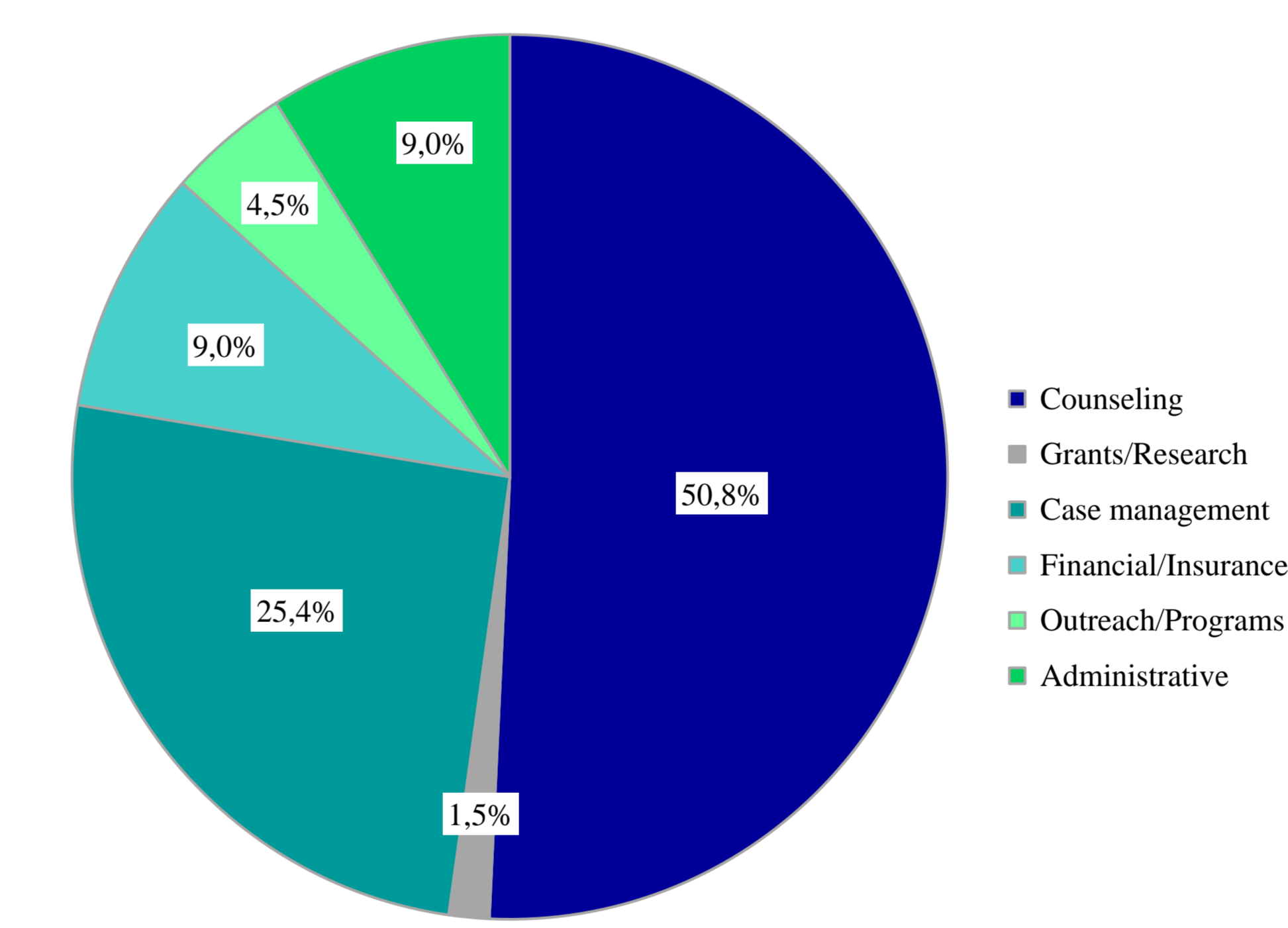


Table 1. Percent of SWs Identifying Roles as Not Being Met and Requiring More Training

Role/Responsibility	Role Not Being Met <sup>1</sup> No. (%) (n=69)	Need More Training <sup>2</sup> No. (%) (n=67)
Counseling	11 (15.9)	20 (29.0)
Case Management	1 (1.4)	3 (4.3)
Financial/Insurance	5 (7.2)	18 (26.1)
Outreach/Programs	19 (27.5)	11 (15.9)
Administrative	12 (17.4)	15 (21.7)
Grants/Research	25 (36.2)	32 (46.4)

<sup>1</sup>27.2% of SWs are meeting the needs of all roles

<sup>2</sup>11.6% of SWs do not need more training in any role

## Results Summary

- Of the 147 surveys emailed, 81 surveys were completed and returned, yielding a 55% response rate.
- Given the 6 categories of SW roles, all respondents noted that their responsibilities were comprised of a combination of 2 or more role types.
- For pediatric patients, adult patients, and families, SWs responded that the most important or “ideal” role is counseling; 50.8% ranked counseling first. However, only 13% of SWs indicated that they practice counseling the most.
- Case management is the second most important role for pediatric patients and families, while financial assistance is the second most important service for adult patients.
- The role practiced most by all SWs is case management; the roles practiced least are administration and grants/research.
- Almost 75% of SWs feel they are not meeting their patients’ or families’ needs in one or more roles.
- 88.2% of SWs feel that they need more training in one or more roles; almost half need more training in grants/research.
- Potential barriers to practicing ideal roles are lack of autonomy, a need for more SW hours, and a need for more training.
- There were no associations between SWs responses and any of the demographic variables analyzed.

## Conclusions

- There is a discrepancy between the “actual roles” that HTC SWs are undertaking and the “ideal roles” that these SWs believe they should be performing.
- This survey revealed that SWs believe that counseling is, by far, the most important SW role in HTCs across the nation.
- These results may be an impetus for the examination of SW roles and the elimination of barriers to the “ideal roles” that SWs should be performing:
  - SWs should advocate to determine their roles in HTCs.
  - SWs should advocate for enough budgeted SW hours to support the provision of clinical counseling and other SW role responsibilities.
  - SWs should request adequate training in the SW areas of priority, including counseling, financial issues, research, grant writing, etc.

## Literature Review and Bibliography

1. Wagner E. The role of patient care teams in chronic disease management. Br Med J 2000; 320: 569–72.
2. The demographics of the United States haemophilia treatment centre social workers: the results of a national survey. MK Geary, L McGeary, L Dunn, L Pennick, M Johnson, and A Stolfi. Haemophilia (2014), 1–6.

