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## Abstract

Social Workers (SWs) have been active members of the multi-disciplinary teams at Hemophilia Treatment Centers (HTCs) for many years. However, their roles may differ greatly from center to center. Social Workers advocate for patients, provide a variety of psychosocial and case management services, are a primary source of information and referral, and may provide counseling and therapy to patients and families, as well as consultation to staff. Despite being a vital HTC member, little research about the HTC SW role has been done. Since many HTC SWs work in isolation, it is important to define the job tasks they undertake and identify the variables which influence their roles.

## Goals/Objectives

- To describe the various roles tasks of the HTC Social Worker
- To identify the influences on the HTC Social Work role

## Methods

- An on-line survey was developed by a group of HTC Social Workers who received the **National Hemophilia Foundation's Social Work Excellence Grant** award.
- The survey was piloted with a group of former HTC Social Workers.
- A refined survey was e-mailed, in December 2015, to 147 HTC SWs through their regional Social Work Working Group representatives.
- Associations between demographics and roles were analyzed using chi-square tests.

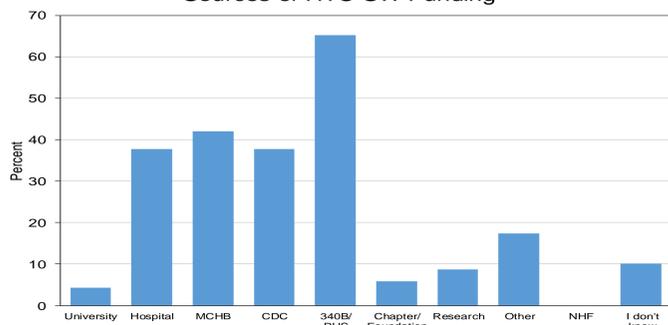
## Results – Demographics & Salary

Of 147 surveys sent, 81 were returned, for a 55% response rate. 69/81 were completed in full; results for the 69 are reported.

- 43.5% of HTC SWs indicate 3 or more sources of funding
- 65.2% of HTC SWs are funded at least partly by 340B/PHS funds, and MCHB & CDC federal grants partly cover the salaries of 42% & 37.7% respectively

Figure 1.

Sources of HTC SW Funding

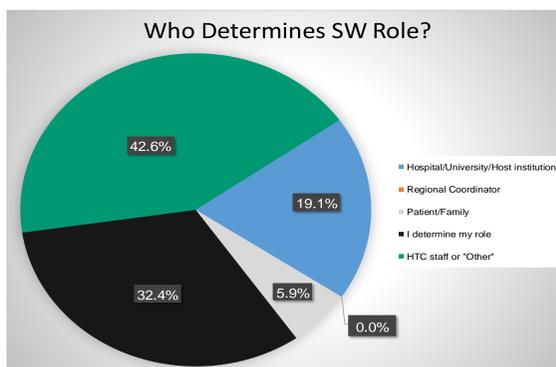


## Results – Roles

For purposes of this survey, HTC SW roles include, but are not limited to:

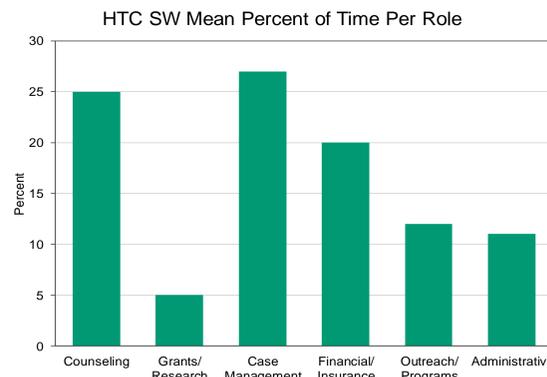
- Counseling:** Includes psychosocial assessments, individual, family, group, mental health, crisis, grief and supportive counseling and support groups
- Grants/ Research** (may include one, several, or all of the following): Work that involves managing MCHB and CDC grant projects, writing grants, grant 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

Figure 2.



- 22/68 (32.4%) SWs indicated that they determine their own roles in the HTC
- Overall, HTC staff determines the roles of 42.6% of SWs. This percent is consistent across university based, hospital based, and freestanding HTCs (Figure 2)

Figure 3.



Case Management (27%), Counseling (25%) and Financial/Insurance (20%) are major roles of HTC SW staff, who are less involved in Outreach, Administrative and Grants/Research roles (Figure 3).

## Results – Funding & Role Determinants

More Important HTC SW demographics

- 22 SW (31.9%) were ≤ 35 years old; 46.4% ranged from 36-55 years old, and 21.7% were > 55 years old
- 95.7% have a Master's in Social Work
- 49.3% work with both pediatric and adult patients. 34.8% work primarily with pediatric patients and 15.9% work with adults.
- 25% of HTC SWs have no SW supervision; another 20.6% rely on peers or pay out of pocket for SW supervision
- 60/69 (86.9%) were in a University or hospital based HTC. Of 19 that were university based, 3 (15.8%) had their salary paid by the university. The hospital paid the salaries of 21 (51.2%) of the 41 who were hospital based
- HTC SWs perform a wide range of roles, which also include Outreach (12%), Admin (11%) & Research/grants (5%); this is more than and unlike most other health care specialty SWs
- Salary ranged from \$17 to \$52/hour; median \$ 31.30/hour

## Conclusions

- Many HTC Social Workers draw salary from multiple sources
- CDC & MCHB funds have been flat for many years
- Potential cuts of 340B programs, which have been under critical attack and review in Congress, may negatively affect funding for HTC Social Work roles
- Comparison across the country show no associations between demographic variables and percent of time practicing each role
- Development of more consistent HTC SW job descriptions might serve to clarify the key roles and important functions that Social Work can play in rare chronic diseases
- Shared standards of practice would greatly benefit new or isolated HTC SWs, and can enhance patient expectations and satisfaction

## Review of Literature & Bibliography

Little research has been done on the roles and characteristics of Social Workers (SW) in Hemophilia Treatment Centers (HTCs) in the United States.

- Literature reviews reveal little research on the characteristics of the social worker in chronic care for any disease state has been conducted.<sup>1,2</sup>
- In Canada, in 9 of 25 programs, NO resources are allocated to certain core disciplines, notably...social work.<sup>3</sup>
- In a survey of hemophilia care in Europe, 11 of the 19 countries surveyed (58%) did not offer psychosocial support, which may be considered a major deficiency.<sup>4</sup>

1. The role of patient care teams in chronic disease management. Wagner E. Br Med J 2000; 320: 569-72  
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 3. Penny wise, pound foolish: an assessment of Canadian Hemophilia/Inherited Bleeding Disorder comprehensive care program services and resources. Page, D; Crymble, S; Lawday, K; Long, M; Stoffman, J; Waterhouse, L; & Wilton, P. Haemophilia (2016) 1-6  
 4. Haemophilia Care in Europe: a survey of 19 countries. O'Mahony B; Noone D; Giangrande PL; Prihodova L; Haemophilia 2011; 17:35-40