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The actual and ideal roles of haemophilia treatment centre social workers in the United States and the barriers to ideal roles

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Abstract

Introduction: Social Workers (SWs) provide valuable services on multidisciplinary teams of Haemophilia Treatment Centres (HTCs). However, their roles have not been defined and standardized. This paper identifies six major SW roles, including counselling, case management, financial/insurance, outreach/programs, administrative, and grants/research. Roles were further classified as 'actual' roles, those that SWs were actively practicing, and 'ideal' roles, those that SWs felt were most important for their clients.

Aim: The goal of this study was to determine the actual and ideal roles of HTC SWs and the barriers to ideal roles.

Methods: An online survey was tested with a focus group and then e-mailed to 147 SWs who were working in the 141 HTCs across the United States.

Results: Fifty-five percent of the SWs completed the survey. Data revealed that SWs' most prominent actual role was case management in their work with three client sub-populations: adult patients, paediatric patients and family members. However, SWs identified counselling as the ideal role that was most important for all client groups. Barriers to practicing ideal roles included lack of SW input, insufficient budgeted time and inadequate training. Salaries were found to be stagnant compared to 2010. Twenty-five percent of SWs reported no supervision.

Conclusions: Survey results gave evidence that although HTC SWs were primarily engaged in case management roles, they wanted to take on larger counselling roles. Efforts should be made to eliminate barriers to ideal SW roles so that SWs can provide additional psychosocial services for HTC patients.

KEYWORDS
barriers, indexing, haemophilia treatment center, roles, social worker

1 | INTRODUCTION

Social Workers (SWs) have been productive, valued members of the multi-disciplinary teams at Haemophilia Treatment Centres (HTCs) for many years. However, their roles may differ greatly from centre to centre. In general, SWs act as advocates for patients, provide a variety of psychosocial and case management services, are a primary source of information and referrals, and may provide counselling and therapy to patients and families, as well as consultation to staff.[1,2]

Since the origin of the HTC network in the United States in 1975,[3] little research has been done regarding the roles of SWs on these multidisciplinary teams. It has been noted that most HTC SWs are the sole

SWs in their respective centers.[4] Therefore, it is important to define their job tasks to establish evidence-based similarities and variations of SW purpose and practice in HTCs. The authors hypothesized that there may be a difference between the 'actual roles,' the primary set of tasks that HTC SWs perform, and the 'ideal roles,' those they consider most important and would like to undertake.

The purpose of this descriptive study was to: (1). Determine the 'actual roles' of HTC SWs, (2). Explore and identify their perceived 'ideal SW roles' they would like to practice, and feel are the most important for bleeding disorder patients and their families, and (3). Define challenges or barriers to the practice of HTC SWs' ideal roles.

2 | METHODS

Utilizing the Survey Monkey application, a group of HTC SWs created an online survey consisting of 40 questions that solicited background demographic information, educational levels, work settings, training, supervision, and other job role variables (See Supplement 1 for the full survey). Several inquiries were made about tasks and actual roles that SWs undertook in their positions and the ideal roles that they felt were more important in their patient and family work.

The instrument was piloted for clarity and objectivity of the questions and process by testing a focus group composed of seven former HTC SW professionals known to the authors; they were not included as part of the survey sample. The survey was revised, and Institutional Review Board approval was obtained. Then surveys were emailed in December, 2015 to 147 SWs working in the 141 federally-funded HTCs identified through the CDC website. Responses were considered anonymous and confidential. Results were tabulated and analysed using descriptive statistics. In some cases, comparative data was available from an earlier survey of HTC SWs conducted in 2010.[1]

3 | RESULTS

Of the 147 HTC SWs invited to participate in this survey, 81 completed and submitted it, yielding a response rate of 55%, representing all geographic regions. In the data analyses, percentages may not total to 100% due to rounding of decimals and the number of responses for each question.

Demographics provide a general understanding of the group characteristics of the SWs who worked in HTCs during the 2015 time period. Other variables included gender, educational level, age and salary (See Table 1). The demographics of the 2010 and 2015 groups were similar except for differences in age and gender. There was an 8% increase in the number of SWs in the 35 years and under age group and drops of 8% in the 46–55 and 6% in the 56–65 ages. The number of female respondents decreased from 88% to 82% in the intervening years.

In 2010, 85% of participants held a Master's Degree in Social Work (MSW), with another 9% holding a Master's Degree in a related field. By 2015, 95% held an MSW, with only 1% holding a related degree (See Table 1).

TABLE 1 HTC SW demographics: 2010 versus 2015

Social worker characteristics	2010		2015	
Number of survey respondents (response rate)	100/133	75%	81/147	55%
Gender				
Female	82/93	88%	66/80	82%
Male	11/93	12%	14/80	18%
Age				
<36	21/96	22%	24/81	30%
36–45	20/96	21%	22/81	27%
46–55	30/96	31%	19/81	23%
56–65	22/96	23%	14/81	17%
66+	3/96	3%	2/81	3%
Education				
Bachelor in social work (BSW)	4/99	4%	2/80	3%
Masters in social work (MSW)	84/99	85%	76/80	95%
Related degree	9/99	9%	1/80	1%
Doctorate of philosophy (PhD)	2/99	2%	1/80	1%

In 2010, participating SWs' salaries ranged from $12.50 to $50.00/h; the median was $28.00/h and the average was computed to be $28.80/h. Using the CPI Inflation Calculator from the United States Bureau of Labour Statistics, the 2010 salaries were equivalent in 2015 dollars to a range of $13.49 to $53.96/h, median $30.22/h, and mean $31.08/h. By 2015, HTC SW salaries ranged from $17.00 to $52.00/h; the median was $31.00/h and the mean was noted to be $31.30/h.

In 2015, 50.7% (38/75) of responding SWs worked with both paediatric and adult patients, while 34.7% (26/75) worked primarily with paediatric patients and 14.7% (11/75) with adults only. Eighty-eight percent (66/75) worked in an University or hospital-based HTC, while the remaining 12.0% worked in independent centres or chapter/consumer centres.

Another work-related parameter in the 2015 survey revealed limited availability of supervision. While 51.9% (42/81) of respondents received supervision from their HTC or institution staff, 24.7% (20/81) of HTC SWs reported having no SW supervision available through their jobs. Another 21.0% (17/81) relied on peers, and 2.5% (2/81) paid out-of-pocket for their own SW supervision.

For the determination of actual roles and ideal roles in the 2015 survey, SW roles were divided into categories of associated HTC work tasks. The six major roles included counselling, grant/research work, case management, financial and insurance tasks, outreach/programming duties, and administrative tasks. Table 2 displays the six major SW roles and the associated tasks defining each role.

Initial role questions were aimed at determining the baseline role or 'actual role' of HTC SWs. Because of variations in working hours, participants were asked to assign the percentage of time they spent doing each of the six described roles in a typical week. This was necessary because the average budgeted SW hours per week in the HTC

TABLE 2 HTC SW roles

Roles	Task descriptions
Counselling	Includes psychosocial assessments, individual, family, group, mental health, crisis, important grief and supportive counselling 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 Haemophilia 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.
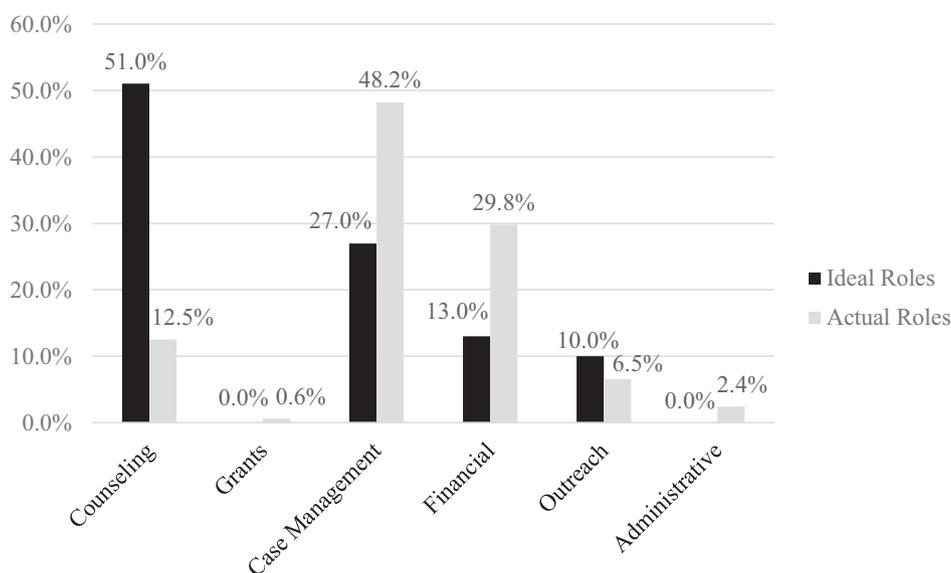
FIGURE 1 1 HTC social worker percent of time for ideal versus actual role with total client population

was 28.8 h and the mean total number of SWs at HTCs was 1.3, with a range of 1–5.

Given the six categories/types of SW roles, most respondents noted that their weekly responsibilities included a combination of three or more role types. Overall, SWs reported that the actual role they practiced most was case management (48% of the time), followed by financial/insurance (30% of the time). The rest of a typical week was spent performing counselling, outreach/programming, administrative tasks, and grants/research roles (See Figure 1).

Participants were then asked to rank the six categories/types of roles in order of importance in their work. Level of importance was used as an indicator of SW 'ideal' roles. Again, using the total client population, 51% of SWs responded that the most important or 'ideal'

role was counselling. Case management was the second most important role with 27%, followed by financial assistance with 13%, outreach at 10%, while administrative tasks and grants/research both rated 0% (See Figure 1).

When the larger overall client population was divided into three different sub-populations (paediatric patients, adult patients, and family members), discrepancies between actual and ideal roles were seen in all three subgroups.

For work with paediatric patients, the actual roles, ranging from highest to lowest, were case management, financial/insurance, counselling, outreach/programming, administrative, and grants/research roles. The order of importance for SWs' ideal roles began with counselling first, followed by case management, outreach/programming,
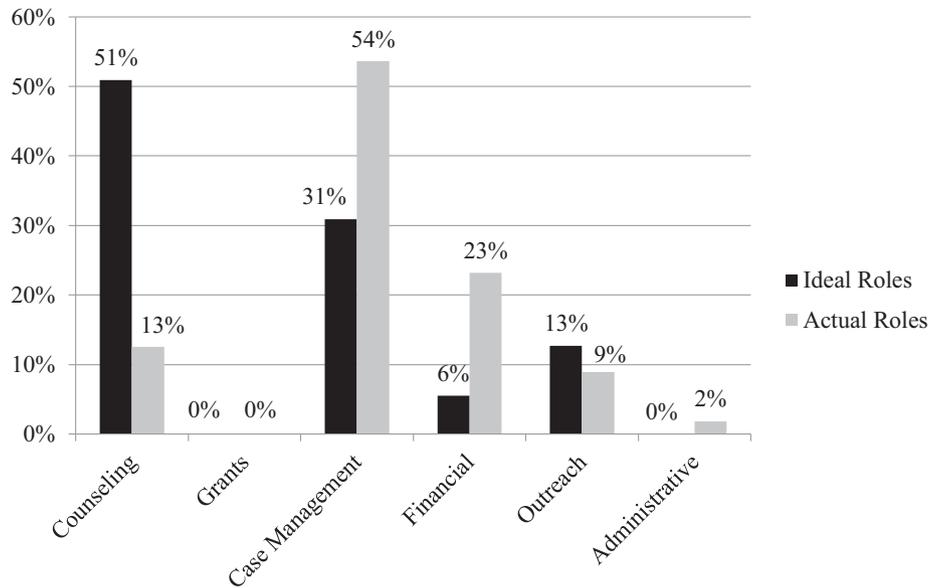
FIGURE 2 Ideal versus actual roles with paediatric patients
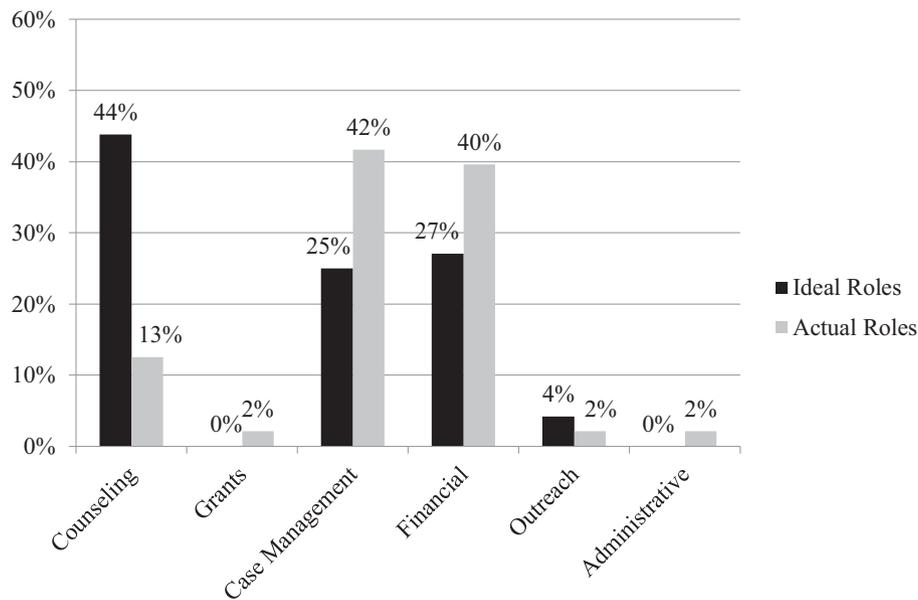

FIGURE 3 Ideal versus actual roles with adult patients

financial/insurance tasks, administrative duties and grants/research duties. Figure 2 gives the visual percentages of both the actual and ideal roles for the six role types in work with paediatric patients.

For the adult patient population, as in paediatrics, the actual roles were highest for case management and financial/insurance, descending through counselling, outreach/programming, administrative and grants/research, although the financial/insurance role became notably higher for adult patients. The most important or ideal role was counselling, followed by financial/insurance, case management, outreach/programming, administrative and grants/research. See Figure 3 for percentages of actual and ideal roles with adult patients.

Lastly, the most highly practiced actual role with families of both adult and paediatric patients was reported to be case management, financial/insurance, counselling, outreach/programming, administrative, and lastly, grants/research roles. SWs reported the most important or ideal role with families was counselling, before case management, outreach/programming, financial/insurance, administrative and grants/research (See Figure 4).

In summary, when work with the total client population or any of the sub-populations were considered separately, SWs primarily performed case management duties, but the majority felt that counselling was the ideal role and should be provided most to their patients/clients.
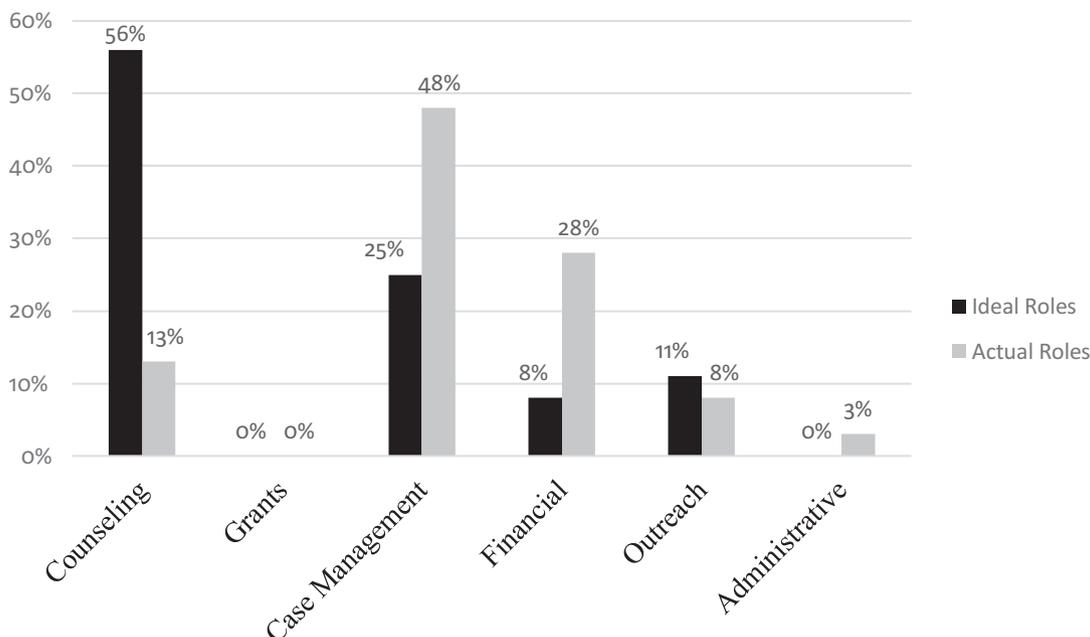
FIGURE 4 Ideal versus actual roles with family members

TABLE 3 Percent of SWs identifying roles as not being met and requiring more training

Role/responsibility	Role not being met No. (%) (n = 69)	Need more training No. (%) (n = 67)
Counselling	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)

Why aren't HTC SWs performing the ideal role tasks that they feel are the most important? To identify barriers to performing these ideal roles, participants were asked who determined their SW roles. Interestingly, only 32% (22/68) of respondents indicated that they determined their own roles in their work, with 43% indicating the HTC staff determined their roles, and the remaining 25% were designated by either the hospital/university/host institution (19%) or actual patients and families (6%). No survey respondents selected regional coordinators as their SW role determinant.

In response to a question asking why roles were not being met, 42% percent (29/69) of respondents felt there was a conflict between budgeted work time and actual time spent working in the HTC. Table 3 ranks the unmet roles with grants/research first, then outreach, administration, counselling, finance, and then lastly case management, which appeared to be a role need that was met. Thirty percent (21/69) thought that additional budgeted time and staff would help address this issue. Also, 46% indicated a need for more training in

grants/research. This was higher than the 29% who indicated a need for more training in counselling, and the 26% who reported a need for more training in financial/insurance issues, perhaps reflecting on roles they were actually performing.

Social Workers also reported a lack of adequate training when they were hired. Survey data showed that 30% felt that training received within the first year did not give them an adequate knowledge base of haemophilia, and 12% received no initial training. Table 3 lists the role areas in which SWs felt the need for more training.

4 | DISCUSSION

The authors of the 2010 survey concluded that HTC SWs were a group of older, highly experienced, and highly educated professionals.[1] Interestingly, the differences in demographic variables between the 2010 and 2015 surveys indicate that SWs were younger in the 2015 group. This variance could be explained by a trend towards retirement of older professionals and/or an expansion of the field over the 5-year interval between the studies. However, the number of HTCs and SWs has remained stable, thus pointing to turnover as the cause of decreasing age. Why this shift in age has occurred is unclear.

Even though only 51.9% of respondents received supervision from their HTC or institutional staff, supervision of cases is a hallmark of SW practice.[5] Ideally, supervision of SWs should be done by a SW familiar with the practice of their specialty, but since haemophilia is a rare disease, SWs with experience with other rare diseases or chronic illnesses could be appropriate. Relying on peers may have limits, but having other non-SW professionals in the HTC provide supervision is not ideal. The cost of supervision may present a barrier. A 2020 post-hoc

survey of general Haematology/Oncology SWs found that they paid an average of $40–$60/h for supervision.

The major finding of this study was that a significant discrepancy exists between the work HTC SWs were actually doing (actual role), and the role they thought was the most important and relevant to undertake (ideal role). The data demonstrated that SWs were generally performing the case management role most of the time (leading actual role), but they felt their time would have been more valuably spent providing counselling services to patients and family members (top-rated ideal role). This was found to be true in HTC SWs' work with total client populations as well as within the subpopulations.

Evidence supports the need for counselling in the domains of anxiety, depression, and pain for people with bleeding disorders. Published studies have found a high prevalence of mental health disorders, including depression, in men with hemophilia.[6,7] Higher depression scores were related to lower adherence, and higher depression and/or anxiety were related to higher uncontrolled pain in persons with bleeding disorders.[8] Some of these issues could be ameliorated by counselling from HTC SWs.

It was not surprising that case management was the most practiced SW role, followed by financial/insurance services and then counselling. Case management is a task-oriented job, for providing concrete services to inpatients and outpatients. Inpatients frequently require discharge planning to evaluate needs and initiate referrals for post-hospital care, equipment, and services. HTC SWs are also often responsible for providing ongoing outpatient assessments and referrals for case management services. In some HTCs, there may be a division of case management duties between the nurse and SW, resulting in SWs taking on more tasks outside of their ideal scope.[9,10]

Financial and insurance services was reported to be the second most practiced role after case management by SWs in HTCs. To obtain medical services, patients need to have adequate health insurance coverage. The responsibility of helping patients and families obtain insurance benefits often falls on the medical SW. Medical institutions have only recently begun to hire financial counsellors to address these needs. SWs are still often the primary resource for patients who need help exploring and obtaining financial support for their patients and families.

Obvious questions arise: If HTC SWs felt that counselling was the most important role, what prevented them from performing this ideal role? The survey results indicated that potential barriers were the lack of autonomy with respect to their roles, a need for more budgeted SW hours and staff, the need for additional training in several roles, and the lack of SW supervision. These barriers were not ranked in the survey.

A striking finding from the survey was that some SWs pay out-of-pocket for their own supervision if it is not provided. Since most SWs work alone at their HTC, they may not have a mentor to guide and educate them in their roles. The multidisciplinary small team approach utilized in HTCs may also add role requirements such as outreach, administrative tasks, and assisting with grants and research. Interestingly, the training areas most requested by SWs were grants/research (which were not performed often), and counselling which SWs wanted to perform the most.

HTC staff expectations, as well as individual preferences and expertise for certain tasks, may lead to blurring of roles among SWs, nurses and other HTC staff. This may also be a source of role confusion in these small work teams.[9,10]

While only 32% of respondents indicated that they determined their own role, 43% percent of respondents reported that other HTC or institutional staff make the decisions about SW roles. In turn, it is questionable whether other staff on the multidisciplinary or medical teams have the knowledge of and experience with SW roles to make decisions about SW job descriptions.[11]

Another barrier may have been the result of inadequate budgeted SW hours in some HTCs. Forty-two percent of respondents thought there was a discrepancy between budgeted time and actual time in the HTC, and 34% expressed the opinion that additional budgeted time would help address the issues of unmet needs. It is also possible that SWs did not feel that they had the time required to conduct counselling services they felt were most important. Given the limited SW work hours, increasing funding for more full-time positions could open access to SW services in HTCs and benefit patients. However, future research needs to occur to further explore the funding sources of SW roles.

5 | STUDY LIMITATIONS

One limitation of this project was the small number of SWs who work in the HTC network across the United States. The authors were able to locate and invite 147 SWs who were actively working at the 141 HTCs. However, haemophilia SWs outside of federally-funded HTCs were not surveyed. It is known that there are private haematologists and clinics that provide bleeding disorder care without federal funding, but there is no central database that identifies these SWs. It is surmised that the results of the 55% response rate are representative of the population of HTC SWs who have expertise in bleeding disorders and captures the opinions and experiences of the majority of HTC SWs who participated in this study. However, geographical distribution was not tracked in the survey, so it is possible that the responses may not represent a uniform distribution across the country introducing response bias. Another limitation was the survey design restricting some questions to multiple choice answers without open-ended narrative options or rank ordering.

6 | CONCLUSIONS

The major finding of this survey was the identification of discrepancies between actual and ideal roles for HTC SWs working in overall client specialty populations and within the individual sub-groups. This could be interpreted to mean that while SWs most often provide case management services, they consider counselling services to be the most important, and should be the primary role that SWs practice in HTCs, especially considering that depression, anxiety, and pain influence adherence to treatment[8]

Most HTC SWs work in isolation, so strategies that may reduce barriers to practicing their ideal role would include ensuring adequate training about bleeding disorders, and providing appropriate clinical training, supervision and/or mentorship, possibly under the guidance of leaders or peers within the HTC SW network. Shared standards of practice, resources, and training would greatly benefit new or isolated HTC SWs and could perhaps enhance job expectations and satisfaction. Development of consistent HTC SW job descriptions might serve to clarify the key roles and important functions that SWs can play in the care of those with rare chronic diseases. Incorporating relevant evidence-based practice may also demonstrate the value of HTC SW roles in enhancing the psychosocial quality of life for patients. This may help reframe/reinforce the SW role expectation to include practicing the ideal role of counselling and other mental health services such as psychosocial evaluations, crisis intervention, patient education, and supportive therapy. It is hoped that these study results will emphasize the need for increased budgeted SW time and standardization of SW practice in a multidisciplinary team as a model of psychosocial care in the HTCs in the United States.

The authors hope this study raises awareness about SW roles and inspires SWs to discuss these issues within their HTCs and in national organizations. More research is needed to determine and validate SW roles in HTCs in the United States, and to explore barriers to the performance of ideal SW roles, including but not limited to salary, training and supervision, and self-determination of roles. Research could also seek to demonstrate positive outcomes of HTC SW counselling, when supported by HTCs and their parent institutions.

AUTHOR CONTRIBUTIONS

Margaret Geary designed the research, performed the research, analysed the data, and wrote the paper; Ellen Kachalsky designed the research, performed the research, analysed the data, and wrote the paper; Aric Parnes analysed the data and wrote the paper.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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