Navigating Time and Space: Experiences of Aging with Hemophilia

NHF FINAL REPORT | INNOVATIVE INVESTIGATOR AWARD

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Acknowledgments

We would like to thank everyone who shared their stories during our interview process. Through these narratives, we are able to highlight diverse voices and experiences.

We would also like to thank everyone who helped with recruitment including the Hemophilia Treatment Centers in California, particularly the UCSF HTC and local NHF chapters.

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We also thank The National AIDS Memorial for their support and encouragement.

Project Team

Faculty

Tam E. Perry – Associate Professor, Wayne State University, School of Social Work

Dr. Perry's research addresses urban aging from a life course perspective, focusing on how underserved older adults navigate their social and built environments in times of instability and change. She is co-director of the NIH-funded Community Liaison and Recruitment Core of the Michigan Center for African American Aging Research. She also currently serves as research chair for a multi-agency coalition, Senior Housing Preservation Detroit. She has recently been selected to be a fellow in the Gerontological Society of America and currently serves as president of the Association for Gerontology Education in Social Work (AGESW).

Sara L. Schwartz – Clinical Associate Professor, University of Southern California

Dr. Schwartz brings a diverse personal and professional experiences to this project. Trained in social work education and research, she is a Clinical Associate Professor in the University of Southern California Suzanne Dworak-Peck School of Social Work. Dr. Schwartz pursues research on topics to include workplace communities, nonprofit management, HIV/AIDS and the intersection of HIV and hemophilia. In addition to her work in academia, she applies her social science research skills to her role as the Vice President of Research and Evaluation for Kramer, Blum and Associates in San Francisco. In this capacity, Dr. Schwartz works with philanthropic organizations to evaluate programs and grant making. Additionally, Dr. Schwartz serves on the Board of Directors of the National AIDS Memorial and co-chairs the Storytelling Committee. It is through this work that engages with the hemophilia community to capture its history with AIDS and memorialize lives lost in Hemophilia Circle at the National AIDS Memorial Grove.

Charles D. Kaplan – Former Associate Dean, University of Southern California

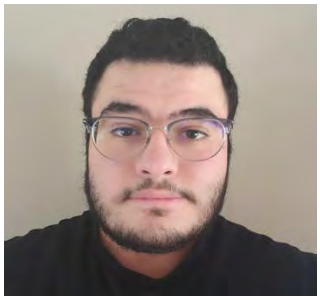
As a medical sociologist, Dr. Kaplan has a long-standing special interest in bio-behavioral health research with a primary focus on drug abuse, mental health, and HIV. His research focuses primarily on the lifestyle dynamics related to chronic diseases and their preventive and treatment service delivery across the lifespan. Dr. Kaplan has worked as an Investigator with several research groups on NIDA, NIMH, CDC, HRSA and SAMHSA research projects with multiple populations. He is especially interested in how biopsychosocial factors interplay with health lifestyles to achieve coherence in the lives of persons with chronic illness in the aging process. He examines these processes in the blood-born diseases of HIV and STDs with a special attention to stigma and non-recognition of patient needs in the process of seeking treatment. Methodologically, Dr. Kaplan applies predominantly mixed methods designs that integrate quantitative and qualitative data; bringing extensive experience in research methodology, social psychiatry, and drug abuse research in Europe where he has been a Principle Investigator on multiple Dutch, German and European Commission studies. Dr. Kaplan's NIH and European research experience have also included the provision of research education to early career scientists from diverse backgrounds to have them grow into becoming independent scientists. His role in the NHF Innovative Investigator Research Award is to apply expertise in qualitative interviewing for data collection.

Practitioner

Dana Francis – Social Worker, University of California San Francisco

Dana Francis, MSW, is a social worker who specializes in working with adults with bleeding disorders, their spouses, partners, and family members. He joined the UCSF- HTC team as their adult social worker in September, 2000. His passion to address the issue of men's emotional isolation, and to that end he has worked to create forums, retreats and ongoing groups for men and couples to gather and share strategies for coping with the challenges of living with a bleeding disorder. He has written a number of articles about hemophilia issues for the NHF publication "HemAware".

Student Research Team and Project Reflections

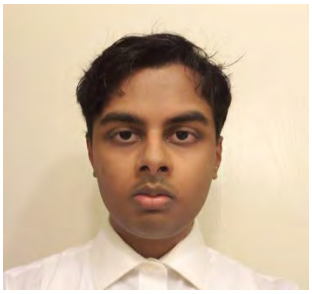


Samir Al-Khouri is a pre-med student with a major in biological sciences and a minor in psychology. His involvement in this research project will allow him to achieve his long-term goal of gaining the necessary experience he needs to be ready to apply to a medical school and a post-baccalaureate program at Wayne State University. He has had previous experiences in a clinical setting that will aid him in his research study about patients that are dealing with hemophilia as they age.

"This project has shown me the importance of being part of the research process as it allowed me to develop a vital understanding of the techniques involved in conducting research with a specific group of cohorts that have otherwise been ignored and forgotten in the past. Discerning the various ethics and procedures involved when studying an underserved population is crucial for a student like myself that is entering a research environment in the field of social work and other studies of human behavior. Participating in this research has allowed me to achieve a set of skills that will aid me in my future career in the medical field."

Aisha Patel is a pre-medical student majoring in neuroscience and minoring in psychology. Her involvement in this project will allow her to have other research opportunities along with more knowledge to be able to develop her own studies. Her involvement in this project will also help her with medical school in the future along with her masters.

"Being a part of this research project has really given me more knowledge on the idea of research itself and the hemophilia community. Prior to entering this research project, I knew very little information about hemophilia, but throughout working on this project, I was able to understand more about the community and the techniques necessary to be a good researcher. This research project really helped me recognize more about those with hemophilia and hear their stories along with understanding the efforts of research. Being able to participate in this research project has, overall, gave me a better idea of research procedures and the hemophilia community."



Sukrut Nadigotti is a pre-medical student majoring in biology with a minor in psychology. His involvement in this project will allow him to conduct research on a field heavily related to medicine, particularly gerontology, which will allow him to burgeon the skills necessary to be a competitive student in medical school. His interest in evolving healthcare infrastructure and previous experiences in clinical settings is valuable for this research project.

"This research project has helped me to gather a fundamental understanding of the research procedures and techniques that are required to be a stand-alone researcher. Through participating in interviews and coding these transcripts, I developed a deep connection with these participants. I was able to hear the private stories that they had told no other, and these narratives I consider to be part of a foundational discography of the human experience. In participating in this research, I was directly interacting with the affected population at hand, being aging persons with hemophilia, and this comprehensive review provided new avenues to better help this underserved population. One of my future goals is to enter the medical field, and this research has certainly shown both my capable skillset and passion for navigating through complex issues."

Misha Ansari is a pre-med student whose involvement in this project will assist her in applying to medical schools as well as other post-baccalaureate programs. This research project is meaningful to her, as she's worked with older people for most of her life, and her previous experiences are supplemental in the research aspects of this project. Being involved in this project has provided her with skills in research methods as well as given her an opportunity to unlock her potential in many aspects of her education and beyond.

"I involved myself in this research due to its unique intersection of medicine, social work, and public health. This project exposed me to a vital outlook on an underserved and marginalized population in the medical world. Interacting with the participants of this project, I've been privy to the significant lack of care that has gone into this cohort throughout their lives. I believe this project is essential in hearing the voices of those who have been overlooked for so many years, and assuring that their lives, no matter their age or sickness, are still valuable. The passion I have gained for this project has impacted my life tremendously, beginning with my decision to turn away from my original major to pursue public health after learning about how public health policies have affected persons with hemophilia and other underserved populations. I also learned and now have experience in new research techniques and the practical uses of theories in both research statistics as well as social work. Overall, this project

acted as a catalyst for me, resulting in helping me decide what I would like to pursue as my academic career and life's work."

Abeer Gobah is an accounting student that is on the pre-med track. Her involvement in this project will help her in applying to the Post Baccalaureate Program at Wayne State as well as medical school. This project will provide her with experience in research as well as an opportunity to be involved in a field related to her future plans.

"This research project was a challenge to both my knowledge of social qualitative research and hemophilia. It was an opportunity to upskill myself and expand my capabilities in research. I was mentored with professionals who guided me on how critical interviewing the participants were and how sensitive the information they were sharing was. I was able to see how hemophilia controls more than the health of a person but also affects every aspect of their life. This research opportunity has motivated me to pursue more research on autoimmune diseases whether it is a social qualitative research project like this one or a biomedical quantitative project. I'm very fortunate to be a part of this research and to have heard the stories of these participants. This research opportunity is the encouragement in my pursuit of knowledge in autoimmune diseases and medicine."

Abstract

Background

For the first time in human history, individuals with hemophilia are living beyond their 30s and 40s. Aging persons with hemophilia (APWH[2]) have witnessed unprecedented treatment changes including factor concentrate availability for home infusion (1970s) and synthetic factor (mid 1990s) to counter dependency on a knowingly contaminated blood supply (1980s).[3] Given these contexts and emerging medical advances, this cohort continues to face unique challenges as they age with hemophilia and other conditions. Medical providers and APWH may navigate the diagnosis and treatment of multiple health conditions that are evident in aging populations in tandem with a lifelong trajectory of medical care for hemophilia.

Project

This project, "*Navigating Time and Space: Experiences of Aging with Hemophilia,"* explores the experiences of people aging with hemophilia and those who serve them. We investigated strategies to optimize functioning, shifting perceptions of time, and four gerontological domains: self-care, social networks, the meaning of home/aging in place and contributions. Our team interviewed 27 APWH (50 and older) and 8 professionals from different caregiving sectors.

Results

Data illustrate that all participants *intentionally select activities to optimize their functioning.* Eighty-eight percent of older participants report that their *unexpected longevity has affected them in profound ways*. Some identify ongoing challenges such as *advocacy for medical coverage* and *education* for medical providers to understand the unique needs of APWH. Furthermore, participants note their unexpected longevity has led to *caregiving roles* and *concern about care* (e.g., Who will care for me?) in older adulthood. Two additional themes emerged from the data. *Gender matters* in important ways for APWH including diagnosis and treatment addressing gender-specific challenges. As the interviews probed a lifetime of experience, the participants noted *complex trauma histories* related to social exclusion, stigma, and bullying/cruelty and an interweaving of physical and emotional pain.

Future Directions

Attention should be given to current and future cohorts of APWH, with detailed recommendations offered at the end of this report. We encourage expanding knowledge of this population in terms of gender, race/ethnicity, socio-economic well-being, non-English speakers, documentation status/Immigrant communities, and attention to those living in states without GHPP (or similar insurance). Programming should address shifting identities and new social roles that emerge with extended longevity.

Project Background

Introduction

For the first time in human history, individuals with hemophilia are living beyond early adulthood. A generation of aging persons with hemophilia (APWH) witnessed unprecedented treatment changes over their lifetimes and are living longer than ever before. The APWH examined in this study experienced the introduction of cryoprecipitate in the 1960s, factor concentrate for home infusions in the 1970s and lived through the 1980s and 1990s, where it is estimated that half were infected with HIV by contaminated blood products.[1] While advances in treatment [e.g., synthetic blood products] have changed the life trajectory of people with hemophilia, science has also changed the life course of individuals who received earlier treatment modalities. Given these contexts, this cohort continues to face unique challenges as they age with hemophilia and other conditions. For example, APWH can question whether symptoms are related to natural aging processes, disease or comorbidity of multiple health conditions[4][5], and some struggle to plan for the future.

What we know about APWH:

There has been limited inquiry into the experiences of APWH, with most of the research highlighting specific medical needs and comorbidities. Hematologists and clinicians note limited experiences treating APWH living with common concurrent age-related complications such as joint disease, cardiovascular disease, malignancy, renal insufficiency, and liver disease.[6][7][8][9] Research demonstrates that APWH often experience greater emotional variability, and physical pain, as compared to younger people with hemophilia or individuals without lifelong bleeding disorders.[10][11] Literature points to how adult engagement with the larger hemophilia community and treatment providers can be cyclical, suggesting that providers consider these patterns and tailor interventions to different life stages[12][13]. A small literature explores the quality of life and the psycho-social impact of having a bleeding disorder across the lifespan. APWH report that their medical conditions have, at times, negatively impacted their education, employment, family life, relationships, and mental health.[14] Our study adds knowledge about the psycho-social challenges (e.g., depression, social isolation) in order to truly develop best practices for an integrated and comprehensive system of care.[15][16]

Two Important Theories to Understand this Population:

1. Theory of Strategic Functioning: Selection, Optimization with Compensation

This project utilized Baltes and Baltes' (1990) *Selection, Optimization with Compensation* (SOC) model as a theoretical lens to understand the experiences of APWH. Based on research from the Berlin Aging Study,[17] the SOC model proposes that older people often make strategic decisions about their lifestyle that will hopefully result in more optimal functioning. Baltes and Baltes argue that to promote functioning, older persons "select" activities to concentrate on and sustain which inevitably includes selecting against continuing other lifestyle activities. These selections may result in "optimized" functioning for the older person. Often, included in this paring down of activities may be "compensatory" or adaptive behaviors to support the continuance of the selected activities. Another way older adults may compensate in order to optimize their selected goal is to utilize assistive technologies or other individuals.[18] We use this theoretical lens to understand what activities and/or relationships APWH are actively selecting or involuntarily giving up that may or may not result in optimized functioning.

2. Interweaving strategy and the perception of time: Socioemotional Selectivity Theory

We cannot overlook that this cohort never expected to age. Researchers have documented that perception of a time horizon often influences our actions, emotions and goals. Socioemotional Selectivity Theory (SST) suggests that when individuals perceive having less time or nearness to death, they strategize who to spend time with and what type of activities in which to engage.[19] People differentiate between knowledge-driven and emotionally driven goals, suggesting that the latter will be prioritized if time is thought to be limited.[20] This project allowed us to understand what it means to APWH when nearness to death expands rather than contracts.

SOC and SST provided theoretical perspectives to examine four domains of health and well-being: 1) self-care, 2) social networks, 3) the meaning of home, and 4) contributions to holistically capture what means to age for persons with hemophilia. The definitions of these domains are as follows:

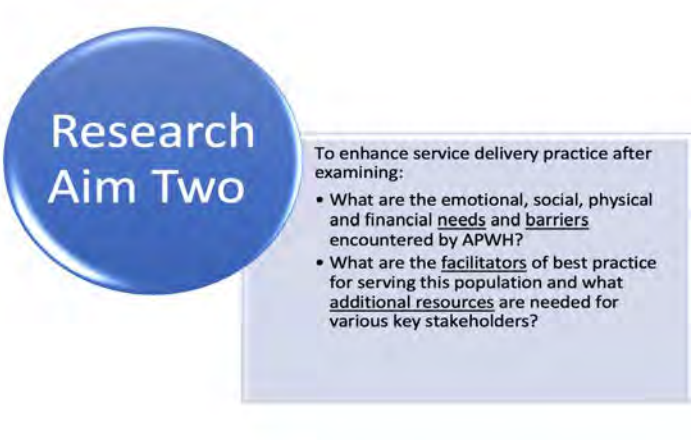
1. *Self-care:* The physical and mental health care behaviors used and initiated by participants were explored, including coping strategies and compensations used to achieve goals. Sometimes these self-initiated goals involved support from others and possibly reciprocally providing support to others, thus the other domains are intertwined.

2. *Social network:* The data helps understand participant social networks and how these networks have changed over time.

3. *Meaning of home/aging in place:* As we age, we assess the suitability of our living environments and resources. Some choose to relocate, some age in place with compensatory home modifications, and others grapple to secure affordable housing. Historically, people with hemophilia endured lengthy hospitalizations for whole blood transfusions. When factor concentrate became available in the late 60s, bleeds were treated at home, introducing freedom to travel and strategies to prevent bleed-related joint damage. Thus, home is a complex construct for APWH.

4. *Contributions:* The field of productive aging (employment, caregiving, and volunteering) highlights older adult's contributions, rather than framing older adults as solely recipients of care and resources.

Specific Aims of this Project



Hypotheses

The team developed three hypotheses to be tested in this study based on specific aims, theoretical frameworks, and gerontological domains:

Hypothesis One: APWH strategically select activities and/or relationships to "optimize" their functioning and add "compensations" to anticipate losses.

Hypothesis Two: Due to advances in medical science and care, APWH have altered their conception of their time horizons as they approach an expanded life expectancy.

Hypothesis Three: Due to their historical milestones/trauma experience, APWH experience unmet needs in 2 or more of the four key gerontological domains (self-care, social networks, meaning of home, contributions) that require specifically tailored interventions and programming.

Methodology

Sampling Strategy

Non-probability sampling strategies were used to recruit 27 APWH and 8 service providers for individual interviews. A multi-stage sampling process began with email distribution of a recruitment flyer (Appendix E) to UCSF HTC patients and providers. After examination of the sample who responded to the flyer, purposive and snowball techniques were used in collaboration with community partners in both Northern and Southern California to diversity the sample. For example, after our initial interviews with APWH, we purposively targeted females with bleeding disorders, individuals with diverse socio-economic backgrounds, and non-English speakers. Snowball sampling proved useful to access individuals not associated

with HTCs. For professional interviews, we carefully identified professions and positions that we wanted to include in the study to ensure interdisciplinary perspectives on our study topic.

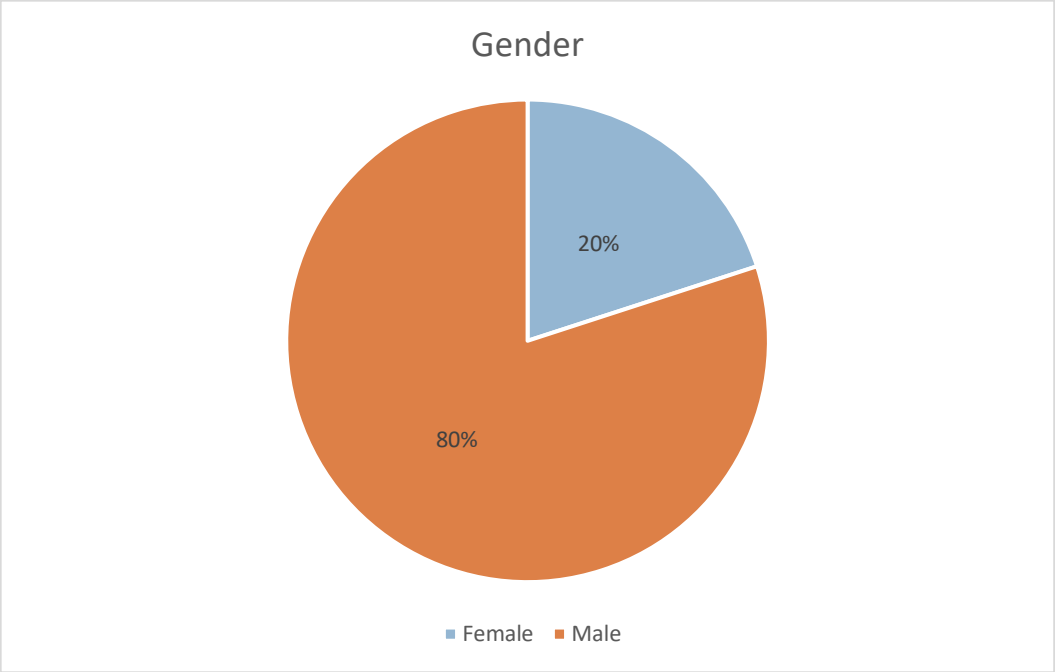
Similar strategies were used to recruit a sample of both APWH and providers to participate in focus groups. Our initial recruitment flyer yielded no response. The research team then moved to recruit a group of APWH participating in a monthly men's group to volunteer for a focus group attached to their monthly meeting. Group members declined this invitation. In another attempt to coordinate focus groups, two female participants offered to coordinate a focus group for women with bleeding disorders. Both participants felt confident that they could quickly recruit participants; however, neither materialized.

While recruitment for individual interviews did not prove difficult and several individuals indicated interest in a focus group discussion on the same topic, when the recruitment for focus groups occurred, interest waned. Our inability to collect focus group data during the COVID-19 pandemic may be due to several reasons, including other health and family concerns that take precedence over research participation, and/or with this population, research fatigue.

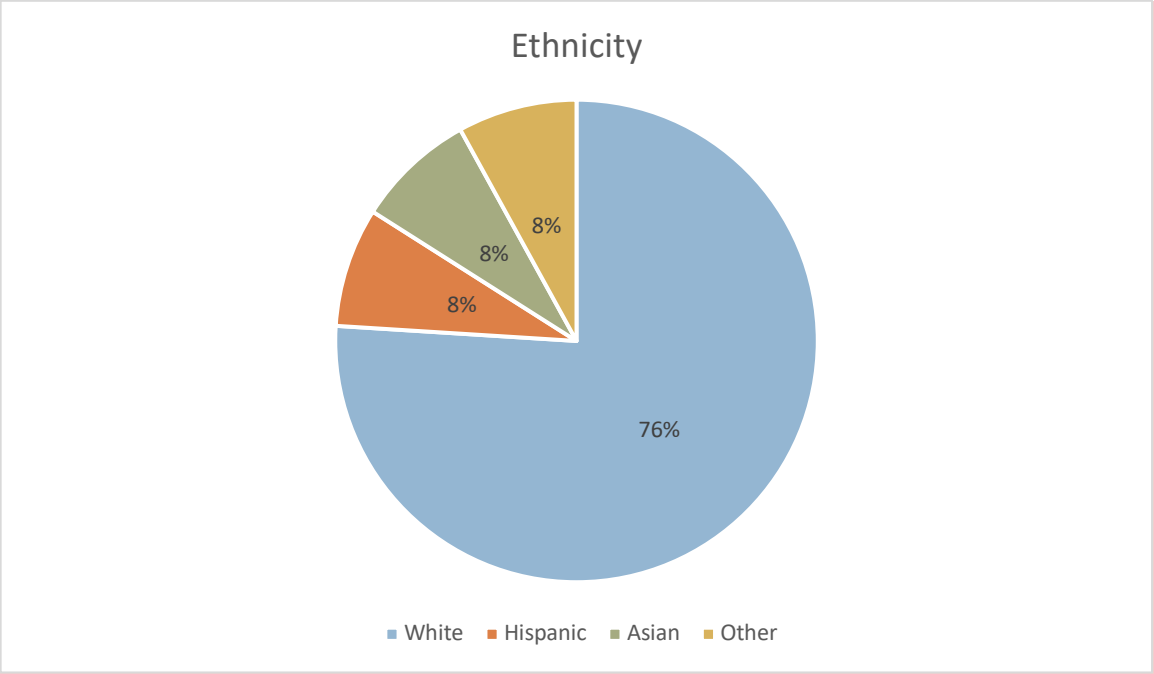
According to Dana Francis, the UCSF HTC social worker, APWH are frequently invited to participate in research on their experiences with bleeding disorders. Many of the individuals targeted for the focus groups had already participated in interviews. They may have felt fatigued by their interviews, or perhaps as if they had already contributed enough time to the study. Another possibility is that they were not interested in exploring the themes addressed in this study in a focus group format. It is also necessary to also consider the role that zoom may have played in diminishing the appeal of a focus group. Originally, the focus groups would have occurred in-person in a shared space, with shared snacks. COVID-19 made this impossible and it is plausible that a zoom focus group did not appeal.

Sample Demographics

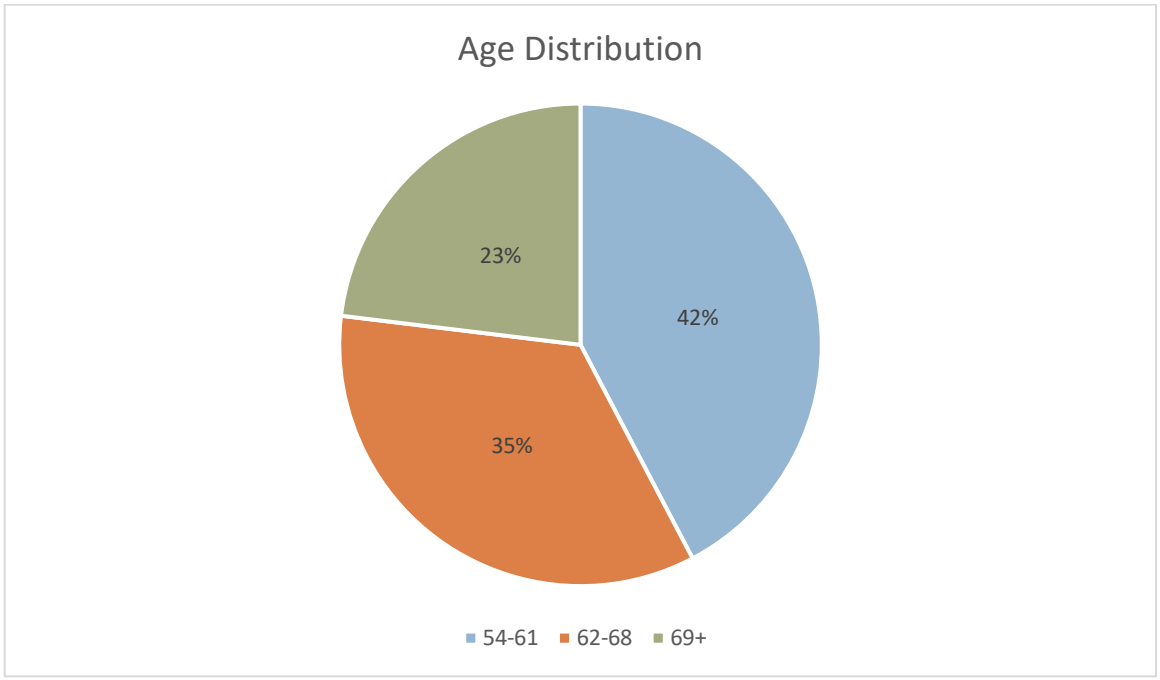
The figures below feature our sample's demographics.

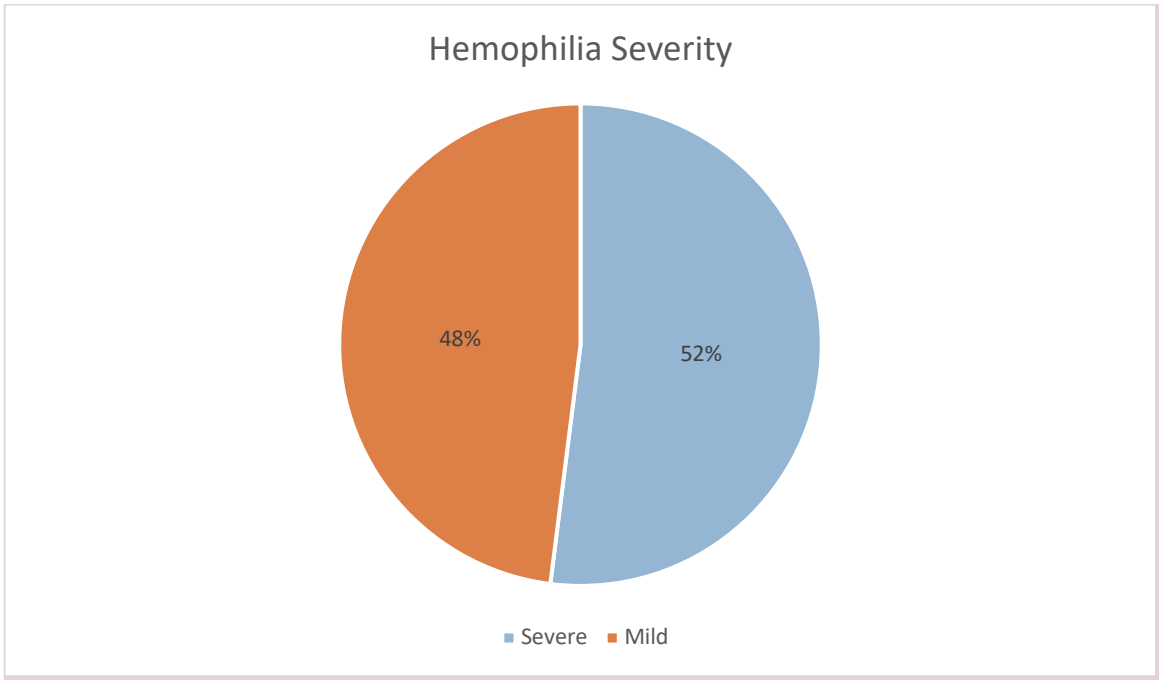


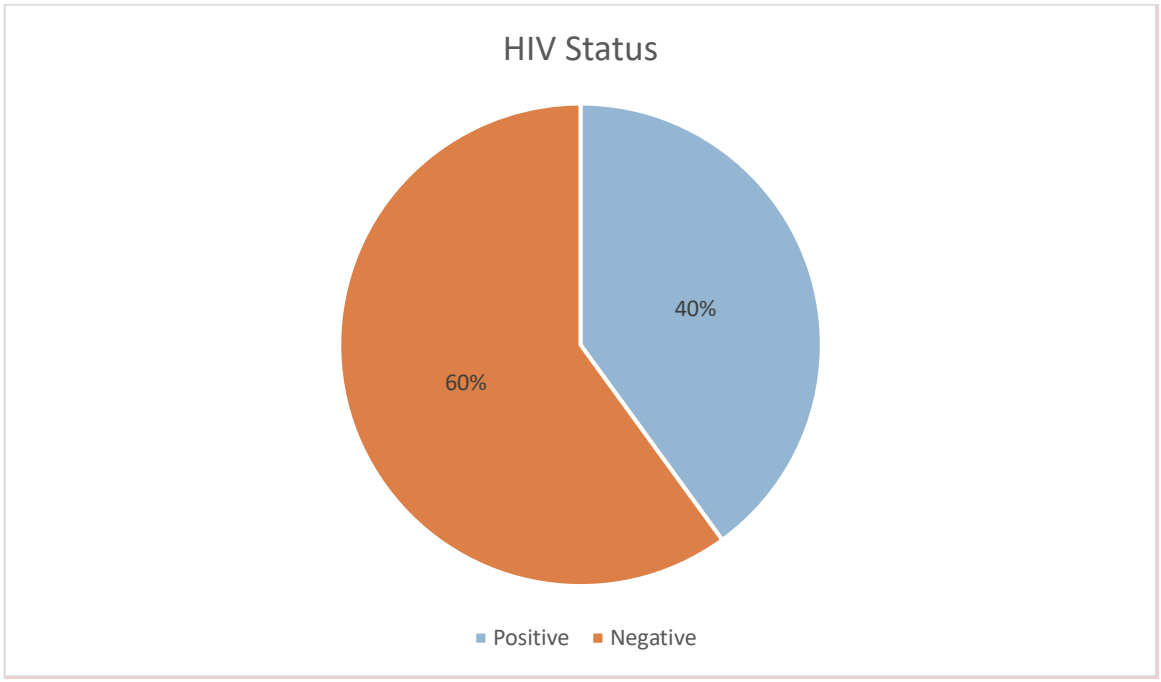
Although hemophilia predominately affects males, females are not without bleeding disorders.



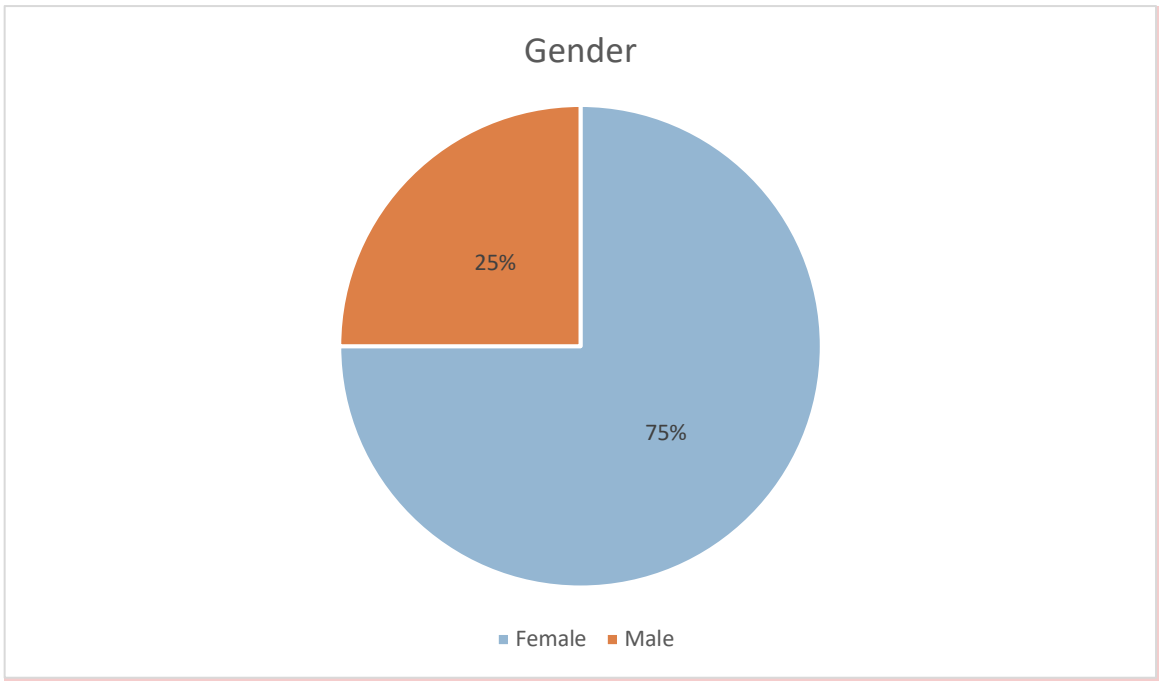
The majority of the sample is White, with Hispanics, Asians, and other groups making up 24%.

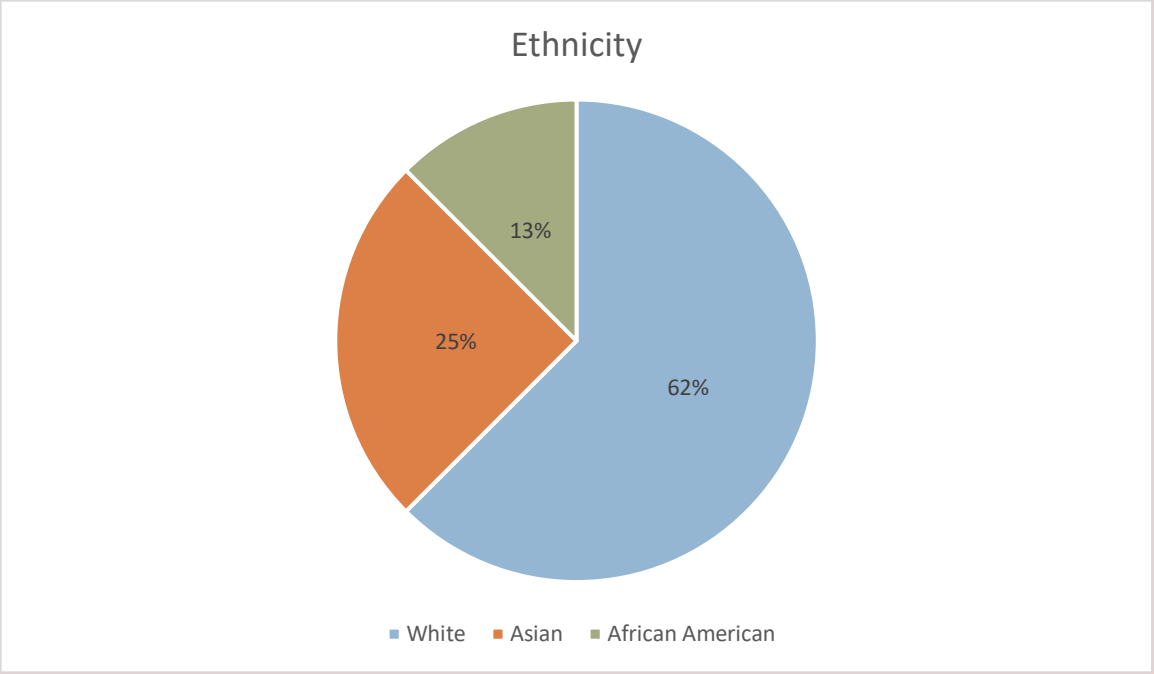

Age Distribution
23%
42%
35%
54-61
62-68
69+


Hemophilia Severity
48%
52%
Severe
Mild



The professional sample is featured in the chart below (*n*=8).





**Asian or Asian-American including Chinese American.*

Professional Backgrounds

- 2 Social Workers
- 1 Physical Therapist
- 2 Nurses
- 3 Administrators/Professional Advocates involved with the hemophilia community in California.

Sample Profiles

Interview #4:
• Mary was diagnosed with Von Willebrand at birth and had transfusions since the day she was born. Mary lived in an abusive household with her mother, who also had a bleeding disorder, and her stepfather. She had to learn to advocate and take care of herself especially after her mother passed away. She wasn't provided with the care she needed for her bleeding disorders. She suffered really bad menstrual cycles from a young age until she reached menopause. She contracted HIV through blood transfusions and was afraid of the stigma that would follow her. Mary was also diagnosed with a stage 4 terminal illness. Her support group is made up of her several children, grandchildren, best friend, and fiancé. Her life was filled with the trauma of her severe bleeding disorder, abusive household, unsupportive ex-husbands, HIV contraction, and her cancer diagnosis. She manages her pain and positivity by reminding herself she is blessed every morning she wakes up. As she ages she realizes that all that matters is that she lives her best life while she's still alive and able to function.

Interview #6
• John has severe hemophilia. He had a near death experience at a young age which led him to acept and embrace his hemophilia. When he was sent to the hospital due to the near-death experience, his mother described the situation saying she took a young child to the hospital and came home with an old man. Growing up, he was bullied but had a small group of friends that gave him social stability. When he was a teenager he went through a rebellious stage and did 'dangerous' and 'crazy' things. Things were going well until AIDS, which he was worried about because he took every product given. Fortunately, he tested negative for HIV. He feels guilty that he has access to good healthcare while there are others who don't. He doesn't want children and believes that he won't be a good father. As a man in his thirties, he had a shift in how he views his life expectancy. He started believing that he may live longer. Believes that the younger generation should have optimism due to prophylaxis, and that they don't know what a bleed feels like since they take factor from birth. He is afraid of dementia and of forgetting things in the future so he tests himself every day.

Interview #11	Interview #12
• Chris was diagnosed at birth with hemophilia. He didn't see hemophilia as a barrier. When people tried to bully him, he would only have to fight one person to prove 'himself'. He doesn't know another person with hemophilia. He grew up with a short life expectancy all his life and short time horizons. His parents are divorced. He worked in a field that required strength and a lot of physical intensity. By the time he was a teenager he was financially independent. Chris went through a reckless phase because he was told he would be in a wheelchair by the time he was a young adult. He was told he was accidentally given HIV and would die soon. Chris refused to take the medicine that was offered which turned out to be pure poisonous AZT. He then refused taking any sort of medicine for years until he got terminal cancer due to chemicals from the enviornment he worked in. He also contracted HIV which caused his first marriage to suffer. Eventually he married someone 'on the same board as he is' because she had HIV as well.	• Mark has mild hemophilia. He best manages his pain by ignoring it. Mark is very self-aware in what affects his body and how it effects his body and how much he can tolerate. He goes to support groups and is open to sharing his issues. He exercises to maintain his tendons. After the changed his diet, he is concerned with his health. He doesn't like to be in a wheelchair- the idea of no legs doesn't suit him. He tries to exercise as much as he can to be able to use his legs. He enjoyed being able to travel the world and have more freedom now that he doesn't have to take care of his parents the way he did before. He plans to travel with his boyfriend to different countries after COVID. He dodged HIV because his mother found a way to send in blood from a different state. He discusses how certain laws need to change regarding infusing factor not being allowed at an assisted living facility.

Data Collection

The two principal investigators, Sara Schwartz and Tam Perry, conducted the interviews over zoom and, in some cases, by telephone. Data were collected between December 2020 and July 2021 and interviews lasted between 1 and 2 hours. Most of the interviews were conducted in one zoom session, although for a few cases, a second interview session occurred. In two interviews, a translator (a PhD trained specialist in health disparities among Latinx persons) was brought in to transcend the linguistic barrier of an English-only study. Topics ranged from experiences with diagnosis, childhood, the HIV/AIDS pandemic, insurance and other resources and changing horizons due to longevity. For the complete semi-structured interview schedule with persons with hemophilia and professionals, see Appendices F and H. For the Spanish translation of the primary interview schedule, see Appendix G.

All interviews were recorded on zoom and transcribed by either transcription software (Rev.com) or undergraduate students. While zoom can generate transcripts, the discrepancies and the de-identifying of names, locations, and other confidential information, required further editing of the zoom-generated transcripts. Each participant received a $100 Amazon gift card, delivered electronically due to their logistical convenience.

Data Analysis

Phase 1 of the project: Analysis secondary data set for aging themes

Phase I of the project involved analyzing a subset of previously collected interviews for themes on aging. Thirty-two semi-structured telephone interviews were conducted with long-term survivors, family members, and professionals who supported these families as part of a previous project spearheaded by Dr. Schwartz. Thematic analysis resulted in several overarching themes related to trauma and lack of a roadmap for aging with hemophilia. The results of this first dataset were presented at the 23rd International AIDS Conference and the 2020 Annual Scientific Meetings of the Gerontological Society of America.

Seven of these 32 interviews in the first dataset were with long-term survivors of both hemophilia and HIV. The two principal investigators analyzed the 7 interviews using the qualitative data software program, Dedoose. Results of the thematic analysis guided the hypotheses generated for this study.

Phase 2 of the project: Analysis of interviews with persons with hemophilia and professionals

For the 35 Phase 2 interviews, data were analyzed using qualitative data analysis principles of coding, theme discussions among research team members and member-checking where clarification was needed (Padgett, 2008). The research team engaged 6 pre-med

undergraduates (one later withdrew from the project) from Wayne State University who were interested in working with the project team. Dr. Perry and Dr. Kaplan provided ongoing training on qualitative methods. After several group discussions, the five students were divided into subgroups to work with each other, with careful mentorship from Dr's Perry, Schwartz and Kaplan. These subgroups met regularly on zoom to code transcripts with attention to key codes related to physical and mental well-being, social networks, challenges/barriers and strategies. The coded transcripts also included memos to capture themes that should be cross-checked with interviews, clarifying questions about the data and key "juicy" quotes that document the richness of the study participants' perspectives in an innovative method that utilized Excel software. The subgroups also created several presentations to discuss emerging themes to the entire research group. In the final stages of analysis, the themes relevant to the three hypotheses and new emergent themes were analyzed across the transcripts.

The team also obtained supplemental funding for the data analysis phase. Wayne State University offers "Undergraduate Research and Creative Projects Awards" to students who will work on projects supervised by a faculty member. The students received funding for "Aging with Hemophilia" between Spring and Fall of 2021. With this grant, main responsibilities for the research involved: a general familiarization about hemophilia through the examination of sources, writing literature reviews, learning how to code data about aging with hemophilia, developing multiple coding strategies, and developing an overall coding approach from the coding of different transcripts. The students will present their work at the Wayne State University Undergraduate Research and Creative Work student symposium. Along with this, the students will be involved in presenting the research findings in national and international conferences that may include American Public Health Association (2022), Gerontological Society of America (2022) and World Federation of Hemophilia Global Policy and Access Summit (2022). In addition, they will co-author manuscripts.

Project Modifications due to the Covid-19 Pandemic

The team designed the project with interviews and focus groups to be conducted in person, including driving to individual interviewees' residences and hosting focus groups in institutional spaces (e.g., HTC) in Northern and Southern California. As one of the Principal Investigators is based in Michigan, the team planned that she would fly out several times during the data collection and analysis phase for in person collaboration and discussion. Also, the Principal Investigators envisioned a balance of data collection occurring across Northern and Southern California.

With the project converting to a zoom modality in line with Covid-19 guidelines, the data could be collected anywhere in California as driving distance was not a factor. Time of day

was also more flexible as some interviewees from California were residing in other time zones temporarily.

By using zoom for interviews, zoom generated transcripts and recordings reduced transcription costs which allowed the team to reallocate project funds to hire the students. By using zoom for team meetings and subgroup meetings, accessibility between California and Michigan as well as among the Michigan based students facilitated engagement and communication. For example, in the coding process specifically, the “share screen” function of zoom facilitated team members to review the passages and discuss appropriate codes in real time.

Results

Phase A: Secondary Data Analysis

After analyzing seven interviews of data previously collected, the following themes emerged that captured APWH experiences of aging. These initial findings are based on analysis of secondary data guided development of our interview and focus group questions, as well as the research team members' familiarity with the study population in preparation for primary data collection. In addition, these initial interviews were used to train the students involved in the research project.

Key themes across both presentations included the following:

(For additional examples of these themes**,** please see Appendix B and D.)

Understanding a Cohort	
Theme	**Example**
Community Trauma	*..losing children and friends, it was really hard. And going to those funerals with all those little coffins. And just the sadness and the grief in our community, and just feeling like you couldn't really share that with other people outside of the community for fear of being ostracized.*
Rebuilding Community	*I have this experience of just coming out of my shell, like 20, 25 years later and, in my head, everyone has been there all along, you know...I know we lost a lot of guys but the guys that are still around ….I kinda assumed that they didn't go hide away like I did, which isn't true…..alot of them came back sooner than I did but, when I really start talking to people, it really is a common experience.*
Wisdom Sharing	*…at this point in time when the little ones are young, it's the parents that are able to shape and show the little ones how to live. And if the parents are able to see older hemophiliacs and see that, hey my son has a chance in life…that's huge.*

Childhood Experiences	*I became very um - afraid of - of even going to the hospital, because I was very attached to my parents. And the idea of being separated was just tremendous ang - anxiety for me. So when the doctor would say yep, we need to put him into the hospital I would definitely you know, just start whaling. And um - the pediatrician that I had when I was about four or five years old, um – [name of doctor] um - she was uh - a very good doctor. Um - but she had little patience for kids who cried. And so she would you know, go into the wow you're a big boy now. And you shouldn't be crying. And she had no - no time or patience for you know, any kind of emotional outburst.*
The Intersection of Health and Social Networks	*I could work in - in like a company office at home, we built a company office next to our house, that that would be a great way to you know, earn money and you know, still be kind of protected. They were very protective of me. I was their only child.*
Looking through a (Protective) Lens of Social Withdrawal	*in the 1980s, I, um, made a conscious effort not to take factor unless I absolutely had to. I lived kind of a monk's life. I, I stayed in most of the time. I didn't go out. I didn't go out running around chasing girls or anything like most young men do at that age. And I was able to skirt HIV/AIDS. I did not get that. But I did get Hepatitis C.* *'m sure in that period I had quite a few micro-bleeds that we didn't treat with the factor because of AIDS. And so my joints um - progressively got a lot worse than if AIDS had never been in the equation to begin with. Um - so I - I was pretty housebound from 1982 to 1988, about six years. I was pretty housebound. And um - that really kind of kills your dating life.*
Silence	*So, and, so, there's just very few people….it's weird…in my generation, like around my age, there's almost no one left. There's, there's guys that are younger, a little bit younger, and*

	guys that are older and, but something happened with the guys that were my age. They just didn't make it. And that feels weird, you know. *I think that's a traumatic thing. I think it's a traumatic thing to live for a really long time with a life-threatening illness and not talk about it with anyone and, people are still not talking about it*

Unexpected Longevity and Matters of Aging	
Theme	**Example**
Identity	*is this a chronic disease yet or is it still fatal? You know? I feel like then it was still fatal in my head...*
Socioemotional selectivity theory: Carstensen's theory of time horizons	*There is still a lot of unknowns about what the future is going to be like. But I often think that the hemophilia is gonna be what takes me out , not the HIV….* *…many of us with HIV started to shift our mindsets that things were getting a lot better and that, you know, we could start thinking about a future. And, that……it was starting to seem like more of a chronic disease…..*
Generativity (Eriksonian Theory of the Lifecourse)	*That there shouldn't have been, you know, an AIDS kind of holocaust, that's what they call it. [01:03:00] Um - because it could have been prevented, and then you really end up with two divided camps as far as um - generations. Cause the new generation doesn't want to hear it. They don't want to hear about HIV, AIDS, they don't want to hear any of that. And the old generation can't figure it out because they're saying, you know, if you're not vigilant with the blood supply you know, it's*

	- you're - you're playing with fire. *at certain times if I was to let myself dwell or look back on certain things that happened to me um - I probably would stay in bed all the time. There would be too much. So in that way I think I share a little bit like with some of the moms who lost kids, but they ended up um - being very proactive um - in the community. And you know, it's - it - it's kind of therapy in that way.*

Phase B: Primary Data Analysis

Analysis of Three Hypotheses

Strategically Selected Activities Over the Life Course

Hypothesis 1: APWHs strategically select activities and/or relationships to "optimize" their functioning and add "compensations" to their anticipated losses.

All participants one way or another and across a lifespan strategically have selected activities to "optimize" their functioning. The data illuminates strategic selection is a long process and not only associated with aging. APWH have strategized to optimize their functioning throughout their lives and their current life stage introduces another phase of adaptation. The mental process associated with these adaptations suggests a cost-benefit analysis for navigating activities. As children, these decisions were driven by parents, caregivers, and providers. In emerging adulthood, APWH independently select activities to optimize solo functioning or in collaboration with partners and providers. In older adulthood, most participants report increasing compensations to accommodate the aging process. Comprehensive understanding of this hypothesis considers strategic selection of activities during three life stages: childhood, emerging adulthood, and older adulthood (50 and above for our study).

Childhood Activities Selected by Caregivers

During childhood, APWH relied on caregivers to meet their healthcare needs. These decisions occurred in partnership with medical providers or other family members. Most

commonly, parents carefully selected activities to prevent bleeding episodes. Rules varied across families often related to bleeding severity, as treatment for severe bleeding disrupted the entire family unit with children spending days in the hospital and parents taking time away from work. Many caregivers discouraged participation in contact sports, physical education classes and high-risk activities such as riding bikes. A 60-year-old born and raised in Bombay, India with mild hemophilia recalls that while he played some team sports, he avoided sports with high contact potential and was not allowed to ride a bicycle:

> *I did not learn bicycling. And...I still don't know how to ride a bike because I would fall and get injured and then I would start bleeding. That one, I did not do, but I did play cricket and badminton and volleyball. And those, there is not much contact. But biking, I did not learn and I still don't know how to bike. But I don't play football, or soccer. Uh, soccer is what we called football back then. But, uh, no I did not play contact sports like soccer.*

A 74-year-old white male raised in a rural community outside of London reminisces on exclusion from physical education and woodworking courses. As compensation, he spent extra time during school hours on homework and helped his friends with their studies.

> *I couldn't participate in things like the gym, and later on in woodworking. I had to sit there in a corner in the gym while the kids were jumping around and doing a gymnastic thing. And the woodwork came. I just sat on a bench. And that was okay, because I could work on the homework assignments instead of whittling away two pieces of wood.*

A white 58-year-old with severe hemophilia raised in the San Francisco Bay Area by parents familiar with the disease benefitted from their decisions based on prior experiences. For example, his parents opted to send him to a small private school and encouraged no-contact sports such as skiing and swimming. He recalls:

> *I did PE when it was swimming. And then actually my dad he set it up to where I think a lot of people knew like, "This kid's got a bleeding problem and we're not going to let anything happen". So I think there was a lot of attention and I was encouraged to do swimming, which is great in the summertime and the wintertime cold water is not fun to go in.*

Participants had diverse reactions to the restrictions placed on their activities. A 61-year-old white male with mild hemophilia recalls frustration with his pediatrician's advice:

> *When I was diagnosed with hemophilia,[the] doctor said, well, you know, don't ride your bike, don't go jogging, don't go sailing, don't ride your horse, don't go running. Um - basically don't do anything, and so what happens if I sit in a padded room all day, well, I believe, he says, yeah, you'll still bleed and die, it's like, well, you know, what's the point you know.*

A male participant, 67, reflects on the mindset of a child with hemophilia suggesting that "*you probably run [into] this repeatedly with guys my age that we were all told we were going to be dead by the time we were 13 so we always had this short-timers attitude towards things……then we didn't have to worry too hard because we were going to be dead".*

A 54-year-old female with Von Willebrand shares how her peers reacted to her during physical education classes. *"In elementary school when we did PE, I couldn't play dodgeball….or those kind of games, but it was almost like, you know, it….brought attention on me. You know, because why is she sitting out or whatever……so it was almost like the class knew about my bleeding condition".*

Others recall 'breaking the rules' or pursuing forbidden activities. These actions, one could argue, involved the 'selection' of unsafe activities despite directives to avoid contact sports and risky activities. For example, a 62-year-old with severe bleeding episodes recalls that *"I wasn't allowed to ride a bike. But you know what, I'd go around the corner, and my buddy would have a bike and we would go bicycle riding and stuff".*

This same individual remembers craving the experience of a contact sport and inviting a football player to play ball. Despite the painful outcome, he has fond memories of this moment:

> *One day, I asked one of the football players, hey, I want to line up against you. Just, let's just mano-a-mano. This guy plowed me, just plowed me. But I just wanted to see what it felt like. And that cost me a week in the hospital. But man, I wouldn't have traded that experience in for the world. How stupid is that?*

Similarly, a 58-year-old recalls participating in activities discouraged by his parents. He remembers hiding his injuries to avoid trouble.

> *I mean growing up I would wake up. I would end up hurting myself, and then I would have to tell my dad later on in the evening when my knee is already the size of a grapefruit, like "I was doing something I shouldn't have done. Now I'm hurt. I need to infuse." I mean, there was a lot of, "What are you doing? You know you're not supposed to do that." But riding a bike is fun. Sorry, I fell off.*

A 60-year-old Hispanic who was one of four children raised with severe hemophilia remembers that she, her siblings, and her parents were aware of their life expectancies. She notes that her brothers regularly engaged in risky activities resulting in many lengthy hospitalizations.

> *….my mom and dad knew that our life expectancy was very short and that we wouldn't live to be senior citizens. And I think a lot of these kids knew the same thing, because they did risky behavior. My brothers roller skating, my brother's skateboard and you weren't supposed to and they did.*

In some cases, this behavior can be associated with youthful perspectives of invincibility, as one individual reflects:

> *Yeah, I was not supposed to make it out of my teens. If I make it out of my teens, you're going to be wheelchair-bound. But I was just a kid, man, I was still 10 feet tall and bulletproof, it wasn't that bad then. It all catches up with you later. It was just, oh, God, there's a bleed man, I'll be ready to go in just a little while, no problem. But then it started to really become a problem.*

Others had different experiences. One 67-year-old with severe hemophilia and an additional inhibitor recalls that his parents helped prepare him and his brother for making smart decisions as an adult:

> *It was the early '50s, my parents were very active people themselves. We had an active lifestyle as a family. They wanted to contain us so nothing would happen to us, but they also didn't want us to be too contained so more things would happen to us. So we wouldn't know how to prepare ourselves and take care of ourselves better in situations. So the big word (at) home when we young, I still remember today is think. They made us responsible for ourselves at a young age realizing what was going on. And they tried to do what they could to keep us from being boys or kids playing. But regardless of that, we found our own way in life, like any kid does, I think……I think that we learned to, as kids also through my parents, to become stronger and active in between incidences so we could manage to survive not getting more injuries. That was part of the education, I think, that we went through it.*

Selecting Activities in Emerging Adulthood

As APWH moved into emerging adulthood, they often separated from caregivers and pediatric hematology to make their own decisions. A 61-year-old male with mild bleeding sought a fresh start:

> *I decided to get out and separate myself from everybody, and I got accepted to the {name of college} in {name of city}, and that was an attempt for me to get away from everybody. I figured, no one knew me there and my parents couldn't call and I could do what I want and figure out how to live with this and just kind of be on my own to figure it out.*

Similarly, a white 63-year-old with severe bleeding recalls his development during this time and learning to navigate activities independently:

> *….when I was in college, I think I was catching up. So, my abilities were, I was more focused on making sure I didn't have injuries. I would calculate the risk and take on the risk, but not being afraid of it and that, again, was developed from my parents and my doctors as a child.*

A white 67-year-old also with severe hemophilia looks at the evolution of his behavior from college to today. He started college close to home with his medical team in place but slowly emerged from safety to pursue independent travel. He describes how these experiences helped him grow and build a better control over his bleeding disorder:

> *After high school, I went to college, art school for four years in [town name]. So, I was still close to home and hospitals. And I felt like I had my safety net still in case I needed it. And then during that time, I decided to, I got the wanderlust. So I decided to travel across country. And I started doing that. And I started realizing that I'm on the middle of the ocean without a life jacket. No one knows what hemophilia is, but here I am denying that I even have it, and I'm having one great time, meeting people and just seeing the world around me that I had been afraid to go out too far to venture into. And so I did that quite a bit in between the four years. And ended up, over the next 10 years traveling across country 12 times by car and just having good adventures, some safe, some not, but I didn't ever need to go to a hospital anywhere the whole time. So something happened at that age where I was strong enough and smart enough and knew my limits enough. And I think I became better at thinking as well.*

Selecting Activities Over 50

APWH face physical, mental and emotional changes associated with aging alongside complications from a lifelong bleeding disorder. The lack of a road map for aging is described by a 67-year-old male with severe hemophilia: *"I feel like I'm in uncharted waters, given the hemophilia and the HIV. I don't know many guys that are my age... I know one or two".*

All participants report modifications during this phase of life; limitations are recognized, and activities are adapted. There is a hint of loss when this process is discussed; however, the predominant tone is less about loss and more about the future. APWH are looking ahead and striving to preserve functioning through lifestyle changes and activities to promote wellness. This is an interesting shift in perspective for a generation who, at birth, was not expected to live to their 50s and beyond.

A mild hemophiliac, 62, shares concerns about losing physical functioning. He is particularly concerned about losing greater mobility in his joints and tendons.

> *The other issue is just mobility. I don't want to be in a wheelchair. I have to caregive for my parents in an assisted living facility. And watching people go to wheelchairs is really like... Anybody going to a wheelchair at any age is life-changing, let me just say it that way. Life is very different without the use of our legs. And so, I'm trying to keep that as best I can.*

An Asian male, 57, with severe hemophilia echoes this sentiment. He especially worries about joint deterioration and the impact that it could have on his leisure activities. He shares the perspective that it is important to keep moving and stretching:

> *I am apprehensive about the deterioration and, you know 60 to 70….what's that going to look like that, you know, it's pretty scary……I try to internalize that so it's good incentive to keep moving, keep using what you have - and you know, keep walking, I'm going to keep walking in the park and things like that…I try to keep active and keep everything working okay um - I mean, I think when you know, what is defined as old age and when that happens to me if - if the rate of deterioration will just be, you know, very - very steep that all of a sudden, I won't be able to move my arm won't be able to play violin and things like that.*

While most participants acknowledged increased attention to their physical limitations, they also continue with familiar cost-benefit analyses to carefully select activities. This balance is illustrated by a 62-year-old male with mild hemophilia:

I can go out and walk an hour with my wife every day, no big deal. But, like I said, just going to a park and doing a hike through the trails and stuff, I have to really know what I'm getting into before I do it. Here's how my life's always been, I can do whatever I want. And I do whatever I want. But there's consequences to doing whatever you want, when you want. And doing what I want, I could do an activity 10 times with no repercussions but the 11th time, there's the repercussion. There's the bleeds.

Changed Time Horizons

Hypothesis 2: Due to advances in medical science and care, APWHs have altered their conception of their time horizons as they approach an expanded life expectancy

APWH represent a unique cohort undergoing an extraordinary evolution in the management of bleeding disorders. Science transformed their lifestyles and life expectancies. While all participants are current California residents, they reflect diverse backgrounds and childhoods, representing rural and urban communities within and outside of the United States that is characteristic of the nation's largest state in population and immigration.

Eighty-eight percent report altered conceptions of time horizons, described in different ways. Some recognized their fragile health at a young age and this understanding impacted their worldview. Individuals with an early understanding of life expectancy typically had family members with hemophilia or had experienced a medical emergency. A 73-year-old with severe bleeding recalls a childhood of lengthy hospital admissions. He remembers this as scary and confusing but offers that a traumatic accident helped make sense of his situation:

> *When I was 6 years old, I had a near death experience and coming out of that I had a tremendous acceptance in this whole thing and I realized I was never going to be able to fight it. And so I don't have the words as a 6 year old, but what I did was embrace it somehow that this was life. As far as all of these traumas and all of these hospital visits and whatever, I came to just accept it. …I knew things were different, you know. And my mother knew it. She didn't know what to say but she said, well, I took a 6-year-old kid into the hospital and I brought a 40-year-old kid home….*

A 58-year-old with severe hemophilia, HIV and hepatitis also recalls learning his life expectancy young. He reacted with a fierce determination to live each day to the fullest and have as many experiences as possible, no matter the consequences, noting, " *it's pretty much like everyday could be your last so you might as well have a great time with it. I kind of remember when I was 12 they told me I'd probably in a wheelchair by the time I was 20. And….that really made me want to go faster, you know. I got eight years".*

Another participant with an unusual history of a Von Willebrand diagnosis with an inhibitor at age 52, recalls asking his medical team 14 years earlier how his diagnosis would impact the aging process. He was shocked to learn that his nurse had no answers to this question: "*she (nurse) just stared at me, and I said it's not that hard to question, I mean, what is their old age like...I said, there's something they're not telling me I said, I just wanted to know about people my age and older with hemophilia and she says well there aren't any. And that was the sort of 'holy shit moment' for me".*

Older participants, those in the late 60s or 70s, or with severe hemophilia recall childhoods spent in and out of hospitals to manage bleeds. Those born before the mid 1960s recall lengthy hospitalizations for intravenous treatment with fresh blood. The discovery of frozen cryoprecipitate in the mid 1960s shortened hospital stays and allowed for outpatient treatment; however, home infusion products did not readily become available until the 1970s and some participants in this study did not begin self-infusions until adulthood. This population faces greater disability compared to those who began self-infusions at a younger age because the time that elapsed between bleeding episodes and treatment created severe joint damage. One participant who, like his brother, was born in the 1950s with severe hemophilia, details the changes in treatment during his formative years:

> *When I was about seven, I recall being pushed down in the playground at school and biting the tip of my tongue off. This was when, before there was any kind of treatment other than whole blood and plasma. I recall spending about a month in the hospital as they tried to get the bleeding to stop in my tongue. I just bled for months. Would not stop. It would grow a big black blood clot, tumor looking thing, and then that would fall off, and it would bleed some more. It wasn't looking good. Then, it was right about that time that Cryoprecipitate was invented. I was able to get some of that. That stopped it just dead in its tracks. It just cleared it right up. That was the big turnaround for me as far as treatment went. Although it was very primitive, in that we still had to wait for a bad bleed to occur, and then go to the emergency room. In the meanwhile, 8 to 12 hours have lapsed before you get treated and the bleed, whatever it might be, is out of control. Anyway. It wasn't until a few years later, when they came out with the concentrated form of factor that we were able to treat it at home and treat a little more aggressively.*

Another individual, a decade older at 74 years also recalls when treatment for bleeds was not readily available. Typically, he would manage bleeds at home with ice and elevation.

> *I did go to the hospital for a nosebleed….and I had a lot of repeat bleeding into the knee quite often, but that didn't require hospitalization……..there were no infusions other than if you were bleeding out, then you could have replacement plasma or red cells, I suppose. But there was no treatment for hemophilia until around 1970 or so.*

A 76-year-old echoes treatment limitations and healthcare for he and his brothers as children despite multiple bleeding incidents and swelling. He recalls that "*it was different back then, you know, people didn't really infuse that much……..because they didn't have factor and the factor they had was somehow gathered from hundreds if not thousands of blood donors".* This individual, and his brothers treated bleeds with ice and elevation, and only received infusions for dental and surgical procedures. He did not begin treating non-procedural bleeds until he relocated to the San Francisco Bay Area in the 1980s and began receiving treatment at an HTC.

Older participants recall the treatment evolution and the hope that came with new protocols. Ability to keep product in their homes and infuse on demand created opportunities to imagine and build futures that included education, careers, family and travel. One individual recalls, "*when the treatments started, or at least when I became aware of them in England about 1970, years ago, it seemed like a miracle. Obviously, the life expectancy was greatly increased with the availability of factor VIII replacement".*

Tragically, this renaissance was interrupted, and life expectancies shortened by HIV. Some vividly recall learning that the blood products were compromised. A 67-year-old male with severe bleeding describes this period as "*this golden age of hemophilia where we had factor, and we could get you know - do anything we wanted and people were making stuff up and guys we're living longer and everything was wonderful and then came AIDS. And.... and then we started dropping like flies"*. A 73-year-old recalls the emotional whiplash and its influence on his conception of time.

> *I had a completely fatalistic attitude. I did some of the most dangerous crazy insane things when I was let's say…somewhere between……as soon as I got my driver's license, you know, that's when everything just went off the rails in terms of….I took the most ridiculous….I didn't think I would make it to 20…I was just….quite reckless. I guess reckless is a good word, you know. And then, around about 30, I started to think, well you know, now we got factor and you things are much more control and….geez, you know, I might be around for awhile. So, yeah, I mean I definitely modulated my attitude around age 30. I think when factor came out, you know lyophilized factor over cryoprecipitate. The cryo was a pretty crude approach. Not very efficient would be the right word. But when lyophilized factor 8 came out, then I started to really feel great except it became 1984 I am sitting in the doctor's office and I pick up Time magazine and there is a like a 25-page article about all of these hemophiliacs dying of AIDS. It was quite upsetting.*

One individual, age 55 who learned to infuse on demand young and imagined a relatively normal life expectancy reflects on how this information impacted his life and worldview. He recalls that as a child he had heard: *the number 36 was like a life expectancy during those years [childhood] but I didn't think about it much. Not until I was 19 when I found out that I was HIV positive. So, then I started thinking about death a lot more.*

Some recall actively avoiding taking products to control their bleeds. This was another type of 'cost-benefit analysis' to minimize their exposure to contaminated blood. While activity selection was not new, the consequences felt more dire. Life and death was involved with contracting HIV before there was effective treatment. However, decisions not to take these products could have saved their lives if they avoided contracting the HIV virus**.** A 60-year-old

mother recalls protecting her children and avoiding products while focusing on the development of future products that would be pure and available to all who needed them.

> *We did what I think a lot of families did, and a lot of mothers of children with hemophilia - you padded your kids, you helmeted them you cushioned them, you prohibited them from doing, doing and doing. And you tried, as much as possible, because at the same time, the new drugs were just coming up the pure drugs right.*

At age 62 and with mild bleeding also recalls decisions about product use during this time:

> *When was HIV... sort of '81, '82? I was doing some good physical retail jobs. Jobs that I shouldn't be doing but I was doing them. And I think by being a little more active and stuff I went through a pretty good period. But when I did have a bleed, I would look at my product and go, can I get by without it? Because, you just never knew which shot was going to be the one. There were times I let things go that now I would infuse in a second.*

A retired nurse working at an HTC at that time recalls patient confusion. She offers that NHF was instructing patients to keep infusing products; however, some patients decided that they were not going to treat their bleeds to try to avoid contaminated products. She shares that "*of course, by then, they were probably all infected because when you look back at plasma samples that a lot of the hospitals have kept you know, they were all infected by 81. Clotting factor was, you know, contaminated".* As this nurse predicted, some discovered that they were already infected with HIV. This was unequivocally a devastating experience that APWH faced in isolation and often with denial. One 76-year-old recalls learning from his physician that he was HIV positive as *"horribly traumatic".* Likewise, a 57-year-old African American with severe bleeding recalls that he learned that he was infected through a family safety study conducted by his treatment center. He recalls, "*the whole family…somebody would come down and draw our blood and that is how I found out that I was positive. Because I participated in that safety study……..How did you react? Denial, shock, denial. I was in denial for many years".*

Another participant learned her HIV status through a safety study. At 58, she recalls that, "*I didn't think that it was gonna affect me. And when I found out and I had a baby and I did the transfusion safety study….that is how I found out I was HIV positive, from a blood transfusion that they dated back to possibly I was positive in 84 when I had my second son".*

A 63-year-old male with severe bleeding recalls that in *"November '83, like everything changed. I got a phone call from the nurse at Stanford where I was seen. They tried to explain it to me. I said, "What's the timeframe?" And it's like, "We don't know. Worst case scenario is you'll be dead." There wasn't a whole lot of optimism*". He shares that his mental health suffered considerably after this phone call and he did not take an HIV test for a decade. He

fixated on improving his physical health through a restrictive diet and alternative health care methods such as acupuncture and Chinese medicine.

> *I didn't really worry too much about hemophilia after '83. It was more of worrying about HIV. And then '93, when I got tested, it was a very ... it was not the most comfortable. I mean, there was no prep. It was like, "Well, these are your options." It was more like, "Oh, your HIV test came back and your positive." They thought I already knew. So, I'd say that's where I really took a nosedive mentally and I started being more militant about my health and also coincided with my ankles deteriorating.*

Envisioning a Future

This sample of APWH span an age range of 22 years, with the youngest at 54 and the oldest, 76 years. Having survived a changing landscape of hemophilia treatment, the tumultuous AIDS crisis, and, for some, a diagnosis of hepatitis, they are moving forward and planning for their futures. Most never envisioned a life in their 60s and beyond. Some received life expectancies that are ingrained in their memory. A 67-year-old shares that his "*mantra since 12 has been that I have two years left".* This was based on a comment made by his provider. Others watched family and community members die at early ages and understood that they likely had a similar fate. A 76-year-old recollects, "*with my grandfather dying in his 40s, I always thought I would die young. And I've never felt I was going to live very long really, ever since then. But I'm still here".*

A nurse working with this population for many years comments on how APWH are facing an unexpected longevity. She also notes that many have not thought this far ahead or prepared for aging, "*this is really the first chance that a lot of hemophiliacs have been able to age. I mean, yes, maybe people live to be in their 60s, but they didn't really expect to be living until their 80s. They didn't expect to have this longevity, and so there was little preparation".*

Watching family and friends age has illuminated blind spots related to the aging process. This is especially true for a person who has held a positive attitude and has not dwelled on mortality, despite severe bleeding and HIV. In his case, witnessing his parents rapid decline has triggered an awareness that he, too, will continue to age. The 57 old referenced earlier shares:

> *I wonder with some apprehension, how, you know, once that aging….curve starts to hit me with…. my joints are already in bad shape and [I] have arthritis in all of them and so while I try to keep active and keep everything working okay…..I think when, you know, what is defined as old age and when that happens to me – if the rate of deterioration will just be, you know, very steep that all of a sudden, I won't be able to move my arm,*

> *won't be able to play the violin and things like that…..its sobering to see my parents age like that because, I mean, I think in a way, it's good because I have some appreciation of what is going to happen and hopefully I will not be as surprised as some people, you know?*

Another participant echoes that he does not know what to expect as he ages. He shares "*I've never really felt, until now, that I'm going to live very long. And I worry about that, because I'm 74 now. I think I'm going to live to be 80. And that makes me nervous".* At 63, one individual describes feeling as if he is in "*uncharted waters, given the hemophilia and the HIV. I don't know many guys that are my age... I know one or two".*

A 73-year-old shares fears of a mental decline over physical decline. This person has lived a life with severe bleeding and considerable disability. The possibility of dementia on top of his physical challenges terrifies him, as described in the following passage:

> *But what would totally drive me crazy would be being in this condition and being demented and not being able to take care of myself and my own [body], you know, that has me, you know worried…. [Interviewer]: So you've accepted the fact that a bleed might be the end? Oh, absolutely, when I was six I knew that obviously, it did it to me then and I knew what it meant – well, this is going to kill me so, you know, don't fight it, find a way to embrace it. [Interviewer]: But your – your mind – losing your mind is your worst fear? Oh yeah – that's pretty much the worst future I can envision so, you know, I have to make plans to be sure that I am in control, if you get my drift.*

A younger participant, at 61, feels certain that he will live another ten years. He is awed by "*the fact that I'm alive at 60 is pretty amazing considering all of the stuff I have missed and avoided".* Unlike the individual above who fears dementia, this participant is convinced that he will lose his life to cancer. He currently is estranged from his family and children and has no retirement savings. He shares that "*I think, probably, in five years I'll end up with liver cancer. You know, that's just the way that it is going to go….and if I do, I don't think that I will get treatment. You know, it's like, what's the point".* He explains:

> *it's just been a life of constant struggles and having to fight and…it just gets really hard to fight for everything all of the time. You know what, you know, everyone else seems to just kind of ride along and, you know, I had to fight through school, I had to fight through college, I had to fight through, you know, my entire life with, you know, medical problems and it's just caused problems left and right.*

Medical Advancements to Prepare for a Future

Advances in medicine generated pathways for APWH to manage pain and increase mobility. Prophylaxis, joint replacement, and gene therapy are interventions available to APWH as they focus on a future. Prophylaxis involves regular infusion of clotting factor to prevent bleeding, particularly micro bleeds that can be hard to diagnose and treat. Prophylaxis emerged in the mid 1990s; however, some APWH have been slow to adopt interventions. Traumatic childhoods spent managing treatment at home, a treat-on-demand mindset and experiences with contaminated blood products resulted in hesitation. As one individual, a 62-year-old male puts it, "*I'm in a state of questioning, but I have finally got to the point, and it's probably only been over the last 10 years that there's this saying: when in doubt, infuse".*

An individual, age 60 and of Asian descent, continues to resist new treatment modalities. He explains fear of the consequences and feels that he is getting by without these interventions.

> *Five years ago, as I said, I went to see the orthopedic surgeon for my knees and they said you can replace it but then you will uh you may get reinfected and it may need to be removed and redone, and there will be a lot of bleeding. So I said let me try to postpone, and I did and that was five years ago and I saw the same people last week and they said the same thing that it is better to do it now than later, the knee replacement. I said well, ok, I am not ready to do it so I am going to continue as much as possible without doing it. Maybe that is a bad decision on my part, maybe I should get it done.*

A nurse working with adult hemophilia patients at an HTC explains this resistance to new medications: "*If they've gotten to a point of using a product and they're at that generation to have had that trauma, they are very hesitant to just switch products. It's like, I've used this for 20 years. It works. I don't know what the other product will do to me or for me. So what's working, I'm not going to change".*

Those who transitioned to prophylaxis report considerable improvements and pain management. On participant reports feeling safer and more protected with prophylaxis, identifying the treatment as a , *"life changer"* but acknowledging that *the whole mindset was different for the prophylactics was that….avoiding issues with – with joints and so it's important – somewhat kind of beating them. You don't wanna…cause a bleed".* Another individual, aged 72, finds the prophylaxis amazing. He shares that" *with the care for Hemlibra, it's simply unbelievable. I take Hemlibra and its like you don't have hemophilia".* Prior to Hemlibra, usually administered weekly, his wife injected him every three days. Another participant, 55, shares that prophylaxis has "*been an amazing improvement in my life, since 2013".*

Fusions and joint replacement surgery are other strategies APWH pursue to improve physical ability and quality of life as they focus on a future. A 67-year-old shares that he:

> *had a knee replacement in my left knee over 10 years ago and that's been a real lifesaver in a lot of ways, getting in and out of cars and being able to go a little bit faster upstairs, not too fast. And then I have a right knee that's fused. And so the pain has actually kind of gone out of that knee because there's really no room for it anymore. But I have ankles that have suffered over the years because of knees.*

At 74, another APWH had a knee replacement 5 years ago and also found it life changing:

> *I had the knee replaced five years ago. And I don't know. The cost must have been staggering, really. I estimated at one point half a million bucks. And I don't think it cost me anything. I had loads and loads of factor, which I continued for weeks and weeks after finally getting out of the Kaiser hospital. It's a new leash on life, really. I can walk. I couldn't really walk hardly at all until I got the knee fixed. It's been wonderful.*

A 58-year-old with severe bleeding discloses that his future planning involves not only financial well-being but also fusions to repair the target joint damage from earlier bleeds. Since he is taking daily prophylaxis, he does not worry about new bleeds and wants to stop having to take painkillers to manage the damaged joints.

> *I guess, maybe I'm thinking long-term because I'm paying attention to money and I'm paying attention to planning. I don't know. I don't know how long I'm thinking, but that's why I got my ankle fused. It's like, I don't want to take drugs anymore. That's the only, that's the last target joint that I have on my list and I'm not going to get anymore because I infuse every day.*

A 55-year-old recently had gene therapy to treat his bleeding. He has been an early adopter of all new strategies to manage hemophilia. He began prophylaxis in 2010, which helped with managing micro bleeds. Although unsure of the long-term efficacy of gene therapy, he describes his experiences in the following quote.

> *A year ago, I took the gene therapy for Hemophilia B and I haven't had any factor for a year now and my body feels amazing. Like I'm not in pain anymore. Even the really destroyed joints – they just don't hurt anymore. I think that it's probably just microbleeds or something that used to happen and would keep me in pain and now just don't happen because I am at 60% of my factor, naturally produced.*

Experiences like this are confirmed by a retired HTC nurse. She reflects those patients feel like they have a "*whole new body".* The availability of joint replacements, prophylaxis and gene therapy creates "*a whole new world, you know, where they are able to kind of do whatever they want to do and travel and, you know, everything else".*

Domains of Aging

Hypothesis 3: Due to their historical milestones/trauma experiences, APWHs are experiencing unmet needs in 2 or more of the four gerontological domains: self-care, social networks, meaning of home, contributions that require specifically tailored interventions and programming.

In the interviews, questions were asked about all four key gerontological domains. We hesitate to quantify these data as participants focused on different aspects of their life at different times throughout the interviews. Some of the interviews occurred over multiple days, thus there was sometimes not a linear flow to the information gathered. Although we cannot provide statistics to represent needs in each of the four key gerontological domains, we provide a few example quotes that highlight participants' thinking and perspectives on their needs at this point in their development.

Self-Care and Putting Care in Place

APWH are focused on health maintenance and looking towards a future. Some are moving closer to loved ones and others are building medical teams familiar with bleeding disorders in an aging population. Most have a history of educating medical providers on their needs and advocating for proper care. A 58-year-old female with severe Von Willebrand and cancer shares her most recent experiences with a broken foot:

> *when I go to the hospital I have to go through, jump through hoops and teach them what they need to do for me. And tell them what I need. I need factor, I need to be infused…I have a broken foot, I am healing from broken fibula right now, um, you know and I have to go to the hospital and tell them what I need…they think that they know everything so I have to teach them how to infuse me because they want to hook it up to a machine and I say no, it's just a slow steady push of humate. You don't need to hook it up to a machine. I have been doing this for a long time, I'll show you how to mix it. You know, a lot of schooling, you know, teaching them how to do their job*.

At 62, one individual shares that *"if you are patient with hemophilia, you have to be your own advocate. You have to stand up for yourself, you have to, in a way, in a nice way demand that you expect better".* Considering how treatment for hemophilia has changed over 25 years, APWH are concerned about a younger generation of providers unfamiliar with bleeding disorder management. A 72-year-old with a wife in failing health offers that in this phase of life: "*Having the right doctors and support staff to take care of us. We are trying to be more careful. [name removed] had a bad fall in 2018 and was in a nursing home for a period of time. That was very tough because that is where she celebrated her 70th birthday".*

One provider confirms that a big part of her job as an HTC social worker is to educate physicians and nurses about bleeding disorders. She provides several examples of common issues facing the APWH population over the age of 50.

> *There's also the fact that, you hit 50 and then all these other issues come up. They need colonoscopies. They need all of these things, and so they have to be treated prior to these. And like I said, some of the women have needed stents and things, and even some of the men. And right now, it's sad but I think we have like five that are going to die, because they have had cancer. And cancer mixed we bleeding, it's a huge thing. You treat with this. Will this make you bleed more? Will this make you clot? It's a whole ... I know it's a struggle for the doctor to try to figure out, what is the right thing to do?*

To prepare for aging, APWH adopt new interventions to prevent bleeding and to manage pain. While these interventions are physically life changing, it is also important to attend to the mental health needs of this community. One participant, aged 52, offers that pain and mental health are intertwined – noting that his generation of hemophiliacs have suffered enormous pain caused by both physical and mental trauma that led some to get off track in their lives. He explains:

> *I think that growing up, I realized that I was in a lot of pain and pain takes away your focus on stuff and I think that not to jump off topic, but I don't know if this would be something for somebody presenting to the foundation. But if pain and mental health are, I think that's where the hemophilia community needs to go, dealing with those two things.*

He continues "*that there were moments in the last 30 years that I can point back to, like I had to have been in a ton of pain because nothing got done".* Others offer similar experiences – noting that their pain interfered with normal life progression, sometimes leading to mental health and substance abuse issues. For some, there exists emotional pain associated with a complicated grief for the loss of friends, family members and a whole community. As one mother who lost a son to AIDS contracted from the blood products:

> *there's a little survivor's guilt, I suppose, all hemophiliacs probably feel that but I mean, but I probably feel the more because I know the story, I mean I think hemophiliacs today don't know the story, they do not know the price that was paid by a whole generation of our children so that they can now live healthy and have synthetic treatments and not be, you know, live the rest of their life*

The male referenced earlier connecting pain with mental health, recalls seeking out mental health support from the gay community in the mid 1990s because they were familiar with the fear, trauma and anxiety of having a positive HIV diagnosis.

> *I started seeing somebody, I think around '96, maybe. I started, I think the only people that really gave a shit was the gay community. So I tapped into, there's a place down here called L.A. Shanti and I just started tapping into that. I went to tons of groups, it was all gay guys and I'm the only straight dude in there. We just talked about how we felt and that definitely helped. I mean, there wasn't a lot of stuff that I did that I didn't use as something to help me get to the next day.*

Accessing services from the gay community was a wise and unorthodox solution at this time in history. A provider working with the population notes that the gay community was one of the only places offering support groups for individuals with an HIV diagnosis. However, rampant homophobia often prevented APWH, particularly men, from seeking out these services. This provider began hosting support groups for men with hemophilia "*with 80-90% of the guys being HIV positive, so we were focused on that and coping with that and treatment and fear. We moved quickly into grief and death and dying stuff because, you know, early 90s, from month to month we'd lose somebody".*

Finance and insurance can be essential for pursuing the self-care options. Given that the APWH population did not envision a future, some never saved money to support their aging. A 67-year-old, recalls that he purposefully did not acquire resources because of a fear that they would be repossessed if future care was needed:

> *One of the thing it [HIV] did was…why would you ever accumulate assets of any sort because you know the hospital corporations and doctors are going to just take it all away, just like that. Because you went to the hospital and you couldn't afford to pay so they would just come and take away your furniture and your car and all that stuff.*

Another participant, 62, worries how to pay for medical conditions that are unrelated to his hemophilia, but he sees as holistically related. His severe bleeding impacted his work history and therefore his finances and insurance. He is dependent on public assistance and shares:

> *GHPP only covers stuff for your bleeding disorder. They don't cover CPAP machines or none of that stuff. No. They used to cover vision and they used to help with dental. They don't even do that anymore. And I chipped my teeth. I had a seizure, I accidentally double dosed my blood pressure medicine, had a seizure, and I chipped my tooth and I just got that fixed. That was $250.*

Social Networks

APWH in this study enjoy a network of friends. While some faced challenges with social relationships in childhood, as adults they have found partners, raised children, and built networks of support. As with anyone in mid-life, some are in second or third marriages, some have retired and some have relocated to live closer to adult children. At 57, one participant remains exceptionally close to his parents and siblings. He has also maintained close relationships with college friends for over 30 years, "*with my siblings, it's all been very close. My……college friends um - we, so that's one thing that I was active in that's a little bit - possibly surprising, even for a hemophiliac, I guess my age is that we snowboarded regularly".* Other participants also describe long-term friendships. Another 76-year-old shares that, "*roughly in the mid-1980s I ran into two or three extraordinary people and I've been associated with them ever since, and I would say that's where my life really changed".*

Some built lifelong relationships and supports via engagement with the hemophilia community during different life phases. A few participants find themselves as playing an 'elder' role within this community, exemplifying what aging with a bleeding disorder looks like. One 67-year-old retiree notes that "*I tried to be a good example of an older person with hemophilia for the younger kids, to have confidence in themselves that they could continue on".* A woman with and mother to children with severe bleeding shares:

> *I have a mother's group that started in kindergarten at that school where they started and I'm still meeting with them once a month minimum. And those mothers prayed for my children from the day they met them today. And I pray for their children.*

Support groups play a vital role in the lives of women somehow affiliated with the hemophilia community – whether having a formal diagnosis or not. A 59-year-old woman with a late-in-life diagnosis shares that there are several support communities for women who are "*struggling with symptoms of a bleeding disorder….heavy, painful periods….and bruising"*. These communities host virtual meetings, in-person meetings and retreats that provide vital social opportunities that some participants grow to rely on. At age 58, one participant shared her disappointment that her HTC support group cancelled its Christmas party because of COVID-19. She shares that they canceled our "*hemophilia Christmas party that we've had every year since my kids were little, and they canceled it this year they're only doing it in Northern California. So I was a little disappointed in the hemophilia community for taking away what little we had here in the valley".* Support groups for our APWH population appear to play an important role in the lives of some of our participants, particularly the females.

Meaning of Home

APWH did not specifically address the role that home plays in their lives. However, being cared for was discussed by several participants. Some are now becoming caregivers, which is addressed in the key generational domain Contributions. Asking the question "who will care for me" can be attaches meaning to places or spaces for aging. This is an especially complicated issue for APWH who are single or never had children. A life-long bachelor observing his parent's decline wonders who will be there for him when he ages:

> *So, so my both my siblings have families. Have two kids and they have, you know, they're like……..with the family structure, they'll be taken care of in some ways. And so, some of my mom is a little bit, she's like, you know, someone better can take care of you…. you know, when you get old…. being a single person, I guess.*

A female participant, 54, living with and caring for an aunt since separating from a husband she has been with since high school also wonders who will take care of her as both she and her aunt continue to age. She offers, " *I think about who's gonna take care of me because I don't have kids, so I think about my niece or whatever. I don't know, we'll see when we get there".* This is also a concern for those who have children but are divorced. A few disclosed strained relationships with children, ex-spouses and finances. One individual, 61, shares that "*I don't have retirement money, I don't have all kinds of stuff that you know most people have at this age because of divorce and disease and all kinds of stuff".* However, he recently remarried reflecting that upon meeting, "*we started to talk and we went out to dinner a couple of nights. And then I went down to LA a couple of times where she lived and I said 'what the hell, let's get married'. I don't have a lot of time left. I'm tired of being alone".* .

APWH, particularly those with limited family support, have good reason for concern. Options for assisted living are scarce and complicated as explained by a 63-year-old man living alone:

> *Law does not permit infusing factor inside these facilities [assisted living]. So my ability to be in a retirement/assisted living facility is non-existent – I'd have to go out to the a parking lot or have somebody come. I can't even keep the factor VIII in the facility with me. The laws have got to change from that standpoint because that's a really challenge for us.*

An HTC social worker confirms this situation, sharing a real-world client example:

> *So we had a person, he was sick and he was dying. And he had to be in that facility. And so, do you know that every time he needed an infusion, they would have to take him by*

> *ambulance to our hospital? So what we did was, we found the skilled nursing facility down the street from our hospital. And literally, they would bring him over to the ER. He's get his infusion, and they would take him back.*

Lack of a safe places for APWH concerns social workers engaging with this population. As one HTC social worker shares that, "*a lot of our men who are older….they didn't get married, maybe because they have HIV, because of something that happened or they have HepC and they don't want to pass it one…..And so, they kind of live alone, not huge families. And so, one of my concerns is that your out there by yourself. If something happened to you, who would know"?*

Finding a safe home to age is also complicated for APWH who have had long and happy marriages. A 72-year-old man with severe bleeds is now watching his wife of 51 years physically decline with a rare illness. The couple recently relocated to live closer to one of their children and her family. He offers that, at this point in life, his biggest focus is *"just making sure we keep our health and our wits about us and enjoy the kids".* Although this APWH did not share concerns about what will happen as their health continues to decline, an HTC social worker relates that this is a conversation that tries to have with her clients. For example,

> *We have people's spouses who are dying, and so I'm like, "Well, what is the plan going to be for you when your wife passes? Because she's sick." We have one that has Alzheimer's. "She's the one who infused you. What's your plan going to be? Who's going to be there to help you, take care of you?"*

Contributions

Despite the many challenges that have faced this population, they also make important contributions. Some are actively involved in political advocacy to improve care for people with hemophilia. The hemophilia community, overall, has been politically active in their advocacy efforts over the past four decades leading to, for example, The Ryan White CARE Act and a lawsuit against pharmaceutical companies who sold contaminated blood products. APWH in this study recall engagement in advocacy around medical insurance coverage denied by employers. A 76-year-old remembers that, "*I went all the way to the one level below the Supreme Court in {name of city} and because {name of insurance company} wouldn't insure me I got a {name of insurance company} through a job and then {name of insurance company} dropped me when I changed jobs"*.

Although GHPP provides a cushion for APWH who need coverage for care, each year, the hemophilia community activates to advocate for continuation of this very important healthcare coverage. A 63-year-old participant offers a stark reminder of why it is important to continue this advocacy work:

> *people don't realize this but, I, being a hemophiliac, I was under a pre-existing condition and, in fact, I think this month the US Supreme Court is going to either throw out the affordable care act. If they throw it all out, then pre-existing conditions come back and that is a scary thought. As a hemophiliac, again, we recognize had it not been for GHPP, with is a Genetically Handicapped Persons Program in California, it was a viable step for me and I did have some bleeds.*

An HTC nurse serving adults with hemophilia confirms that the need for continued advocacy around GHPP and other resources for the bleeding disorder community: "*Even though the state of California has GHPP, that's a rare thing, and GHPP could go away tomorrow. Our HTCs have fought long and hard to keep it in place, but it'd be nice if there were wider guarantees, not just for the state of California, but across the United States".* Another provider, working in administration, also shares that "*we work really hard in Sacramento with keeping that program [GHPP] funded with making sure that if there's any issues with people's GHPP applications, we resolve it immediately".*

Others have contributed to the hemophilia community through hosting social events, support groups and providing education for families new to bleeding disorders. One mother recalls that:

> *I was also running family camp at the time we started that I think in 90 we started that in 1990. So, we were doing family camps, I was also doing a lot of the chapter outreach to young families because I had three young children and I wanted to make sure that they were active and in the community because of what previous history we've had had with contamination.*

A 72-year-old with severe bleeding recalls that when living in Scottsdale, Arizona, he visited the Hemophilia Treatment Center to inquire about volunteering. He quickly adopted a leadership role, becoming President of the HTC for seven or eight years. Another participant launched a pharmaceutical company offering home delivery of factor products. He developed this model after experiencing long waits for products to manage his bleeds. In addition to creating an alternative way for families to receive their products, he also created a career pathway for teenagers and young adults with a bleeding disorder, and then cared for them when they became too ill to work.

> *For most of them, it was... It ended up being a career path. The ones I'm thinking of... Actually, they all passed……They all died. There was probably 10 or so different ones that have worked for me over the 30 something years. Then, that became their main job. It was a full-time job for them, until they got too sick to work.*

APWH continue to visualize opportunities to contribute to the hemophilia community. A long-time provider shares that support groups are important for this generation. She explains that, "i*f they've made it past HIV and Hep C, you know, its quite amazing and, um, I think the support groups are good because they get to meet other people who've survived and know that they are not alone".* Another provider believes that there is an important role for APWH. She shares that her organization recently hosted a program called Ages & Stages of Having a Bleeding Disorder where individuals across the lifespan shared their stories. She recalls that "*an older guy, I don't know his age…it was really powerful, I think, for the children to hear from the older men. Especially, you know, we're always trying to talk about the HIV crisis because it is shocking to me that people don't know".*

Given their anticipated life expectancies in childhood, some APWH are engaging in caregiving roles that they had never visualized. Several care for aging parents, particularly during the COVID-19 pandemic. One individual supporting his parents over this past year identifies that his experiences with disability are useful for helping his mother cope with physical losses:

> *I have a little appreciation for these kind of phases that – that you have to work through when you have, um, a total loss of functionality….and for my parents, my aging parents – they had it, it's like a lot of ways its kind of [their[first experience that and she's [mom] like 'oh, you know, you don't understand, I don't have my balances' and, like I do understand….um, keep moving.*

A divorced male, age 62, who was not diagnosed until young adulthood and thus with considerable disability shares a home with his mother. While he would like to date and pursue a relationship, he also realizes that "*I'm going to be here with her taking care of her probably until the end or unless she makes a decision to go be closer to some of her family that's her age or whatever – they, you know, live in [name of city] or whatever".*

Another individual, age 62 recalls moving around as a child due to his father's military service. He remains close with his mother, turning 85 this year, and visits her daily to watch The Bold and the Beautiful together. He reflects that this is incredibly rewarding, describing that, "i*t's gone full circle, man. I'm her caregiver now."* Another individual, 72, provides his wife care similar to what she has provided him for 50 years: "*She needs to be more careful. She used to tell me not to do things, now I tell her not to do things".*

Important Emergent Themes

Gender Matters

Six female APWH are included in this dataset. All have a diagnosed bleeding disorder, with four experiencing severe bleeding. These interviews illuminate that gender matters when it comes to diagnosis, disease management, and care. All of the women related complex bleeding histories and note how their bleeding episodes differed from those associated with males. For example, one woman with two brothers identifies that, "*my bleeding was different from my brothers because mine was typically caused by trauma….no spontaneous bleeding and it had to be major trauma whereas for my brothers, any little trauma caused a bleed".*

All but one woman recalled painful and traumatic menstrual cycles. A 58-year-old remembers terrible menstruation and no treatment, "*I had really bad menstrual cycles when I was in high school even though I would have to call my parents in the middle of the day [saying], hey you need to come and get me because I bled through my pads. That was a huge, huge issue. Menstrual cycles. And those stopped for me around 40….around 42".* She recalls that her mother had similar issues with menstruation, and so it was accepted as is.

Another woman, at 60, recalls watching her older sister suffer through menstrual cycles, also having to be sent home from school for bleeding through her menstrual pads. She shares that she was terrified for years about what her cycles would be like once they arrived and *"always carried an extra sweater an extra jacket an extra something and always tied it around my waist thinking that's how it was going to be".* This same participant, who is from Mexico, shares that she received no medical treatment from her physician. However, her family likely understood consequences of severe bleeding as evidenced by her memories of being fed gelatin prepared by her mother and grandmother. "*My mother would give us protein broth so I remember, she would give us a lot of bone broth. She would make bone broth it was what her great grandmother, who was a doctor did, for all her girls in - my grandmother did for all, for all her kids".*

Another woman, not diagnosed with hemophilia until she was 68 shares traumatic bleeding episodes throughout her life, particularly related to menstruation:

> *all now makes sense, with the diagnosis, it was pretty traumatic with a lot of bleeding episodes….it was very embarrassing and in elementary school just constant, I would just gush bloody noses all over my desk and I, it was just always immersing and then the menses was horrific it was like three weeks out of the month. I bled on everybody's furniture, every car I rode in, and it was mortifying and I - it's amazing to me that no one ever thought to say gee, maybe she should see a hematologist. No one ever did, and they just thought Oh, you have like dysmenorrhea, heavy periods you just have you know*

> *and it just - people weren't in that era aware at all there wasn't much treatment, because now we're talking what 50s 60s 70s and people had no idea, and it was - it was really, really rough from childhood to - to being a young woman to even being a mother and very traumatic, you know childbirth……*

A service gap for women with bleeding disorders is clear from the data. Two women were not diagnosed until midlife while raising children with severe hemophilia. The four females diagnosed early had mothers and sisters with existing bleeding diagnoses with provider networks already in place. Lack of diagnosis and treatment for women appears to be an area of exploration in the hemophilia community. As one woman explains, "*I think, unfortunately, we are set aside from being properly diagnosed and treated because they are carriers right, we were just carriers".* A female provider interviewed confirms issues around female diagnosis and treatment, explaining that:

> *I think there's a lot of prejudice by providers towards women, and a lot of this is because historical approach to hemophilia. I was shellshocked by this, that a geneticist will never tell a woman she has hemophilia unless she is diagnosed with both her X genes having the missing gene or whatever. So a woman can have the same levels as a mild hemophilia, but because she, by a geneticist's term, cannot have hemophilia, then medical professionals will just tend to discount that she has hemophilia.*

A social worker providing care to this community for over three decades echoes this sentiment about a historical oversight regarding women with bleeding disorders. He shares:

> *...the disparity in women's health care and the ways in which women are not taken seriously, a lot of the time, particularly with bleeding disorders. There's a whole section of blood disorders called von Willebrand's disease, there's that word again, there's platelet dysfunction situations and because male and female doctors – gynecologists, obstetrician, all of them, had a day or two of training in medical school about bleeding disorders, they often didn't know what they were looking at and, back in those days, they were sending women home who were having their menstrual period for three weeks out of the month and just telling them that there was nothing wrong with them and that they were being hysterical when, in fact, there was something very wrong with them….*

In some cases, women are not aware that they are carriers. A female, 59, was diagnosed after giving birth to her second son who was diagnosed with hemophilia. She realized after the fact that "*I did have two uncles that passed away, but we did not know that they had a bleeding disorder until my second son was born and then we went back and looked and realized that they*

most likely died of hemophilia but weren't diagnosed with it". This experience is explained by a nurse working at an HTC:

> *The sad thing about hemophilia is that it gets lost in generations. So, for example, we had a young child get diagnosed at birth. Circumcision bleeding led to diagnosis. Then, after we met the family, we realized that his older brother, age 4, also had hemophilia, signs and symptoms that had been ignored.*

In another case, a participant knew that she had mid von Willibrand but did not fully understand what that meant. She went in for a surgical procedure at 15 and, because of bleeding, received a transfusion of contaminated blood. She recalls that, "*I remember that my mom wasn't there, she was out of town. My Dad didn't go and I think that there was a little bit…I don't know if I got an infusion before but there was bleeding so they had to give me a transfusion. Then it was cryoprecipitate. It was 1982…"*

Female APWH report a growing acknowledgement of their complicated situations. A mother of three relates, "*it is wonderful to be acknowledged, you know. And that, I think is a privilege if you are a female hemophiliac. Very few women get acknowledged. They get ignored….I mean, where do you think these hemophilia boys come from"?* One provider shares that they are now scheduling women's bleeding programming in front of families because "*we want to overcome that shame culture",* speaking of the heavy bleeding women experience during their monthly cycles.

Wrestling with Complex Emotions

A second emergent theme focuses on the complex emotions that APWH have managed throughout life. For example, consequences of not participating in physical education classes or contact sports contributed to bullying and social exclusion. These memories illustrate how traumatic some continue to be for participants. Sitting out of PE courses or being placed in special education classes could be especially traumatic. A male in his early 60s recalls that:

> *I just that it was…that was a hard thing because at the time we had some kids with, I don't want to say Down Syndrome but slower learning disabilities and I'm not familiar with that. But I was put into a group of those kids and some of them were very slow and it was frustrating because as a child, then you are categorized as a dump kid, stupid. 'Look, he has to sit over there with those kids. And it – that was a really hard thing.*

Some report trauma related to social isolation and misunderstanding. One female remembers attending school during her periods as "*very traumatic",* feeling additionally hurt that her discomfort was misunderstood by her stepfather and teachers. Another participant, male and 76, recalls childhood bullying as "*a horrible thing, a horrible way to go about things. I think it reinforces a sense of cruelty which people so easily drift into sometimes".*

These insecurities and traumas did not always end at the school yard. A male with severe hemophilia and an HIV diagnosis recalls "*pain in sexual intimacy area over the years……So, having to go through that extra step of using the condom, it was like a slap in your face reminder that you had a problem. For me, a lot of times, it overwhelmed me".* A social worker shares that this aspect of intimacy for APWH is complicated and something that he continues to focus on with clients to this day sharing that "*I just think that it is a commonsense thing to think about how having an intimate relationship with somebody is potentially lethal, right?"*

Others recall coping with layers of intersectional identities One participant 62, describes his *"identity as a gay man, a hemophiliac who has survived HIV, who has survived hepatitis C, has joint problems…*" This was a particularly challenging situation given the rampant homophobia in the hemophilia community. A social worker recalls that "*there was a lot of pointing and blaming towards the gay community about 'you gave this to us' and 'we're the innocent victims and that kind of thing",*

Others recalled trauma related to the health care system. Long hospitalizations, painful infusions and providers who may not have had the gentlest of bedside manners. One male participant not diagnosed until young adulthood recalls that:

> *I used to have all these injuries in my hands, in my ankles, in my legs, and missed a ton of school, and spent a ton of time in emergency rooms getting x-rays. And those were always traumatic, because they would try to straighten out an arm that didn't want to straighten out, and so they were causing more pain or as much pain as the bleeding disorder. And they would just say that I bruised easily. They told me that the bruises wouldn't cause any damage, and I found out that was a lie.*

A 74-year-old vividly recalls an incident at age 8 when he was in the hospital for 3 months after an injury. His parents were not consciously aware of his mother's family history of bleeding so no one knew what was wrong with him. After a 3-month hospitalization, they discovered this family history of "bleeding" which ultimately led to diagnosis. He becomes emotional describing this experience and recollects that time as:

> *unpleasant……you know, they didn't know what the problem was so I had to undergo a variety of tests and what have you. And several of those tests were….uh, done incorrectly and had to be repeated. So, uh, that left me with very negative impression of the medical personnel's ability even though I was only 8 years old at the time.*

He later adds that "*I used to go to sleep and hope that…it would st…[cries]…that it was just a bad dream".*

Some participants acknowledge that they hid their hemophilia and, in some cases, their HIV, for their entire lives. A 62-year-old male shares that "*I have lived a big lie my whole life. My whole big lie was, I really don't want people to know I have hemophilia. So very few people knew. I would lie about why I was in the hospital, I would lie about anything to protect the lie".* When asked about the origin of the lie, he responds that "*It was just self-preservation. I just didn't want people to know. And when they did find out I got treated differently".*

Two others from the same generation also recall hiding their hemophilia. One, at 72, "*always hid my hemophilia, from everyone, because I didn't want to be treated differently".* Another, age 74, remembers being told by a medical provider to never to tell anyone about his hemophilia diagnosis, "*After grammar school, which is equivalent to high school here, I never disclosed to anyone, other than some lady friends, that I have or have had hemophilia. It was a secret, really, and until I no longer needed it to be a secret, which was when I finished employment in 2002".*

Hiding this important part of their identities compartmentalized parts of their lives as they managed their treatments, traumas and fears in secret.

Unexpected Opportunities and Barriers

Opportunity to interview non-English speakers

Our original research design intended to include only English-speaking study participants. Therefore, the representation of non-English speakers is not represented in our original proposal. At the end of our data collection period, the social work practitioner on the research team identified two persons willing to share their stories, in their native language of Spanish. In July 2021, we were able to conduct two interviews with Spanish speakers who relied on GHPP. In order to conduct these interviews, the research team hired a CITI-Trained bilingual translator onto our team to assist in the interview. In advance of data collection, the interview guide was translated into Spanish (please see appendix X). These Spanish interviews involved the researcher, the translator, and the interviewee, where the translator asked the questions to the interviewee. After the interview, the researcher and translator reflected on the responses related to the themes of the project.

Due to this additional data collection approach, the analysis of these two interviews has not been fully completed. We plan to have the interviews translated into English in fall 2021 and following that, conduct deeper analysis.

Below, we have summarized the interviews:

Interview One

Our first interview was with a non-English speaking immigrant; this interviewee's insight was extremely valuable. This interview was of an older Mexican male who's suffered from Hemophilia throughout his life. He revealed to our translator that his younger brother had passed away from Hemophilia as a child, and often used the word "suffered" to describe his experience with his condition, as the translator explained. According to the bilingual translator, he came to America undocumented, and he expressed his appreciation for the medical system in place in the U.S.A. Similar to our other interviewees, he spoke of having a fear of dying at any time throughout his life. In addition, like many others in our study, he revealed difficulties as a child because he was bullied and was constrained from full activities (e.g., sports). He works as a professional landscaper; his job requires physical exertion, and like others in our study, sees the connections between their physical activity levels (for work or recreation) and the maintenance of their health. He is a current user of GHPP, so like others in the study, he plans to remain in California to ensure he will have adequate resources for his hemophilia.

Interview Two

The participant is a 54-year-old male born and raised in a small town in Mexico. He has severe hemophilia and lost both a brother and grandfather to bleeding episodes. He recalls three severe bleeds in his life, one resulting in amputation of his toes. He was flown to Mexico City to receive treatment for his bleeds. The participant moved to the United States shortly after September 11, 2001 to join two older siblings living in California. Although he struggles with arthritis and visible physical disability, he tries to live as normal a life as possible. He is single, lives alone and is financially insecure, only working part-time at a restaurant after losing his full-time job because of COVID-19.

To capture the narratives of individuals with hemophilia from different linguistic and cultural contexts, the research team strongly recommends inclusion of non-English speaking APWH as their lived experiences including at times, cross-national and immigration experiences, will help to understand the concerns of this population. We also note that many interviews conducted in English may be with individuals representing different cultural backgrounds.

Barriers Related to Conducting Focus Groups

An objective in this research project was to conduct focus groups. Gender, time of diagnosis, level of community involvement emerged as interesting aspects of aging with hemophilia that we would have liked to discuss more in a group format. Through these discussions, parallels in experiences and emotions would arise leading to greater understanding of this population. However, this idea did not come into fruition due to a lack of participant interest.

Our attempts to assemble focus groups consisted of circulating a recruitment flyer by email to various mailing lists of those with hemophilia, as well as our social work practitioner, Dana Francis, asking potential participants if they would be interested in joining a focus group discussion. Specifically, our research team attempted to put together a group of all male APWH to grasp their particular experiences as they constitute the majority of those aging with hemophilia. Given the unique challenges of women with hemophilia (e.g., difficulty with diagnosis and treatment access), we also wanted to gather a group of women to share their stories. While two female participants offered to assemble a group, ultimately, this too was unsuccessful. There are many possible reasons why we were unable to conduct focus groups.

This project, like many research projects, faced difficulty due to the preoccupation of individuals due to COVID-19 pandemic challenges. Also, the social work practitioner on our team thought some approached had shared their journeys with hemophilia numerous times before, a case of participant research fatigue. Lastly, because the focus groups would have been conducted virtually, it is possible that also zoom fatigue and the digital divide could have contributed to the lack of participation.

In future efforts to form focus groups, we would attempt to manage zoom fatigue and oversaturation by interviewing in-person. For example, making the individual interviews shorter in the future may help reduce the exhaustion of recalling and sharing emotional experience. Also, potentially matching participants based on shared experiences in their individual interviews, as opposed to only through their demographics, may make focus groups a more intriguing idea to participants. Lastly, attempting to produce more comfortability and assurance through face-to-face conversations in the future is definitely essential to the effectiveness of focus groups.

Study Limitations

Recruitment

Our non-probability sampling approach and relatively small sample size did not ensure distribution across race/ethnicity groups, gender, geography or age. We did not have a quota for ceasing recruitment for any of these characteristics. We also must acknowledge the California based nature of this study. Thus, other states with different insurance programs, geographical distribution of Hemophilia Treatment Centers and numbers of professionals serving this population may all affect the lived experiences of those APWH and professionals serving them. We also did not interview participants using languages other than Spanish or English.

Virtual Data Collection

By conducting interviews on zoom or in a few cases, telephone, it made it difficult to observe a study participant's engagement with their residential settings which is one part of the social worker's "person-in-environment" approach. Residences tell much about a person, including their social network (who lives or visits), possibly their socioeconomic status and how their physical health fits within their environment. For example, observation of one's gait or other aspects of their physical ability/disability may impact how they navigate their home, their fall risks, their use of assistive devices or need for assistive devices that are not currently being utilized. So, while interviews were rich, the research team wonders about what is missed seeing only a face on a screen. In addition, we wonder if the research team members had been able to have face to face interaction, would other details of the participants' stories have emerged with greater rapport and trust that would have been attained with an in-person interview.

We also were limited by persons' access to technology. While some chose to use telephone call-in numbers (a zoom-based number was given out, so the interview could be recorded on zoom with voice only). They may be others who did not have this access, who would have agreed to a face-to-face interaction. Zoom fatigue for this research project in addition to other virtual obligations participants and potential participants were experiencing probably contributed to the execution of this research project. The use of technology also privileged email and use of listservs for recruitment rather than more face-to-face recruitment (e.g., in the Hemophilia Treatment Centers).

The study is also limited by the lack of group discussions with participants as discussed above, so we may have lost out on how a group discussion might have spurred agreement or disagreement (e.g., needed policy changes or barriers to service utilization).

Data Analysis

We approached data analysis by reviewing recorded interviews and transcripts. For most of our transcripts, research partners worked together in small groups to develop codes. In some cases, only one member of the research team analyzed the data. While these codes were subjective by the nature of qualitative research design, but after receiving training on qualitative approaches and multiple discussions of coding processes, the codes revealed *themes across interviews* that the research team believes allow us to reach saturation of themes that factors in an intersubjective "human coefficient" to support the validity of our findings .

Plans for Dissemination of Results

We plan to disseminate the results of this project. We have been grateful for the interest in the project and have already received publicity at Wayne State University (see Appendix J) and among national social work audiences (see Appendix K). The National Hemophilia Foundation has also highlighted this project (see Profile in Appendix L).

In late 2021 and early 2022, the research team has the following plans:

- Dr. Perry will be a resident scholar of the Wayne State University Humanities Center to devote time weekly to the dissemination of results from the project. Please see Appendix M for the appointment letter.
- The students will co-author a blog about this project for the Detroit/Wayne County Authority Health to publicize the experiences of this population.
- The students will present their work on the project to fellow Wayne State University students at the Undergraduate Research and Creative Work student symposium.
- Members of the research team plan to apply to present results at some of the following: Society for Social Work and Research (2022), American Public Health Association (2022), Gerontological Society of America (2022), and the World Federation of Hemophilia Global Policy and Access Summit (2022). The team will continue to develop additional presentation venues and manuscript opportunities to present results.
- Project Team members will present at the National AIDS Memorial World AIDS Day on December 1, 2021.
- Dr. Schwartz and Dana Francis are developing plans to archive these data and to continue our work capturing stories of this generation through the National AIDS Memorial Hemophilia Circle of Friends.

- Future grants are being targeted to the NHF and the NIA that will involve larger and more diverse samples and more specific research questions.
- At least three articles are planned for submission to peer reviewed journals that require involve a deeper and more selective coding of specific themes discovered in this analysis. The articles will be co-authored by the students and investigators on this project.

Recommendations

The research team members developed these recommendations based on our study findings based on interviews with APWH and professionals from various sectors related to this California-based project. Our research team, including social work faculty, social work practitioner, and students, organized these recommendations around current and future cohorts as well as systemic recommendations requiring current and future collaborations with multiple stakeholders. We are heartened that some of these systemic recommendations are already being put forth (as we heard about them in our interviews), so our listing them here is to ensure that ideas remain on the table.

The importance of the study site

This study was purposefully based in California due to its innovative insurance program, the Genetically Handicapped Persons Program, and the research team's connections with the community of interest. Beyond those reasons, we point out California's unique past, present and future contexts including its size, population, and diversity. The state also serves as a historical marker in the early days of the HIV/AIDS pandemic and continues to be the site of the National AIDS Memorial Grove. The recommendations below also reflect our study site. For example, partnerships-based models of managed care present in the state of California will have a different composition in other states.

The importance of capturing a range of experiences

This study also offered a diversity of the range of experiences and perspectives of those aging with hemophilia. Many experienced the loss of others, due to their medical diagnoses including HIV/AIDS. Some were living with varying disabilities, due to living longer than expected. Others are active and enjoying enhanced health due to recent medical innovations like gene therapy. Some may not have had plans for the future and had to scramble as longevity offered possibilities and/or challenges. For example, some utilized the Supplemental Security Income (SSI) as a key means of financial support as a result. However, some APWH pursued career

plans and had successful and long careers, with comfortable retirement means. We strongly encourage future research on current cohorts in other states, and with subgroups, to further fill in understanding APWS and conclude our report with our last section on next steps for research.

I. Recommendations to support the current cohort of aging persons with hemophilia

a. Recognize the variation within those aging with hemophilia

Those aging with hemophilia includes those whose life expectancy has expanded (e.g., parents informed would not live past childhood), but also others who develop or become diagnosed after childhood and sometimes, after experiences with parenting and established careers. Therefore, programming and advocacy should address a wide range of experiences across the life course including later life diagnosis due to having an acquired bleeding disorder, or having mild hemophilia that has gone undiagnosed. In addition, there are other important vectors of differentiation, including gender (see more in Recommendation Ic.), race/ethnicity (see Next Steps in Research) and socioeconomic (see more in Imagining a longer time horizon for future cohorts, immigration).

b. Recognize that changed time horizons lead to new identities and new social roles.

These new identities and new roles include considering how to care for oneself in older adulthood to promote physical, emotional, and spiritual well-being and how to decrease social isolation by staying connected to family/kin, peers, friends and local organizations through volunteering or hobbies. These new identities also include considering one's financial well-being and future.

This may also include considering the role within one's family/kin network of being a grandparent or great-uncle/aunt/elder member of the family. Legacy building within a family/kin through passing down stories, traditions or valued possessions may be part of these roles. In addition, legacy building can be considered for contributing to wider communities like local and national initiatives, and organizations specifically supporting persons with hemophilia.

One social role to highlight is that living longer may lead to meaningful caregiving roles, where the APWH offers care to family members including spouses/partners, children and grandchildren, as well as to others in their community like neighbors or friends. For this population, most did not imagine this caregiving role and the reciprocal nature of care, given that 1) most had received care from family members over the years and 2) most had also concentrated on their own health and well-being. Caring for others offers opportunity for reciprocity possibly to those closest to them, and provides purpose in life in new ways.

Lastly, those diagnosed later in life may have to take on the new identity as a person with hemophilia, learning about the disease trajectory, history including medical advances and HIV/AIDS pandemic.

c. Promote visibility of all genders living with hemophilia

Our project aimed to understand the gendered experiences of aging with hemophilia. As gender is non-binary, we wanted to include a range of genders in our study. While our study was not able to include those individuals who do not identify as male or female, we aim to acknowledge and support all genders living with hemophilia.

The self-identified female participants in our study expressed gratitude for their inclusion in the study. For the self-identified females in this study, we recommend visibility of their concerns at different stages. Our study uncovered great lengths that women seeking diagnosis and treatment including access to medications. It is evident that systemic barriers are not facilitating care for all aging women with hemophilia.

In the diagnosis phase, greater access to professionals knowledgeable about symptoms, or asking mothers with children with hemophilia whether they would like access to testing for hemophilia. Specifically, those women who see obstetricians/gynecologists for "heavy bleeding" or "bleeding during delivery" should also be considered for testing for hemophilia. In terms of treatment, women should be treated holistically, acknowledging their medical histories and current concerns such as medication access, but also their social networks and resources. Related challenges like osteoporosis as well as should be addressed through programming.

d. Enhance mental health support and access to those aging with hemophilia

While progress has been made in this area, we want to point out that the complex medical and social histories of this population necessitate ensuring access to quality mental health support remains a key recommendation. Our study identified themes of trauma, shame, stigma, and cruelty that wound. In addition, this cohort has faced a series of unparalleled losses. The access to mental health care is dependent on one's insurance (e.g., those with private insurance may have greater access vs. those on MediCAL/GHPP). In addition, due to these complex histories, we recommend securing access to experienced mental health providers as many individuals aging with hemophilia may offer socioemotional complexities with intertwined family

histories due to the genetic component of this disease, that emerging mental health professionals may not be able to fully address the complex needs of these professionals.

e. Continued visibility of the history of this cohort

Those aging with hemophilia today has experienced so much in their lifetimes in terms of medical and social histories including medical advancements, the HIV/AIDS pandemic and the new social roles that longevity offers. The ongoing COVID-19 has triggered memories of the HIV/AIDS pandemic in many, and the parallels in terms of living with uncertainty, and mobilizing for research and advocacy echo previous work on HIV/AIDS.

In the near future, focus on understanding and rendering visible the lived experiences of those aging with hemophilia will serve as tributes to resilience and offer legacies of learning for future cohorts.

II. Recommendations to support the future cohorts of aging persons with hemophilia across the lifespan

Our study uncovered experiences that clearly impacted the current cohort of those aging with hemophilia. However, we also foresee that some of these concerns will continue to impact those with hemophilia. Addressing these concerns present at earlier life stages may help the future cohorts of when they age.

a. Address childhood and young adult concerns of identity and inclusion

Based on our interviews, we learned much about the current cohort's early decades. We do not see that these experiences would be evidenced in the same ways in future cohorts. In the childhood and young adult stages of future cohorts, we anticipate due to medical advances that neither physical disability due to hemophilia (e.g., limping or crutches) may not be as present, nor policies about not being able to participate in gym class or sporting activities may be preseent. After hearing themes of stigma and cruelty/bullying by others, we are hopeful that future cohorts will have fewer of these deeply impactful, negative experiences. However, stigma, cruelty and bullying may occur in different ways as hemophilia may continue to be in some circumstances a marker of difference. In addition, children and young adults may still need to explain their conditions at times (e.g., when they need urgent medical care to those who don't understand hemophilia). Also, in medical settings they may still need to explain to medical professionals who may not be familiar with

the condition because of lack of sufficient medical education. Therefore, equipping children and youth with the skills to explain this aspect of their identity is important. It is worth noting that there may be new identity issues for children and youth related to their hemophilia unknown at this time.

b. Strategize for disclosure in the workplace

Future cohorts may need suggestions on the critical timing of disclosing their hemophilia in the workplace and in personal relationships. For example, some helpful, perhaps peer-based discussions of experiences, may include whether to disclose during the job interview process or in the early days of starting a new job. In addition, with whom to disclose (supervisor vs. human resources professional) and for what purpose (e.g., accessing health insurance) may also be part of this strategy.

c. Help envisioning the reality of a longer time horizon

Future cohorts may need explicit help envisioning what a longer lifespan will look like for those with hemophilia. These future-related exercises can be related to the professional realm including educational choices, career counselling and financial planning. This can also be related to the personal realm, such as self-care for health and well-being and understanding the impact of a social network over the lifespan. Specific consideration of assembling and maintaining a circle of supportive family members and friends as well as truly helpful professionals may be included. Importantly, support should be framed as reciprocal, including helping individuals imagine themselves in caregiving and head of household/parenting/grandparenting roles.

d. Maintain holistic care offered now at HTCs

While this is part of the systemic recommendations below, it is crucial to offer holistic care to future cohorts of those who will age with hemophilia. While the viability of the Hemophilia Treatment Centers is already being considered and alternative solutions developed, it is important to ensure access to holistic care to those who currently receive treatment and those who currently experience barriers to access.

e. Prepare for current and future pandemics as they intersect with hemophilia

As the world acknowledges that pandemics may be part of our new reality, understanding the COVID-19 pandemic and future pandemics specific impact on those aging with hemophilia will be important to promptly respond with programming and support. For example, as COVID-19 initially devastated older persons and persons of color, a targeted examination of actions needed in those communities who are aging with hemophilia may have been useful as inquiries may be swift to organizations serving those with hemophilia. Future pandemics or other health emergencies should be assessed with the specific impact on those aging with hemophilia.

III. Recommendations to address systems-level concerns

a. Disseminate information and knowledge to enhance understanding and care

There are numerous ways that knowledge gaps can be enhanced as more persons with hemophilia age and engage with health and social institutions. Healthcare providers, particularly those in emergency departments, need continued knowledge about hemophilia because these practitioners may treat persons with diminished symptoms and frequency. Health care providers serving those with hemophilia would benefit from more gerontological knowledge, both in understanding the lived experiences (e.g., knowledge gained from this project) and the key issues in gerontology that are applicable (e.g., pain management, dementia innovations, geriatric care management, end of life concerns and resources). In addition, there should be more development of specialists at the intersection of hemophilia and aging, both geriatricians and specialists such as oncologists, gynecologists, and hospice providers. This could be supported through fellowship programs, grants initiatives and mentorship.

As persons aging with hemophilia have to navigate multiple systems of care, assistance navigating California-based medically related programs such as MediCAL and GHPP remains important. For example, from our interviews, it is important to understand GHPP's fee structure for enrollment and eligibility criteria, particularly for those diagnosed later in life who may be less familiar with GHPP. In addition, assistance understanding the combination of GHPP and private insurance domains to ensure optimal care from a range of options should be included. As each state may have different programs to navigate, tailoring information to specific geographies is also essential.

As those aging with hemophilia become eligible for age-related programs like Social Security and Medicare, knowledge on how to navigate these programs in addition to health-related programs such as those described above will be more important for future cohorts. Strategies about supplemental Medicare plans and at what age to take social security payments are also related to the larger concerns of retirement planning for the intersection of multiple programs and additional resources needed in older adulthood.

b. Ensuring Effective Systems Remain where possible and Enhancing Systems

Many of our interviewees highlighted the importance of hemophilia treatment centers, a holistic or wrap-around care model, to their health and well-being. In fact, respondents emphasized the sense of security and community from professionals employed at the HTCs. We understand form our interviews that the viability of such care is under discussion, yet we have also heard that professionals employed at HTCs are asked to explain the great system established across other sectors. Therefore, we recommend efforts to preserve effective systems, or if they are modified to include other populations or approaches, to ensure that holistic, wrap-around care remains as a cornerstone.

Systems can also be improved. Based on our interviews, there are bureaucratic barriers to the utilization of GHPP that can be streamlined. Once streamlined communication of how to navigate GHPP should be conveyed to patients and providers. In addition, communication between providers can be improved to enhance patient care.

In order to promote best practices or standards of care, we recommend dialogue between HTCs and insurance providers to ensure standards of care in a few domains: medication, medical procedures and social support/psychological services. For some patients where distance is a challenge for visits to providers, innovations necessitated by the COVID-19 pandemic, like telemedicine as an option, and activities tailored for virtual visits (e.g., care instruction and monitoring of some health conditions) may be useful practices to retain. For example, for some patients, perhaps it could be permissible to go multiple years before an in-person visit is required rather than the yearly visit. For others, like physical therapy appointments, too much is missed in a virtual visit. However, for therapy and social work consults, perhaps virtual check-ins would suffice.

Lastly, we recommend continued partnerships that will provide much needed resources for those aging with hemophilia. For example, HTCs might build

partnerships with psychological service providers to expand treatment options, especially in areas where such resources are not easily available. We also recommend that local, regional and national organizations continually raise awareness of mental health needs and need for support for this population.

IV. Recommendations for Content-Specific Programming

We recommend content-specific programming for the current cohort of those aging with hemophilia to include imagining oneself in older adulthood including new roles and new contributions (as discussed in detail above in Ia. and Ib.) and imagining oneself as a caregiver to others' emotional and health-related concerns. The latter would include recognizing the long haul and reciprocal nature of caregiving, and the specific complexity of relationships with those who cared for them (e.g., mothers caring sons). Discussion could also include how to ensure attention to one's own health while being a caregiver as research has shown that many caregivers put aside their own health. Lastly, strategies on organizing short-term respite from caregiving roles or dividing caregiving responsibilities would be helpful.

In addition, to those applicable to current cohorts, we recommend content-specific programming for future cohorts to include financial concerns (e.g., budgeting and retirement planning). In addition, the need for wrap-around approaches to care and well-being should be conceptualized from the moment of diagnosis, where assessment of needs, and barriers should be holistic. Once diagnosed, perhaps those newly diagnosed could be offered an older mentor or peer who has a similar health trajectory as a resource for strengthening social support.

Future Directions for Research on Aging Persons with Hemophilia

To promote understanding and rendering visible the lived experiences of those aging with hemophilia, we recommend the following:

1) Greater inclusion of those aging with hemophilia at every stage of the research process. A community-based participatory research approach would include having those aging with hemophilia as members of the research team to develop research questions, recruit, collect and analyze data and disseminate the results.

2) Expand communities of knowledge in terms of:

    a) Gender

    b) Race/Ethnicity

    c) Socioeconomic well-being

    d) Non-English speakers

    e) Documentation status/Immigrant communities

    f) Attention to those living in states without GHPP (or similar insurance)

    g) Age

3) Innovative research and advocacy dissemination approaches could include blogs, films, zines, etc.

Community talks, and academic talks should be planned and vigorously implemented with local, regional, national and international patient, advocacy and research communities of those living with hemophilia, and those with gerontological focus.

Thank you so much for your support of this project.

Endnotes

1. National Hemophilia Foundation. Retrieved from: https://www.hemophilia.org/Bleeding-Disorders/Blood-Safety/HIVAIDS

2. This acronym is taken from Perlov's earlier materials and used to maintain congruence.

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APPENDICES

Appendix A: 23rd International AIDS Conference abstract

Poster Title

The blood factor: Identity, community and aging among people living with hemophilia and HIV

Citation

Schwartz, S., Perry, T.E., Francis D. & C. Kaplan (2020, July). The blood factor: Identity, community and aging among people living with hemophilia and HIV. Poster presented at 23rd International AIDS Conference.

Abstract

Background

Hemophilia is a genetic blood disorder in which the liver fails to produce the protein factors needed in the clotting process, resulting in potentially dangerous bleeding after injuries. Prior to 1992, treatment for a 'bleed' involved intravenous transfusions of the missing factor from donated human blood. Tragically, this reliance on blood-based factor products resulted in exposure to the hepatitis and HIV viruses. During the 1970s and 1980s, approximately one half of individuals with hemophilia contracted HIV from contaminated blood products, with some infecting their partners and children. The intersection of HIV and hemophilia is one of the greatest medical disasters in United States history; however, it has received limited attention in communities not impacted by hemophilia. This qualitative study offers a unique window into AIDS history through stories of individuals and families impacted by HIV through hemophilia treatment.

Method

Thirty-two semi-structured telephone interviews were conducted with long-term survivors, family members, and professionals who supported these families. Non-probability convenience and snowball sampling procedures recruited participants. The interviews elicited personal narratives and reflections, were audio-recorded, transcribed and uploaded to NVivo11 for analysis. Historical documents such as publications, television reports and films provided contextual data. A narrative approach guided data analysis.

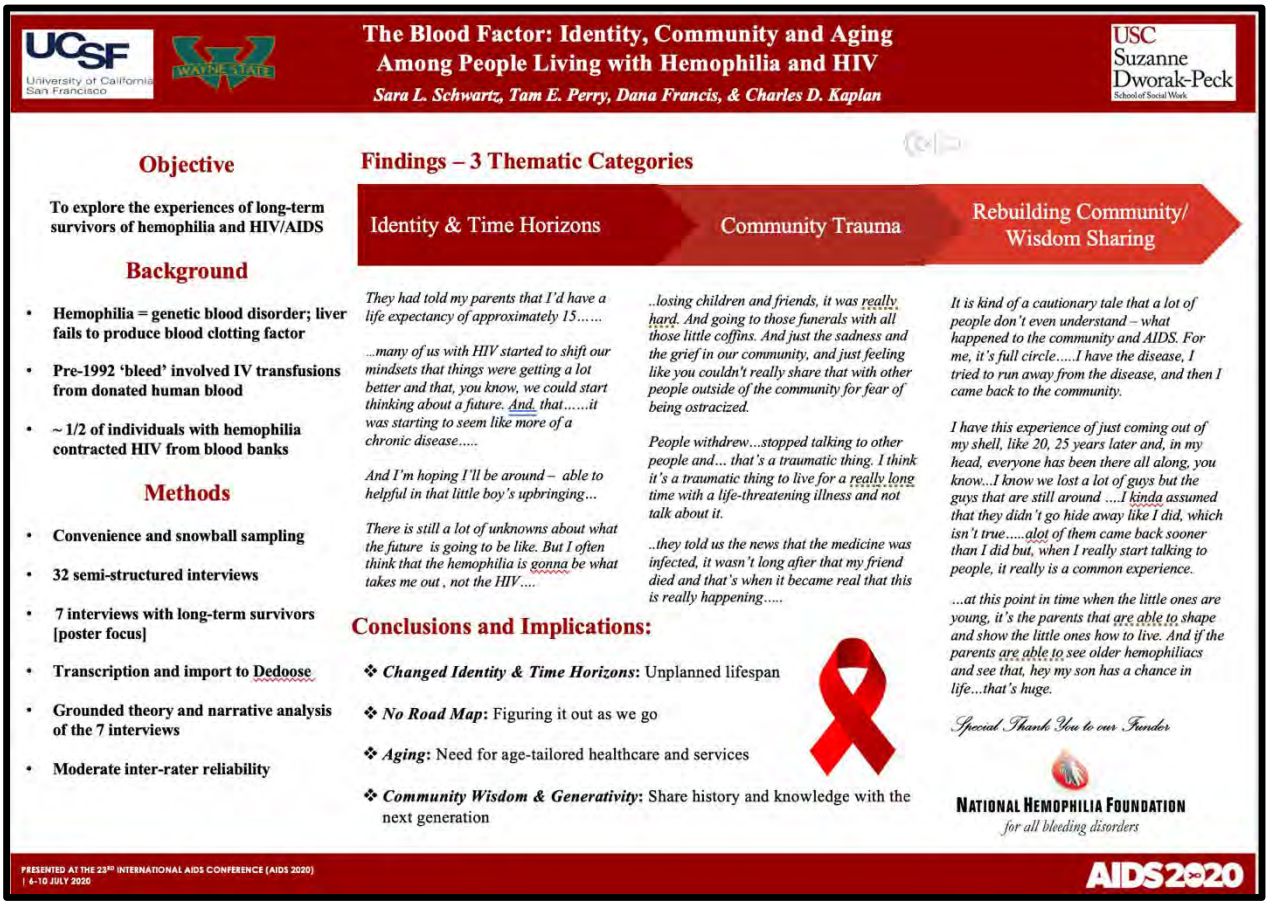
Results

The data illuminates complex, multifaceted relationships among the hemophilia community, government, medical providers, pharmaceutical companies and society. These complicated relationships took place in the wider context of homophobia, stigma and AIDS-related hysteria. Participants recall initial shame, fear and coping through social withdrawal in order to hide their hemophilia to avoid assumptions of HIV status. However, hiding a medical condition complicates individual and collective identities. As time progressed and the hemophilia community continued to be impacted, some individuals and families began to rise up to demand research, treatment and policy change. Advocacy re-engaged and empowered the community to organize, educate and advance safety protocols for blood product manufacturing and distribution.

Conclusions

This study captures an inadequately examined history of the intersection of HIV and an already medically fragile and vulnerable community of individuals receiving treatment for hemophilia. The AIDS crisis of the 1980s and 1990s further marginalized this community and continues to traumatize long-term survivors. The stories illuminate human resilience in the face of trauma and provide insight into the ways that the community was able to rise up, find their voices, build networks and advocate for change. These are important lessons to reflect upon given the current political, societal and healthcare landscape in the United States and around the world.

Appendix B: Poster Presented at 2020 International AIDS Conference



The Blood Factor: Identity, Community and Aging Among People Living with Hemophilia and HIV

Sara L. Schwartz, Tam E. Perry, Dana Francis, & Charles D. Kaplan

UCSF University of California San Francisco · Wayne State · USC Suzanne Dworak-Peck School of Social Work

Objective

To explore the experiences of long-term survivors of hemophilia and HIV/AIDS

Background

- **Hemophilia = genetic blood disorder; liver fails to produce blood clotting factor**
- **Pre-1992 'bleed' involved IV transfusions from donated human blood**
- **~ 1/2 of individuals with hemophilia contracted HIV from blood banks**

Methods

- **Convenience and snowball sampling**
- **32 semi-structured interviews**
- **7 interviews with long-term survivors [poster focus]**
- **Transcription and import to Dedoose**
- **Grounded theory and narrative analysis of the 7 interviews**
- **Moderate inter-rater reliability**

Findings – 3 Thematic Categories

Identity & Time Horizons

They had told my parents that I'd have a life expectancy of approximately 15……

…many of us with HIV started to shift our mindsets that things were getting a lot better and that, you know, we could start thinking about a future. And that……it was starting to seem like more of a chronic disease…..

And I'm hoping I'll be around – able to helpful in that little boy's upbringing…

There is still a lot of unknowns about what the future is going to be like. But I often think that the hemophilia is gonna be what takes me out , not the HIV….

Community Trauma

..losing children and friends, it was really hard. And going to those funerals with all those little coffins. And just the sadness and the grief in our community, and just feeling like you couldn't really share that with other people outside of the community for fear of being ostracized.

People withdrew…stopped talking to other people and… that's a traumatic thing. I think it's a traumatic thing to live for a really long time with a life-threatening illness and not talk about it.

..they told us the news that the medicine was infected, it wasn't long after that my friend died and that's when it became real that this is really happening…..

Rebuilding Community/ Wisdom Sharing

It is kind of a cautionary tale that a lot of people don't even understand – what happened to the community and AIDS. For me, it's full circle…..I have the disease, I tried to run away from the disease, and then I came back to the community.

I have this experience of just coming out of my shell, like 20, 25 years later and, in my head, everyone has been there all along, you know…I know we lost a lot of guys but the guys that are still around ….I kinda assumed that they didn't go hide away like I did, which isn't true…..alot of them came back sooner than I did but, when I really start talking to people, it really is a common experience.

…at this point in time when the little ones are young, it's the parents that are able to shape and show the little ones how to live. And if the parents are able to see older hemophiliacs and see that, hey my son has a chance in life…that's huge.

Conclusions and Implications:

- ***Changed Identity & Time Horizons*: Unplanned lifespan**
- ***No Road Map*: Figuring it out as we go**
- ***Aging*: Need for age-tailored healthcare and services**
- ***Community Wisdom & Generativity*: Share history and knowledge with the next generation**

Special Thank You to our Funder

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

PRESENTED AT THE 23RD INTERNATIONAL AIDS CONFERENCE (AIDS 2020) | 6-10 JULY 2020

AIDS2020

Appendix C: Presentation at Gerontological Society of America 2020

Presentation Title

Experiences of Social Withdrawal: Why Aging Matters Among Individuals with Hemophilia Facing Unexpected Longevity

Citation

Perry, T.E., Schwartz, S., Francis, D. & C. Kaplan (2020, November). Experiences of Social Withdrawal: Why Aging Matters Among Individuals with Hemophilia Facing Unexpected Longevity. In S. Bowland (Chair), Addressing Older Adult Social Isolation in Various Settings with Unique Conflating Trajectories of Care Models. Symposia conducted at the Annual Scientific Meeting of the Gerontological Society of America, virtual.

Abstract

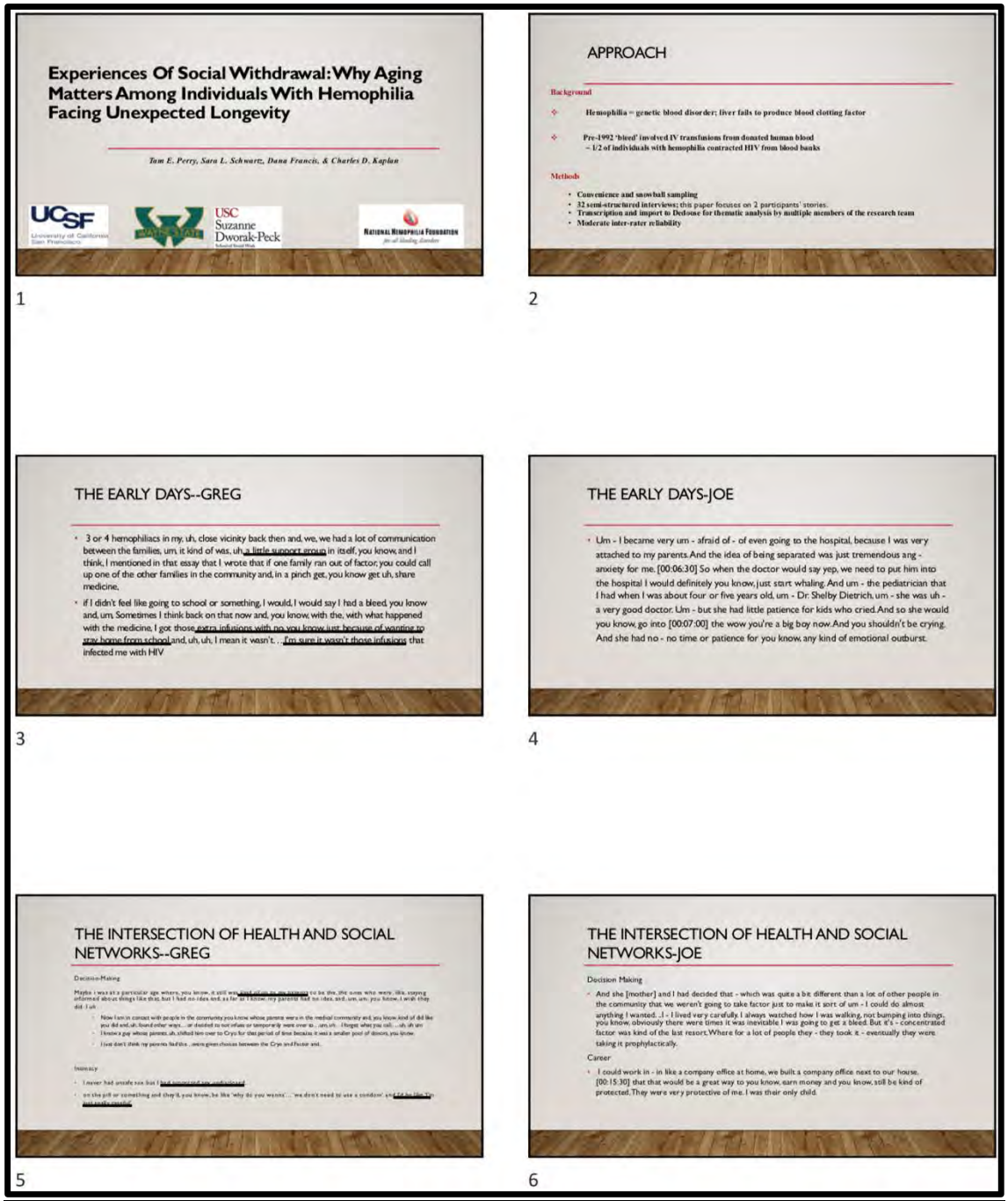
For the first time, individuals with hemophilia are living beyond their 30s and 40s. This cohort, many of whom had been dependent on donated blood and contracted HIV and hepatitis, face unique challenges as they age with hemophilia and other conditions. Little is known about the experiences and health needs of these adults over the age of 40. Scientific advances have changed the life course of individuals who received earlier treatment modalities. Today, a person with hemophilia who has received preventative synthetic treatment can look forward to a long, healthy and active life. Semi-structured telephone interviews (n=32) were conducted with long-term survivors, family members, and professionals who supported these families. Findings include shame, fear and coping through social withdrawal in order to hide their hemophilia to avoid assumptions of HIV status. Analyzing unexpected longevity and why age matters for this historically isolated cohort, we explore what programs are needed.

Symposium Abstract

No matter the age, social isolation is common among older adults due to a number of factors. In looking at social isolation through the framework of the International Classification of Functioning, Disability and Health (ICF) model, the biopsychosocial factors intersect. Care models will be explored that involve the ICF model multi-disciplinary concepts of body functions, activities, participation and environmental factors. Developing more programs to counter isolation is critical for the health of older persons. (1) The experience of vulnerability may be overcome by banding together through assisting others or building a peer support network. (2) A holistic perspective is needed in promoting interventions that support functionality. Regular programming with body

awareness and cognitive reflection is enjoyed by institutionalized older adults. (3) The role of social action and social justice in reducing social isolation is part of training social work students about the importance of culture and advocacy. (4) Collected ethnographic data found that the practice of remembrance reduces social isolation regardless of the program. Gardening and storytelling were found to be opportunities to reduce social isolation. (5) With unexpected longevity in individuals with hemophilia due to scientific advances, researchers also found shame, fear, and coping through social isolation to avoid social assumptions of health status. Care models are being explored to support this cohort. To conclude, Dr. Sharon Bowland will summarize the abstracts and discuss how they revolve around the ICF model of care that can be applied to social isolation as an important social determinant of health.

Appendix D: Gerontological Society of America 2020 Presentation Slides



Experiences Of Social Withdrawal: Why Aging Matters Among Individuals With Hemophilia Facing Unexpected Longevity

Tam E. Perry, Sara L. Schwartz, Dana Francis, & Charles D. Kaplan

UCSF University of California San Francisco · Wayne State · USC Suzanne Dworak-Peck School of Social Work · National Hemophilia Foundation

1

APPROACH

Background

- Hemophilia = genetic blood disorder; liver fails to produce blood clotting factor
- Pre-1992 'bleed' involved IV transfusions from donated human blood
  - ~ 1/2 of individuals with hemophilia contracted HIV from blood banks

Methods

- Convenience and snowball sampling
- 32 semi-structured interviews; this paper focuses on 2 participants' stories.
- Transcription and import to Dedoose for thematic analysis by multiple members of the research team
- Moderate inter-rater reliability

2

THE EARLY DAYS--GREG

- 3 or 4 hemophiliacs in my, uh, close vicinity back then and, we, we had a lot of communication between the families, um, it kind of was, uh, a little support group in itself, you know, and I think, I mentioned in that essay that I wrote that if one family ran out of factor, you could call up one of the other families in the community and, in a pinch get, you know get uh, share medicine,
- if I didn't feel like going to school or something, I would, I would say I had a bleed, you know and, um, Sometimes I think back on that now and, you know, with the, with what happened with the medicine, I got those extra infusions with no, you know, just because of wanting to stay home from school and, uh, uh, I mean it wasn't. . . I'm sure it wasn't those infusions that infected me with HIV

3

THE EARLY DAYS-JOE

- Um - I became very um - afraid of - of even going to the hospital, because I was very attached to my parents. And the idea of being separated was just tremendous ang - anxiety for me. [00:06:30] So when the doctor would say yep, we need to put him into the hospital I would definitely you know, just start whaling. And um - the pediatrician that I had when I was about four or five years old, um - Dr. Shelby Dietrich, um - she was uh - a very good doctor. Um - but she had little patience for kids who cried. And so she would you know, go into [00:07:00] the wow you're a big boy now. And you shouldn't be crying. And she had no - no time or patience for you know, any kind of emotional outburst.

4

THE INTERSECTION OF HEALTH AND SOCIAL NETWORKS--GREG

Decision-Making

Maybe I was at a particular age where, you know, it still was kind of on an element to be like, the ones who were, like, staying informed about things like that, but I had no idea and, as far as I know, my parents had no idea, and, um, um, you know, I wish they did. I uh

- Now I am in contact with people in the community you know whose parents were in the medical community and, you know, kind of did like you did and, uh, found other ways…or decided to not infuse or temporarily were over to…um, uh. I forget when you call…uh, uh um
- I know a guy whose parents, uh, shifted him over to Cryo for that period of time because it was a smaller pool of donors, you know.
- I just don't think my parents had this…were given choices between the Cryo and Factor and…

Intimacy

- I never had unsafe sex but I had unprotected sex unfortunately
- on the pill or something and they'll, you know, be like 'why do you wanna'…'we don't need to use a condom' or I'd be like 'I'm not really worried'

5

THE INTERSECTION OF HEALTH AND SOCIAL NETWORKS-JOE

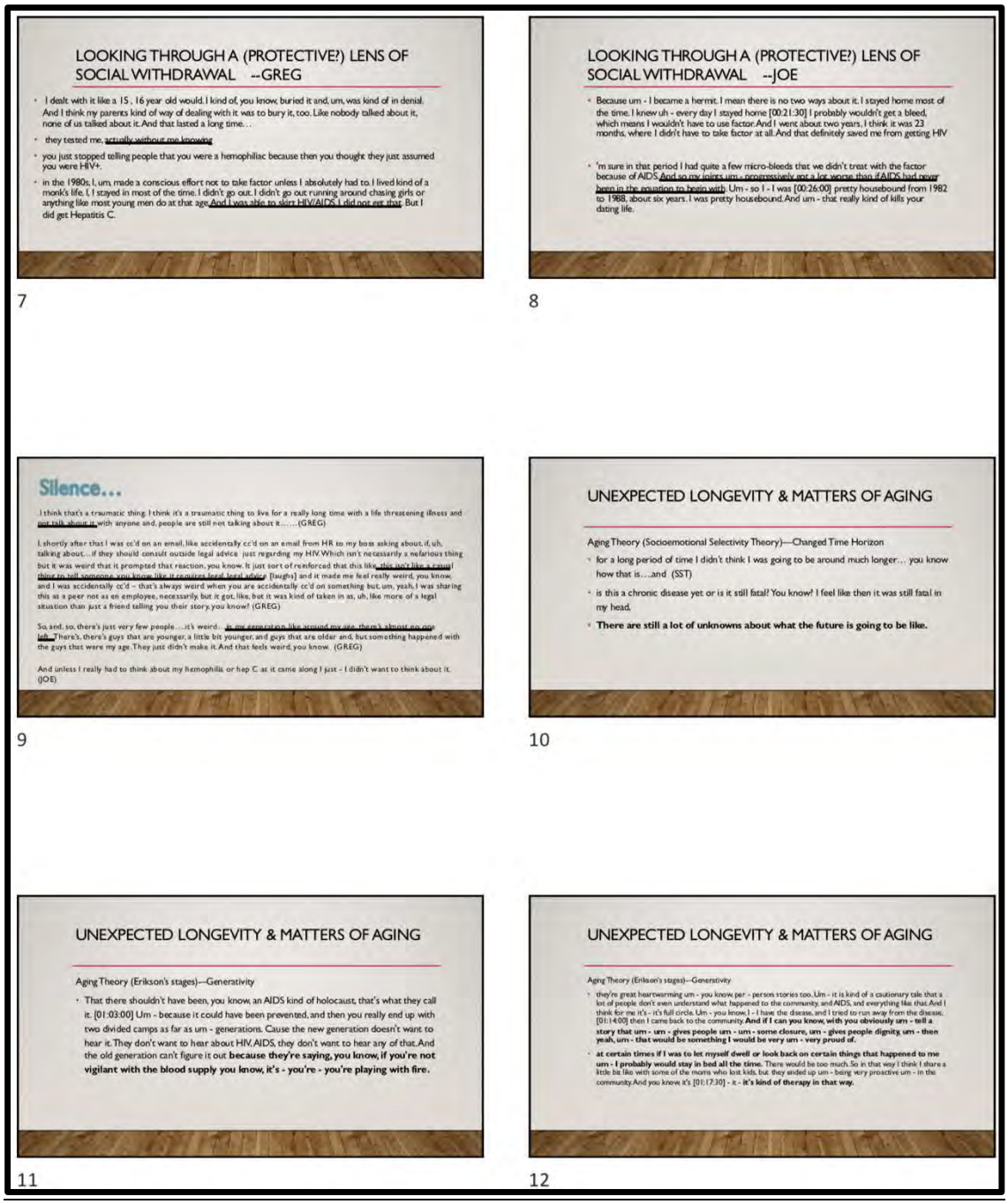
Decision Making

- And she [mother] and I had decided that - which was quite a bit different than a lot of other people in the community that we weren't going to take factor just to make it sort of um - I could do almost anything I wanted. .I - I lived very carefully. I always watched how I was walking, not bumping into things, you know, obviously there were times it was inevitable I was going to get a bleed. But, it's - concentrated factor was kind of the last resort. Where for a lot of people they - they took it - eventually they were taking it prophylactically.

Career

- I could work in - in like a company office at home, we built a company office next to our house. [00:15:30] that that would be a great way to you know, earn money and you know, still be kind of protected. They were very protective of me. I was their only child.

6



LOOKING THROUGH A (PROTECTIVE?) LENS OF SOCIAL WITHDRAWAL --GREG

- I dealt with it like a 15 , 16 year old would. I kind of, you know, buried it and, um, was kind of in denial. And I think my parents kind of way of dealing with it was to bury it, too. Like nobody talked about it, none of us talked about it. And that lasted a long time…
- they tested me, actually without me knowing
- you just stopped telling people that you were a hemophiliac because then you thought they just assumed you were HIV+.
- in the 1980s, I, um, made a conscious effort not to take factor unless I absolutely had to. I lived kind of a monk's life. I, I stayed in most of the time. I didn't go out. I didn't go out running around chasing girls or anything like most young men do at that age. And I was able to skirt HIV/AIDS. I did not get that. But I did get Hepatitis C.

7

LOOKING THROUGH A (PROTECTIVE?) LENS OF SOCIAL WITHDRAWAL --JOE

- Because um - I became a hermit. I mean there is no two ways about it. I stayed home most of the time. I knew uh - every day I stayed home [00:21:30] I probably wouldn't get a bleed, which means I wouldn't have to use factor. And I went about two years, I think it was 23 months, where I didn't have to take factor at all. And that definitely saved me from getting HIV
- 'm sure in that period I had quite a few micro-bleeds that we didn't treat with the factor because of AIDS. And so my joints um - progressively got a lot worse than if AIDS had never been in the equation to begin with. Um - so I - I was [00:26:00] pretty housebound from 1982 to 1988, about six years. I was pretty housebound. And um - that really kind of kills your dating life.

8

Silence…

I think that's a traumatic thing. I think it's a traumatic thing to live for a really long time with a life threatening illness and not talk about it with anyone and, people are still not talking about it……(GREG)

I, shortly after that I was cc'd on an email, like accidentally cc'd on an email from HR to my boss asking about, if, uh, talking about…if they should consult outside legal advice just regarding my HIV. Which isn't necessarily a nefarious thing but it was weird that it prompted that reaction, you know. It just sort of reinforced that this like, this isn't like a casual thing to tell someone, you know, like it requires legal, legal advice. [laughs] and it made me feel really weird, you know, and I was accidentally cc'd – that's always weird when you are accidentally cc'd on something but, um, yeah, I was sharing this as a peer not as an employee, necessarily, but it got, like, but it was kind of taken in as, uh, like more of a legal situation than just a friend telling you their story, you know? (GREG)

So, and, so, there's just very few people…..it's weird. In my generation, like around my age, there's almost no one left. There's, there's guys that are younger, a little bit younger, and guys that are older and, but something happened with the guys that were my age. They just didn't make it. And that feels weird, you know. (GREG)

And unless I really had to think about my hemophilia or hep C as it came along I just - I didn't want to think about it. (JOE)

9

UNEXPECTED LONGEVITY & MATTERS OF AGING

Aging Theory (Socioemotional Selectivity Theory)—Changed Time Horizon

- for a long period of time I didn't think I was going to be around much longer… you know how that is….and (SST)
- is this a chronic disease yet or is it still fatal? You know? I feel like then it was still fatal in my head.
- **There are still a lot of unknowns about what the future is going to be like.**

10

UNEXPECTED LONGEVITY & MATTERS OF AGING

Aging Theory (Erikson's stages)—Generativity

- That there shouldn't have been, you know, an AIDS kind of holocaust, that's what they call it. [01:03:00] Um - because it could have been prevented, and then you really end up with two divided camps as far as um - generations. Cause the new generation doesn't want to hear it. They don't want to hear about HIV, AIDS, they don't want to hear any of that. And the old generation can't figure it out **because they're saying, you know, if you're not vigilant with the blood supply you know, it's - you're - you're playing with fire.**

11

UNEXPECTED LONGEVITY & MATTERS OF AGING

Aging Theory (Erikson's stages)--Generativity

- they're great heartwarming um - you know, per - person stories too. Um - it is kind of a cautionary tale that a lot of people don't even understand what happened to the community, and AIDS, and everything like that. And I think for me it's - it's full circle. Um - you know, I - I have the disease, and I tried to run away from the disease, [01:14:00] then I came back to the community. **And if I can you know, with you obviously um - tell a story that um - um - gives people um - um - some closure, um - gives people dignity, um - then yeah, um - that would be something I would be very um - very proud of.**
- **at certain times if I was to let myself dwell or look back on certain things that happened to me um - I probably would stay in bed all the time.** There would be too much. So in that way I think I share a little bit like with some of the moms who lost kids, but they ended up um - being very proactive um - in the community. And you know, it's [01:17:30] - it - **it's kind of therapy in that way.**

12

Appendix E: Project Recruitment Flyer

Project Survivor

Hemophilia and Aging Horizons

Are you a hemophilia survivor 50 years or older? If so, you are a member of a pioneering group. Until this point in history, few people with bleeding disorders have lived as long as you have!

You could be eligible to participate in *Project Survivor,* our *Hemophilia and Aging Horizons Study* being conducted in collaboration with the social work departments of Wayne State University, University of Southern California and University of California San Francisco. This project is sponsored by National Hemophilia Foundation for All Bleeding Disorders.

Help us learn more about your experiences in a **CONFIDENTIAL** interview or focus group about quality of life issues and the psychosocial impact of aging with survivors/consumers with bleeding disorders. Interviews (stipend $100) and focus groups (stipend $50) will be conducted **by telephone or video conferencing.**

Thank you for considering this exciting opportunity!

If interested, email or call Sara Schwartz, PhD, MSW (510-384-0997) saraschw@usc.edu and Dana Francis, MSW (415) 353-2343 dana.francis@ucsf.edu for more details

WAYNE STATE School of Social Work

USC Suzanne Dworak-Peck School of Social Work

National Hemophilia Foundation for all bleeding disorders

Appendix F: Interview Guide for those Aging with Hemophilia

Aging with Hemophilia Interview Schedule-Primary Participant

Thank you for participating in this study! The information that you share will help develop a knowledge base around the complicated history and intersection of Aging with Hemophilia.

Your identity will remain completely confidential. While your interview will be tape recorded and transcribed, your personal identity will not be attached to the interview. Your identity for the purposes of this study will be your interview number (e.g., Interview #1, Interview #2, etc.). The only individual who will be able to link your name with your interview transcript will be the person conducting the interview. This information will be held in the strictest confidence. Your participation in this study is completely voluntary and no harm is anticipated to occur as a result of this interview.

Do you Consent to Participate in the research?

☐ **Yes (date_____)**
☐ **No**

Demographic Information

What is your gender?
What is your identified ethnicity?
What is the month and year of your birth?

Instructions for Interviewer: Semi-structured questions are below; choose most appropriate to interviewee's story and probe further where appropriate.

Early Life

1. **Can you tell me a bit about your childhood, or life before the 1980s?**
    a. What was your experience being diagnosed and treated for hemophilia?
    b. What were your bleeding episodes like?
    c. Can you recall any instances of singling out or name calling?
    d. Can you describe your schooling history to me? What about your employment history?
    e. What are some examples of strategies you used to manage hemophilia at a younger age?
    f. Were you ever injured in sports as a child? If so, did you ever think about how those injuries might affect you later?
    g. When experiencing bleeds as a child, did you ever think about how they might affect you later?

h. Were you ever given a life expectancy? If so, what was it?

2. **How would you describe the medical treatment that you received?**
   a. Did you and your family engage with the hemophilia community for information and support?
   b. Did you participate in hemophilia community services, such as attending injection camps?
   c. What was your relationship like with your physician?
   d. How did the AIDS crisis in the 80s and 90s impact your health?
      a. (if applicable) How did you cope with the negative stereotypes and assumptions of HIV status associated with having hemophilia?

Life Today

3. **How is life for you today?**
   a. Have you had any health experiences related to hemophilia?
   b. How has your hemophilia changed over time? Have your bleeds changed?
   c. Have you developed an inhibitor? How has that changed your treatment?
   d. Do you experience your pain, and if so, how do you manage it?
   e. Do you have co-occurring diseases [HIV, Hep, etc] – and if so, how do you manage them?
   f. How have your thoughts about your life expectancy changed?
   g. Do you use the Genetically Handicapped Persons Program (GHPP)? Is it adequate for all your healthcare needs? Why or why not?
   h. How is your emotional or spiritual health? Financial well-being?
   i. Would you use the word trauma to describe some of the experiences you have been through?
   j. Have you thought about your financial well-being as it relates to your hemophilia? If so, how?

Gender specific questions

   a. How do you think your gender has affected your experience with hemophilia?
   b. Have you had experiences that you believe were different because you were a woman/man?
   c. (For women) Tell me more about your reproductive history
      i. Starting menstrual cycle/starting menopause?
      ii. Socially
      iii. Health experiences

iv. Effect on hemophilia

4. Questions About Aging

a. What do you think is important to understand about the complex relationship between Aging and Hemophilia?
b. At over 50 years of age, you have lived through a rapid evolution of treatment for hemophilia. How has this medical revolution impacted your physical and emotional health?
c. How have these changes influenced your perspective on life? How has it influenced your view of time?
d. Are there activities as you grow older that you want to do? Are afraid to do/try?
e. Did you have a strategy for treatment (e.g., "as needed" or wellness (e.g., "avoid injury")? Has that strategy for treatment or wellness changed over time?
f. If you had to view your life as having stages, how would you divide it up?
g. Can you pinpoint "transformative" or important events/phases in your life related to hemophilia or other important domains of your life?
h. Do you think time of diagnosis affects how you age?
i. Is there any advice you have about aging?
j. Do you have specific advice about aging with hemophilia?"

5. Social Networks

a. How has hemophilia affected you socially?
b. Has it changed the way you interact within certain relationships?
c. Intimate Partners:
    i. Experience of dating? What is typical or notable of your experiences dating with hemophilia?
    ii. Intimate partners? What is typical or notable of your experiences with intimate/sexual partners while having hemophilia?
d. Kin Networks:
    i. What are relationships with family members who do and/or do not have hemophilia like now?
    ii. Doing anything different based on experiences of other older relatives with hemophilia?
e. Friends/Peers:
    i. How connected are you with others you may have known from childhood who have hemophilia?
    ii. (If applicable) Do you stay in touch with their relatives/parents of those who had hemophilia from your childhood?

6. **Childbearing/Childrearing/Parenting**
    a. How has hemophilia affected your experience with having children?
        i. How did hemophilia affect your pregnancy? Did you use different approaches or strategies, such as IVF or PGP?Being pregnant?/approaches (IVF)/ PGP?
    b. How old are your kids now?
    c. Did you decide to have your children tested?
    d. Others decisions to have kids What do you think about the decision of others with hemophilia to have kids?
    e. Other parenting decisions? Were there other parenting decisions you made that were specific to your experience with hemophilia?

7. **Grandparenting**
    a. Emotions about children's choice to have kids How do you feel about your children's choice to have kids?
    b. Opinions about medical care of your kids/grandkids with regard to hemophilia? Do you have opinions about the medical care of your kids or grandchildren with regard to hemophilia?
    c. Imagine a future for your relative (e.g., grandchild with hemophilia).

8. **Hemophilia Community**
    a. How would you describe your relationship with the bleeding community [NHF, Committee of 10,000, HTCs, etc]? How has it changed over time?
    b. How has technology (e.g., cell phones/facebook/other) changed the community?
    c. How would you characterize your generation of individuals and families with hemophilia?
    d. Are there policies that affect people with hemophilia that they had that have changed over time? What other policies still need to be changed?

9. **Global Pandemic: COVID-19**
    a. Can you tell me how the COVID-19 pandemic affected you?
    b. Are there specific challenges you faced as someone with hemophilia?

10. **The Road Ahead:**
    a. What do you think should be the role of long-term survivors/non-progressors in the community?
    b. How do you view the experiences of a younger person with hemophilia?
    c. Is it important to share stories with the younger generation even though their experience is so different?

Page Break

Appendix G: Interview Guide for those Aging with Hemophilia (Spanish Version)

Programa de entrevistas para personas mayores con hemofilia: participante principal

¡Gracias por participar en este estudio! La información que comparta ayudará a desarrollar una base de conocimientos sobre la complicada historia y la intersección del envejecimiento con la hemofilia.

Su identidad permanecerá completamente confidencial. Su entrevista se grabará y transcribirá, y su identidad personal no se adjuntará a la entrevista. Su identidad para los propósitos de este estudio será su número de entrevista (por ejemplo, Entrevista n. ° 1, Entrevista n. ° 2, etc.). La única persona que podrá relacionar su nombre con la transcripción de la entrevista será la persona que realice la entrevista. Esta información se mantendrá en la más estricta confidencialidad. Su participación en este estudio es completamente voluntaria y no se prevé que ocurra ningún daño como resultado de esta entrevista.

¿Acepta participar en la investigación?

□ Sí (fecha_____)
□ No

Información demográfica

¿Cuál es su género?
¿Cuál es su identidad étnica?
¿Cuál es el mes y año de su nacimiento?

Instrucciones para el entrevistador: las preguntas semiestructuradas se encuentran a continuación; Elija la más apropiada para la historia del entrevistado y pregunte más allá donde sea apropiado.

Vida temprana

1. **¿Puede contarme un poco sobre su infancia o su vida antes de la década de 1980?**
   a. ¿Cuál fue su experiencia cuando lo/la diagnosticaron y trataron por la hemofilia?
   b. ¿Cómo fueron sus episodios de sangrado?
   c. ¿Puede recordar algún caso de singularización o insultos?
   d. ¿Puede describirme su historial escolar? ¿Qué pasa con su historial laboral?
   e. ¿Cuáles son algunos ejemplos de estrategias que utilizó para controlar la hemofilia a una edad más joven?
   f. ¿Alguna vez se lesionó en los deportes cuando era niño? Si es así, ¿alguna vez pensó en cómo esas lesiones podrían afectarlo más adelante?
   g. Cuando experimentó hemorragias cuando era niño, ¿alguna vez pensó en cómo podrían afectarlo más adelante?
   h. ¿Alguna vez le dieron una esperanza de vida? Si es así, ¿qué fue?

g. Cuando experimentó hemorragias cuando era niño, ¿alguna vez pensó en cómo podrían afectarlo más adelante?
h. ¿Alguna vez le dieron una esperanza de vida? Si es así, ¿qué fue?

2. ¿Cómo describiría el tratamiento médico que recibió?

a. ¿Participaron usted y su familia con la comunidad de hemofilia para obtener información y apoyo?
b. ¿Participó en servicios comunitarios de hemofilia, como asistir a campamentos de inyección?
c. ¿Cómo fue su relación con su médico?
d. ¿Cómo afectó su salud la crisis del SIDA de los años 80 y 90?
    a. (Si corresponde) ¿Cómo se enfrentó a los estereotipos negativos y las suposiciones del estado VIH asociado con la hemofilia?

La vida de hoy

3. ¿Cómo es la vida para usted hoy?

a. ¿Ha tenido alguna experiencia de salud relacionada con la hemofilia?
b. ¿Cómo ha cambiado su hemofilia con el tiempo? ¿Han cambiado sus hemorragias?
c. ¿Ha desarrollado un inhibidor? ¿Cómo ha cambiado eso su tratamiento?
d. ¿Experimenta su dolor y, de ser así, cómo lo maneja?
e. ¿Tiene enfermedades concurrentes [VIH, hepatitis, etc.]? Si es así, ¿cómo las maneja?
f. ¿Cómo han cambiado sus pensamientos sobre su esperanza de vida?
g. ¿Utiliza el Programa de Personas con Discapacidades Genéticas (GHPP)? ¿Es adecuado para todas sus necesidades de atención médica? ¿Por qué o por qué no?
h. ¿Cómo está su salud emocional o espiritual? ¿Bienestar financiero?
i. ¿Usaría la palabra trauma para describir algunas de las experiencias por las que ha pasado?
j. ¿Ha pensado en su bienestar financiero en relación con su hemofilia? ¿Si es así, cómo?

Preguntas específicas de género

a. ¿Cómo cree que su género ha afectado su experiencia con la hemofilia?
b. ¿Ha tenido experiencias que cree que fueron diferentes por ser mujer/hombre?
c. (Para mujeres) Cuénteme más sobre su historial reproductivo
    i. ¿Comenzando el ciclo menstrual/comenzando la menopausia?
    ii. Socialmente
    iii. Experiencias de salud

6. **Maternidad/Crianza/Crianza de los hijos**
    a. ¿Cómo ha afectado la hemofilia su experiencia al tener hijos?
        i. ¿Cómo afectó la hemofilia a su embarazo? ¿Usó diferentes enfoques o estrategias, como FIV o PGP? ¿Estar embarazada? Enfoques (FIV/ PGP)?
    b. ¿Qué edad tienen sus hijos ahora?
    c. ¿Decidió que sus hijos fueran examinados?
    d. Otras decisiones de tener hijos: ¿Qué piensa de la decisión de otras personas con hemofilia de tener hijos?
    e. ¿Otras decisiones de los padres? ¿Hubo otras decisiones de crianza que tomó que fueran específicas de su experiencia con la hemofilia?

7. **Abuelos**
    a. Emociones sobre la elección de sus hijos al tener hijos: ¿Cómo se siente acerca de la elección de sus hijos de tener hijos?
    b. ¿Opiniones sobre la atención médica de sus hijos/nietos con respecto a la hemofilia? ¿Tiene alguna opinión sobre la atención médica de sus hijos o nietos con respecto a la hemofilia?
    c. Imagínese un futuro para su familiar (por ejemplo, un nieto con hemofilia).

8. **Comunidad de hemofilia**
    a. ¿Cómo describiría su relación con la comunidad sangrante [NHF, Comité de 10,000, HTC, etc.]? ¿Cómo ha cambiado con el tiempo?
    b. ¿Cómo ha cambiado la tecnología (por ejemplo, teléfonos móviles/facebook/otros) a la comunidad?
    c. ¿Cómo caracterizaría a su generación de personas y familias con hemofilia?
    d. ¿Existen políticas que afecten a las personas con hemofilia que tenían y que hayan cambiado con el tiempo? ¿Qué otras políticas aún deben cambiarse?

9. **Pandemia mundial: COVID-19**
    a. ¿Puede decirme cómo le afectó la pandemia de COVID-19?
    b. ¿Hay barreras específicas que enfrentó como alguien con hemofilia?

10. **El camino por delante:**
    a. ¿Cuál cree que debería ser el papel de los sobrevivientes/no progresores a largo plazo en la comunidad?
    b. ¿Cómo ve las experiencias de una persona más joven con hemofilia?
    c. ¿Es importante compartir historias con la generación más joven a pesar de que su experiencia es tan diferente?

Appendix H: Interview Guide for Professionals Serving those Aging with Hemophilia

Aging with Hemophilia Interview Schedule for Professionals

Thank you for participating in this study! The information that you share will help develop a knowledge base around the complicated history and intersection of Aging with Hemophilia.

Your identity will remain completely confidential. While your interview will be tape recorded and transcribed, your personal identity will not be attached to the interview. Your identity for the purposes of this study will be your interview number (e.g., Interview #1, Interview #2, etc.). The only individual who will be able to link your name with your interview transcript will be the person conducting the interview. This information will be held in the strictest confidence. Your participation in this study is completely voluntary and no harm is anticipated to occur as a result of this interview.

Do you Consent to Participate in the research:

☐ **Yes (date_____)**
☐ **No**

Demographic Information

What is your gender?
What is your identified ethnicity?
What is the month and year of your birth?

Instructions for Interviewer: Semi-structured questions are below; choose most appropriate to interviewee's story and probe further where appropriate.

1) **Professional experience**
    - **a.** What is your professional background/training?
    - **b.** How long have you been in your position?

2) **Knowledge of population**
    - **a.** In your years of experience working with persons with hemophilia, what have you observed or heard about regarding the following:
        - Health concerns about aging?
        - Emotional concerns about aging?
        - Financial concerns about aging?
        - Social concerns about aging? These could include relationships with family members, dating, intimate partners, relationships with others with hemophilia and organizations

3) Can you give me specific examples/stories of what it's like to work with this population?
    a. Can you give me specific examples/stories of what it's like to work with this population with regards to medical challenges/new avenues with these patients?
    b. Have you observed strategies used by persons with hemophilia as they age/plan for aging?
    c. Have you observed how persons with hemophilia as they age/plan for aging consider the concept of time?

4) **Service Delivery**
    a. What type of information do you as a professional working with this population need?
    b. What is the most important information for working with this population?
    c. How do you get information about working with this population?
    d. What additional resources/trainings are needed?
    e. Please tell us what it is like to work with this population professionally.
    f. Are there ways this work has this affected you personally?

5) **Global Pandemic: COVID-19**
    a. Can you tell me how the COVID-19 pandemic affected this population?
    b. Are there specific challenges in the pandemic faced as someone with hemophilia?

6) **The Road Ahead:**
    a. What do you think should be the role of long-term survivors/non-progressors in the community?
    b. How do you work differently with younger person with hemophilia vs. persons aging with hemophilia?
    c. Are there policies that affect people with hemophilia that they had that have changed over time? What other policies still need to be changed?

Appendix I: Focus Group Guide for those aging with hemophilia

Aging with Hemophilia Focus Group Schedule

(Script to be read)
Thank you for participating in this study! The information that you share will help develop a knowledge base around the complicated history and intersection of Aging with Hemophilia.

Your identity will remain completely confidential to members of the focus group and the research team. We would like everyone to agree to keep the identities of the participants here today confidential. While the focus group will be tape recorded and transcribed, your personal identity will not be attached to the focus group. Your identity for the purposes of this study will be your focus group number (e.g., focus group member 1, focus group member 2). This information will be held in the strictest confidence. Your participation in this study is completely voluntary and no harm is anticipated to occur as a result of this focus group. You may discontinue your participation in the group discussion at any time.

Do you Consent to Participate in the research (Research team member must obtain consent from each individual in the group and document the consent):

☐ **Yes (date_____)**
☐ **No**

Demographic Information (Research team member to obtain from each member)

What is your gender?
What is your identified ethnicity?
What is the month and year of your birth?

Instructions to facilitators: These questions are meant to be semi-structured questions; choose most appropriate to focus group members' stories and probe further where appropriate.

1. If you were to think about your life progression as a series of phases, what would these phases look like?
2. Each of you has lived through revolutionary changes in the ways that hemophilia is medically treated and managed. How have these changes impacted your life?
3. Describe your experiences as a person aging with hemophilia.
    a. How has your physical body changed over time? Do you attribute these changes to hemophilia, a comorbidity or general aspects of aging?
    b. How has your mental and emotional self changed over time?
    c. How have your relationships with family and friends changed?
    d. Do you use strategies to stay well as you age?

4. How would you describe your relationship with the hemophilia community as a person aging with hemophilia?
5. In what ways has the COVID-19 health crisis impacted you?
6. Do you use the Genetically Handicapped Persons Program? Is it adequate for all your healthcare needs? Why or why not? What other policies are needed?
7. What do you think should be the role of long-term survivors/non-progressors in the community?
8. What recommendations do you have for people living longer and aging with hemophilia?

Appendix J: Publicity from the Wayne State University School of Social Work

Link: https://socialwork.wayne.edu/news/wayne-state-social-work-faculty-member-named-first-non-physician-recipient-of-hemophilia-research-award-43493

Wayne State social work faculty member named first non-physician recipient of hemophilia research award

May 18, 2021

SHARE

Tam Perry, PhD, is the first non-physician investigator to win the National Hemophilia Foundation's (NHF) Innovative Investigator Research Award. A gerontologist, Perry is an associate professor in the School of Social Work at Wayne State University and holds a doctorate in Social Work and Anthropology from the University of Michigan. Perry's Innovative Investigator Award supports her work with a multi-institutional team studying important aspects of aging for those with a bleeding disorder.

Along with Perry, the research team includes Sara Schwartz, PhD, MSW, clinical assistant professor at the University of Southern California Suzanne Dworak-Peck School of Social Work and a board member of the National AIDS Memorial Grove, Dana Francis, MSW, a social worker in the Adult Hemophilia Program at the University of California San Francisco Hemophilia Treatment Center, and Charles Kaplan, PhD, associate dean of research and research professor at the Hamovitch Center for Science in the Human Services at the Suzanne Dworak-Peck School of Social Work at the University of Southern California. Perry will also be mentoring five pre-med students eager to expand their research experience and support the aims of the project.

"We were very excited to be funded because it's very much a social science project, a social work project, and we didn't know if NHF would really be interested in that," stated Perry. While not focused on developing novel technologies or therapies, the project is very much in line with NHF's commitment to funding research to support the bleeding disorders community. The study "Navigating Time and Space: Experiences of Aging with Hemophilia" aims to examine the lived experiences and time horizons of aging persons with hemophilia (APWH) in order to characterize this community and to enhance service delivery practice after examining needs, facilitators and barriers experienced by APWH. Thus the project looks to add to gerontological and social work theory while also highlighting concrete ways NHF and its chapters can better support older members of the bleeding disorders community.

"We were very excited to be funded because it's very much a social science project, a social work project, and we didn't know if NHF would really be interested in that," stated Perry. While not focused on developing novel technologies or therapies, the project is very much in line with NHF's commitment to funding research to support the bleeding disorders community. The study "Navigating Time and Space: Experiences of Aging with Hemophilia" aims to examine the lived experiences and time horizons of aging persons with hemophilia (APWH) in order to characterize this community and to enhance service delivery practice after examining needs, facilitators and barriers experienced by APWH. Thus the project looks to add to gerontological and social work theory while also highlighting concrete ways NHF and its chapters can better support older members of the bleeding disorders community.

For Perry, who in July 2020 was named a fellow of the Gerontological Society of America and is president of the Association for Gerontology Education in Social Work, this is her first funded grant related to a specific medical condition. Her previous work to advance the Social Work Grand Challenges of advancing long and productive lives and creating responses to a changing environment has ranged from research on health disparities among older adults to examining older people's relationships to their homes and decisions regarding relocating.

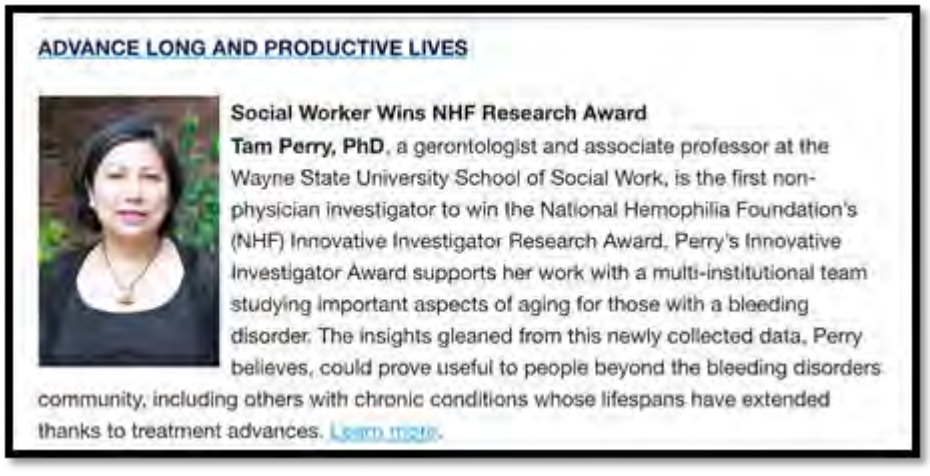
> I really like to look at meaning making, how people make sense of things in older adulthood. - Social Work Associate Professor Tam Perry

The notion of applying for the NHF Innovative Investigator Research Award grant grew from an established partnership between Perry and Schwartz. Schwartz had previously collaborated with Francis on a project about the impact of the intersection of HIV and hemophilia on individuals and families. "Sara had conducted 32 interviews for that project, and she realized so many of these interviews had issues and concerns of aging in them," Perry says. "So in this study we are first going to analyze already collected data for aging themes, and then later we're going to collect our own data with older adults." The insights gleaned from this data, Perry believes, could prove useful to people beyond the bleeding disorders community, including others with chronic conditions whose lifespans have extended thanks to treatment advances. "What you value and where you put your time after having that kind of switch, I think we have a lot to learn from our project to contribute to those kinds of questions."

Perry says she's grateful to be working with NHF on answering these key questions about aging with a bleeding disorder. Partnering with a foundation, she says, offers opportunities not always present when research is conducted under larger federal grants. "A lot of people go after federal grants and it's fine, but it's also a different thing to have that more close mission with your funders," she says. "Foundations have a real reason that they want to fund people and it's different than government mandates to reach a larger countrywide population. So when it comes to my grant with the NHF, I know that there will be a quicker path to directly affecting the lives of people like the people in my study."

Appendix K: Publicity in the *Grand Challenges for Social Work* national newsletter

Link: https://mailchi.mp/ssw/the-latest-news-from-gcsw-84wy1byg07-8739901?e=e69dea3512



Appendix L: NHF Profile

Author

Ian Landau

Innovative Investigator Award -- Tam Perry, PhD

Tam Perry, PhD, is the first non-physician investigator to win the National Hemophilia Foundation's (NHF) Innovative Investigator Award. A gerontologist, Perry is an associate professor in the School of Social Work at Wayne State University in Detroit and holds a doctorate in Social Work and Anthropology from the University of Michigan. Perry's Innovative Investigator Award supports her work with a multi-institutional team studying important aspects of aging with a bleeding disorder.

Along with Perry, the team includes Sara Schwartz, PhD, MSW, clinical assistant professor at the University of Southern California Suzanne Dworak-Peck School of Social Work and a board member of the National AIDS Memorial Grove; Dana Francis, MSW, a social worker in the adult hemophilia program at the University of California San Francisco Hemophilia Treatment Center; and Charles Kaplan, PhD, Associate Dean of Research and Research Professor at the Hamovitch Center for Science in the Human Services at the Suzanne Dworak-Peck School of Social Work at the University of Southern California.

"We were very excited to be funded because it's very much a social science project, a social work project, and we didn't know if NHF would really be interested in that," Perry says. While not focused on developing novel technologies or therapies, the project is very much in line with NHF's commitment to funding research to support the bleeding disorders community. As outlined in Perry's award application, the study, titled Navigating Time and Space: Experiences of Aging with Hemophilia, has two main aims: "1) To examine the lived experiences and time horizons of APWH [aging persons with hemophilia] in order to characterize this community and 2) To enhance service delivery practice after examining needs, facilitators and barriers experienced by APWH." Thus the project looks to add to gerontological and social work theory while also highlighting concrete ways NHF and its chapters can better support older members of the bleeding disorders community.

For Perry, who in July 2020 was named a fellow of the Gerontological Society of America and is president of the Association for Gerontology Education in Social Work, this is her first funded grant related to a specific medical condition. Her previous work has ranged from research on health disparities among older adults to examining older people's relationships to their homes and decisions regarding relocating. "I really like to look at meaning making, how people make sense of things in older adulthood," she says.

The process that led to applying for the NHF Innovative Investigator Award grew from an established partnership between Perry and Schwartz. Schwartz had previously collaborated with Francis on a project about the impacts of the intersection of HIV and hemophilia on individuals and families. "Sara had conducted 32 interviews for that project, and she realized so many of these interviews had issues and concerns of aging in them," Perry says. "So we're first analyzing already

collected data to dissect on aging themes, and then later we're going to collect our own data with older adults." The insights gleaned from this data, Perry believes, could prove useful to people beyond the bleeding disorders community, including others with chronic conditions whose lifespans have extended thanks to treatment advances. "What you value and where you put your time after having that kind of switch, I think we have a lot to learn from our project to contribute to those kinds of questions."

Perry says she's grateful to be working with NHF on answering these key questions about aging with a bleeding disorder. Partnering with a foundation, she says, offers opportunities not always present when research is conducted under a National Institutes of Health (NIH) grant. "A lot of people go after NIH and

it's fine, but it's also a different thing to have that more close mission with your funders," she says. "Foundations have a real reason that they want to fund people and it's different than government mandates to reach a larger countrywide population. So my grant with NHF, I know that there will be a quicker path to directly affecting the lives of people like the people in my study."

Appendix M: Resident Scholar Appointment Letter from the Wayne State University Humanities Center

WAYNE STATE UNIVERSITY

THE HUMANITIES CENTER
2226 FACULTY ADMINISTRATION BUILDING,
WAYNE STATE UNIVERSITY CAMPUS
DETROIT, MI 48202

www.research.wayne.edu/hum/
313 577-5471
fax 313 577-2843
email walter.edwards@wayne.edu

August 3, 2021

Dear Associate Professor Tam E. Perry,

I am pleased to inform you that you have been selected for a Resident Scholar position in the Humanities Center for the 2021-22 academic year, beginning September 13, 2021 and ending August 15, 2022.

During this period, you will be expected to pursue research on your project(s): *"Navigating Time and Space: Experiences of Aging and Hemophilia" otherwise known as "Project Survivor"*

As a Humanities Center Resident Scholar, you are asked to agree to the following conditions:

1. You will spend at least six hours a week working on your project either remotely or your assigned office in the Humanities Center. If you are working remotely, please send the director (copied to Tiffin Carter, Administrative Assistant) a brief statement at the end of each semester outlining the work you have achieved on your project within that period. If you choose to work from your office in the center you should establish office hours at least twice a week, for a minimum of three hours per session (or three times per week for two hours each) which you will spend working on your research projects. You may also work partly remotely and partly in your office.
2. You would also be willing to participate in a monthly roundtable discussion with other resident scholars. During the fall 2021 semester this roundtable conversation will be virtual via zoom. In the winter 2021 semester, if the campus meetings are deemed safe, the roundtable could be held in the Center.

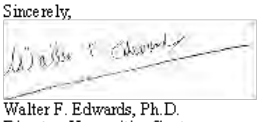
During your residency you will be eligible to apply for up to $800.00 for the 2021-22 academic year to support expenses related to your approved research project (e.g. travel, books, student assistance), These funds must be used by September 30 2022.

If you agree to the above conditions, please reply to this letter affirmatively via email by Friday, August 20, 2021.

Most of the center's computers are PC's, but if it is essential that you work on a MAC, please let us know as soon as possible so that we can accommodate your preference.

Once again, congratulations on your selection as a 2021-22 Humanities Center Resident Scholar!

Sincerely,



Walter F. Edwards, Ph.D.
Director, Humanities Center

I agree to the above conditions for occupying a Humanities Center office. If I choose to work on site, the office hours I will keep are as follows:

**Please check box next to the semester(s) and provide us with your office hours (if applicable) during your stay as a Resident Scholar.*

Fall 2021 ☐	Winter 2022 ☐

Signature: _____

cc:
Sheryl Kubiak, Dean, School of Social Work
Mark Lawrence Kornbluh, Ph.D.
Provost and Senior Vice President for Academic Affairs

Appendix N: Students' Undergraduate Research Opportunity Project Proposal

Project Title

Aging with Hemophilia

Students Involved

Misha Ansari (go6197@wayne.edu) , Abeer Gobah (gobahabeer@wayne.edu) , Sukrut Nadigotti (sukrutnadigotti@wayne.edu) , Samir Al-Khouri (gw2381@wayne.edu) , Aisha Patel (aishapatel@wayne.edu) , Asal Haddad (hf5760@wayne.edu)

Faculty Mentor

Tam E. Perry

- **Research Problem**

Hemophilia is a genetic blood disorder, where blood clotting doesn't occur due to a lack of a clotting factor typically produced by the liver. The symptoms include sudden and/or prolonged bleeding episodes, and restriction of movement due to joint swelling. Before the 1990's, treatment was through transfusions of donor plasma, however, when the HIV and HCV viruses contaminated blood banks, tragically half of those with hemophilia became infected.

The larger study investigates aging persons with hemophilia (APWH), who are experiencing an unprecedented shift in their lifespan because of access to new technology for treatment. Those who have survived experienced the loss of peers, social withdrawal, medical mistrust, and survivor's guilt. Researchers have documented that perception of a time horizon (i.e., nearness to death) often influences our actions, emotions and goals (Carstensen, 2006, p.1913). This project will allow us to understand what it means to APWH when nearness to death expands rather than contracts. The findings from this study will contribute to developing the best practices for serving this population.

The UROP project will focus on a subset of key questions as follows:

1) How have expanded time horizons affected this population?

2) What are the emotional, social, physical and financial needs and barriers

encountered by APWH?

Project Description

Hypothesis

- As APWH live longer we hypothesize that change will occur in strategies and approaches to self-care, social networks, the meaning of home and contributions.
- As APWH live longer we hypothesize that they will encounter financial challenges due to cost of treatment and lack of planning for retirement, social stigmatization caused by HIV and HCV outbreak during their youth, a change in their home, and emotional hardship as a result of this cohort's specific struggles.

Methods and Design

Phase 1: Coding of previous interviews.

To address the key research questions, the research students will analyze already collected interview data that Dr. Schwartz has provided. Dr. Schwartz, in part for an HIV and Hemophilia project, interviewed 32 APWH, and members of their community. Telephone interviews lasted 60-120 minutes recorded in 2017. In order to prepare for this, the students will learn coding from their faculty mentor. Then the students will practice coding small segments of the interviews. Next the students will develop a finalized list of codes to be applied to interview data.

Phase 2: Supporting interview and focus group data collection.

The larger project also focuses on understanding the experiences of current APWH. The study site is located in Northern and Southern California, because the state's Genetically Handicapped Persons Program (GHPP), a health insurance approach for its residents. The faculty research team is recruiting for interviews and focus groups. The researchers will ask participants to recount their experiences with a bleeding disease from childhood until present that has been transformed by new treatment modalities across their lifespans. The research students will have the opportunity to support researchers in the following ways:

- Observing the process of data collection.
- Contributing to data management processes.
- Preparing the results of the study.

Student Responsibilities

The main responsibilities for the research students involve, but are not limited to: a general familiarization on the subject of hemophilia through the examination of sources, writing literature reviews, learning how to code data about aging with hemophilia, developing multiple coding strategies, and developing an overall coding list from the coding of different transcripts. Students will be required to obtain CITI training for proper research ethics. The students will also be supporting members of the faculty research team in formatting transcripts, assisting with the preparation of scientific manuscripts, attending and taking notes of meetings for the multi-university faculty research, and collecting multiple data points through their observation of the

interviews. Along with this, the students will be tasked with presenting the research findings in both local and national conferences that include the Wayne State University for Undergraduate Research and Creative Work (2022), American Public Health Association (November 5 to 9, 2022; Boston, Massachusetts), and The World Federation of Hemophilia (WFH) and the Canadian Hemophilia Society (CHS) (2022). In addition to this, the students will be tasked with submitting a final report for the entire project.

Faculty Responsibilities

The responsibility of the faculty involves, but is not limited to: training the students involved in various coding techniques and research methods, formatting transcripts, as well as general manuscript preparation. Faculty will also be involved in helping the students develop knowledge needed to be able to create and present scientific demonstrations. Another involvement of the faculty involves mentoring the students and helping them foster the skills necessary for their future professional goals. This involves helping the students apply to medical school, alongside involving them in meetings such that they will create professional connections, and necessitating information such that students will write abstracts and applications to apply to local and national conferences.

Duration of Project

The timeframe of this project is designated such that it will reach completion on December 17, 2021, specifically in regards to the coding of interview data and general manuscript preparation. During early spring of 2022, the students will present the project at various local and national conferences.

Budget

The $2,300 award money will be allocated to students with a $366.66 as a stipend for their overall work on the research project. The $100 that is left over will be allocated to general supplies for the research project.

Signatures of Research Students

Misha Ansari

Sukrut Nadigotti

Samir Al-Khouri

Abeer Gobah

Aisha Patel

Asal Haddad

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