Spring 5-12-2017

Response to Quality of Life Surveying: An Analysis of Patients with Wiskott-Aldrich Syndrome

Tara Bani-Hashemi
tbani91@gmail.com

Response to Quality of Life Surveying:

An Analysis of Patients with Wiskott-Aldrich Syndrome

Tara Bani-Hashemi

MPH Candidate 2017

University of San Francisco

TABLE OF CONTENTS

Abstract 3
I. Introduction 4
II. Background 5
Wiskott-Aldrich Syndrome Epidemiology 6
Wiskott-Aldrich Syndrome Treatments 7
Description of The Wiskott-Aldrich Foundation 8
III. Scope of Project 9
IV. Public/Population Health Impact: Findings and Significance 10
V. Conclusion 12
References 14
Appendices 17
Final Learning Objectives 20
Master of Public Health Program FIELDWORK TIME LOG 23
Master of Public Health Program Student Time Sheet 24
Student Evaluation of Field Experience 25
Preceptor Evaluation of Student in Fieldwork Experience 27
MPH Program Competency Inventory 30

Abstract

Patient-reported outcomes and surveying has increased in clinical settings in order to assess outcomes and patient health status. However, there is a lack of these assessments from a pediatric standpoint, an inpatient standpoint, and family perspective. In addition to health status and overall clinic experience, expanding the self-reported evaluation to include quality of life on physical and psychosocial levels will provide a more comprehensive evaluation of the patients' health services. The PedsQL ™ scale scores four domains: physical, emotional, social, and school/work functioning. It includes a parent-proxy report as well as self-report for patients ages 5 to 18 years. Infant scales are also available for children 1-24 months of age that include a parent-proxy report.

The Wiskott-Aldrich Foundation aims to improve quality of life (QoL) surveying to best reflect patient and family sentiments for patients with the immunodeficiency disorder, Wiskott-Aldrich Syndrome (WAS). WAS is a genetically inherited immunodeficiency disease that severely suppresses the immune system to make the patient dangerously susceptible to autoimmune disorders and malignancies. The comparison of family impact and PedsQL™ can paint a picture of the family's coping with WAS and what they may need beyond clinical treatment of WAS.

I. Introduction

Wiskott-Aldrich Syndrome (WAS) is a genetically inherited immunodeficiency disease that occurs almost exclusively in males. Diagnosis of WAS is typically characterized by the triad of microthrombocytopenia, the decrease in the size and number of platelets, eczema, and severe infections. Platelets are the blood cells involved in clotting, so these patients have a reduced ability to form blood clots. This leads to symptoms such as easy bruising or episodes of prolonged bleeding after minor traumas. WAS largely affects white blood cells, which are responsible for immunity. Patients easily develop inflammatory disorders – especially severe eczema and skin irritations (Bosticardo et al., 2009). The large danger lies in the likelihood of patients developing autoimmune disorders because of their lack of immune system function and the body attacking its own tissues and organs. WAS is prematurely lethal and historically has an average survival of 20 years of age (Sullivan et al., 1994).

A pediatric quality of life (QoL) assessment exists, called PedsQL™, to determine a summary score for physical health, psychosocial health, and overall QoL on a scale of 0 to 100. There are 23 items that assess 4 areas: physical, emotional, social, and school/work. The patient scores each item on a 5-point scale from “never a problem” to “almost always a problem”. Each dimension is scored separately (Varni et al., 2006). A family impact module is also administered that includes Parent QoL, family function, and worry. The comparison of family impact and PedsQL™ can paint a picture of the family’s coping with WAS and what they may need beyond clinical treatment of WAS.

II. Background

The defect responsible for Wiskott-Aldrich Syndrome was initially identified in 1994 where the cytoplasmic WAS protein, or WASP, was compromised. WASP has various functions such as cytoskeletal organization, cell regulation, signal transduction, and immune synapse development (Ochs and Notarangelo, 2005). Therefore, disorder in the WASP affects the function of hematopoietic function and therefore damages lymphocyte and platelet counts in patients with the disorder. Genetic testing can show various mutations along the WAS gene. Those missing the WASP expression experience premature mortality. Some may have X-linked thrombocytopenia, or XLT, which is less severe. Another seen phenotype is X-linked neutropenia caused by a missense mutation at the Cdc42-binding site of the protein (Ochs and Thrasher, 2006).

Improvements in supportive care and treatment regimens have been relatively recent. Studies conducted by the Primary Immune Deficiency Consortium (PIDTC) are exploring immunological and clinical effects of hematopoietic cell transplant (HCT) in patients for WAS compared to other treatment options. Analysis of pre-transplant immunity compared to post-transplant conditions will reveal the most effective treatment option to maximize not only years of life, but also quality of life of young patients.

The prevention of infections must be addressed immediately after diagnosis. Intravenous Ig (IVIG) is typically used alongside more invasive treatments. Patients are typically put on prophylactic antibiotics or lifeline prophylactic penicillin for patients who have undergone splenectomy (Notarangelo, et al., 2008). It is currently recommended that all patients with WAS be considered for HSCT (hematopoietic stem cell transplantation) at a young age of less than 5

years old. Donor type is a very important consideration as graft versus host disease (GvHD) is a common adverse event. Post-transplant complications include mixed chimerism, autoimmunity, infections, malignancy such as lymphoproliferative disorder, B-cell lymphoma, large-cell lymphoma, myelodysplasia, and myeloid leukemia (Pai and Notarangelo, 2010). Full donor, successful engraftment limits the risk of these malignancies. Research is currently focused on gene therapy treatments, which avoid the graft rejection and GvHD barriers that HSCT have. The gene would be corrected using viruses to integrate the desired gene back into the genome. There are many efficacy and safety 'gaps' in the gene therapy treatment field, but the addition of these new advances could potentially be a new model for the care of various primary immunodeficiency disorders.

Wiskott-Aldrich Syndrome Epidemiology

WAS is a monogenic X-linked recessive disorder, meaning boys who inherit the abnormal gene are affected by the disease whereas girls who inherit the gene are typically healthy carriers of the disease. The gene responsible for the disorder is located on the short arm of the X-chromosome (Xp11.22-p11.23). The mutation in the WASp gene alters the function and expression of the protein that is involved in signaling, cytoskeletal arrangement, and actin polymerization. Two variations of diagnosis are X-linked thrombocytopenia (XLT) and X-linked neutropenia (XLN) (Ochs and Notarangelo, 2005). WAS diagnosis is scored based on severity on a scale of 0-5. WAS comprises of a group of serious, but rare disorders, affecting 1 in 250,000 live births and there are approximately 500 WAS patients in the U.S (Bosticardo et al., 2009). The disease has a similar incidence in countries around the world. Patients with WAS are at a high risk for developing autoimmune complications and severe malignancies during the first decade of life. Diagnosis of WAS includes microthrombocytopenia, decreased IgM and increased IgA and IgE

levels, poor antibody response via infection or immunization, low CD8 levels, low NK cells, and severe allergies. Due to low immune function, patients have an overwhelming higher risk of developing severe infections due to herpes viruses (Herpes Simplex Virus 1 (HSV-1) and Varicella Zoster (VZV)) (Imai et al., 2004).

Wiskott-Aldrich Syndrome Treatments

Hematopoietic cell transplant (HCT) is currently the only remedying therapy for WAS patients. Because the mechanism of WAS is relatively newly understood, many short-term outcomes have been published. The primary life-threatening complication following HCT is acute and/or chronic graft versus host disease, or GvHD. To prevent transplant rejection and prevent mixed chimerism, conditioning treatments similar to chemotherapy for cancer treatment is administered prior to HCT. The younger the patient, the more successful transplant is and fewer graft rejections are reported.

Supportive therapies for patients diagnosed with WAS include antibiotic administration, immunoglobulin administration, minimizing allergy sources, and managing symptoms of mild immune cases such as eczema. If patient has bleeding episodes due to microthrombocytopenia, platelet transfusions may be administered. There are no therapies to treat severe malignancies such as lymphoma or other severe autoimmune conditions.

Gene therapy (GT) is the newest treatment option to emerge for WAS. Boztug et al. in Germany were the first to treat patients using GT. The process involves the collection of peripheral blood CD34+ cells and transducing a WASP retrovirus vector. Patients would be administered a

conditioning regimen similar to that of HCT days prior to transduction. The study showed 57% and 69% expression of WASP-positive B-cells in patient 1 and 2, respectively. The higher expression meant better T cell and NK cell function and more production of antibodies that are important for immunization. Greater platelet counts to help with bleeding episodes were also accounted for (Boztug et al., 2010). Since this study, various centers around the world are implementing GT and are seeing successful reconstitution. The risk of GvHD and the potential risk in waiting for the proper donor for HCT would be eliminated with this method of treatment.

Description of The Wiskott-Aldrich Foundation

Mission: "The Wiskott-Aldrich Foundation is dedicated to serving children with Wiskott-Aldrich Syndrome and their families worldwide by funding research and providing educational, financial and emotional support."

The Wiskott-Aldrich Foundation was founded in 2003 to inform people of the disease, promote research, and provide support for WAS families. The WAF collaborates with families, physicians, researchers, patients, and charities to serve these families and link them to the resources they may need. In a time of vulnerability and uncertainty, families of children with WAS can turn to an organization whose mission is to improve the quality of life for WAS patients. The momentum created through this online resource and its presence in immune deficiency groups has fostered critical research to grow to better the lives of WAS patients worldwide. www.wiskott.org has over 90 pages of resources that is constantly being updated. On the portal, families can find the most current research, registries, financial resources, support groups, camps, and leading treatment institutions near them. Families are encouraged to share

their stories and engage in forums and attend events to not only become informed, but also to develop a community to help in coping with WAS.

III. Scope of the Project

The primary goal of the project was to improve the quality of life for patients and families of patients diagnosed with Wiskott-Aldrich syndrome through raising awareness of the effects of WAS and encouragement of questioning QoL through surveying.

The personal objectives for the fieldwork experience were as follows:

1. Research past QoL studies and effectiveness
2. Familiarize self with PedsQL™
3. Understand scoring of QoL surveys
4. Maintain IRB consents and QoL surveys through UCSF IRB
5. Administer QoL surveys in various languages when needed
6. Administer QoL surveys to UCSF WAS patients at cross-sectional visits
7. Data entry of QoL results

The Wiskott-Aldrich Foundation's current research has the following objectives:

1. Improve patient's quality of life (QoL)
2. Share the effects of WAS and treatment options on the QoL of patients with healthcare professionals and colleagues
3. Encourage the administration of QoL surveys regularly
4. Improve QoL surveying to best reflect patient and family sentiments
5. Use QoL as a tool to help families and physicians assess treatment options
6. Use QoL study results to impact other conditions outside of WAS on a global level

The Wiskott-Aldrich Foundation collaborates with research consortiums, such as the PIDTC, physicians, statisticians, patient advocacy groups, families, and volunteers to publish and share data on WAS and push for bettering the quality of life assessments to ultimately affect quality of care on a comprehensive level.

IV. Public/Population Health Impact: Findings and Significance

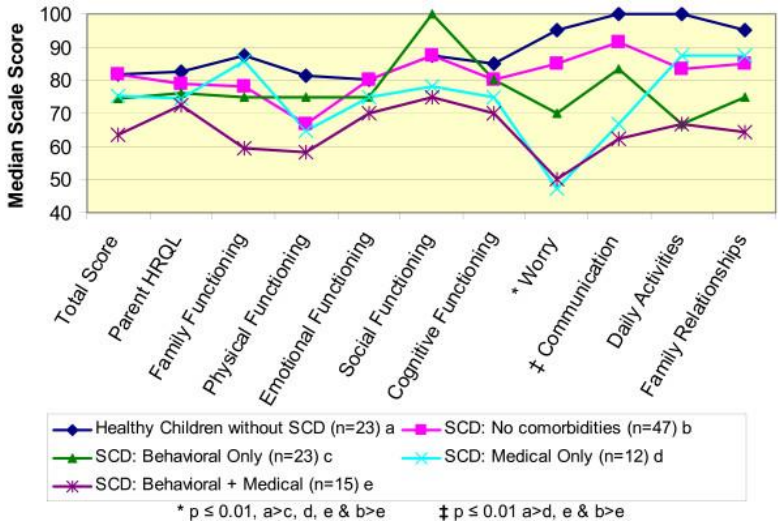
Although the results of the research cannot be disclosed in this paper due to confidentiality and grant renewal reasons, there has been extension research published on the effectiveness of quality of life surveying a pediatric healthcare setting to evaluate patient needs on a comprehensive level.

Desai et al. assessed responsiveness, construct validity, and predictive validity of the PedsQL™ scale in an inpatient setting at Seattle Children's Hospital using a prospective cohort of 7184 participants from 1 month to 18 years of age. 4637 (64.5%) of the participants completed the survey when admitted, and 2694 (58.1%) of participants completed the follow-up survey after discharge weeks later. The study set out to evaluate response to clinical change in critically ill children to determine the effectiveness of quality improvement interventions. On the 0 to 100 scale, the mean PedsQL™ scores were 22.1 for total, 29.4 for physical, and 17.1 for psychosocial (Desai et al., 2014). Improvement scores were derived by calculating the difference between scores on admission and those at follow-up. The study showed construct validity when testing patients with no chronic illness, who had much higher QoL scores compared to the chronically ill patients measured. The highest scores being physical QoL can be explained because patients in a

short-term inpatient setting have the focus of physical health improvement interventions. The score decreased by an average of 10-points with risks for prolonged length of stay (15% [95% CI, 13%-17%]), 30-day readmissions (8% [95% CI, 3%-14%]), and ED return visits (13% [95% CI, 6%-20%]) (Desai et al., 2014). The PedsQL™ model revealed strong responsiveness, construct validity and predictive validity for inpatient pediatric patients.

In a paper by Panepinto et al., PedsQL™ scores were looked at for various diseases and comorbidities. Children without sickle cell disease and without other comorbidities had higher scores for most categories than children with sickle cell disease and medical/neurobehavioral comorbidities. Worry and communication sub scores were the only statistically significant low scores (Panepinto et.al, 2009). Figure 1 illustrates these results.

Figure 1



Nuss and Wilson examined health-related quality of life (HRQoL) of children who underwent a hematopoietic stem cell transplant (HSCT), which includes bone marrow, cord blood, or peripheral blood). Most WAS patients undergo this treatment to prolong life – both quantity and quality of life. The study found a lower quality of life reported in mothers, and a statistically

significant lower physical functioning score in mothers. Children and mothers felt more anxious with older age of transplant, while father felt less anxiety and worrying when child was transplanted at older age. Compared to healthy individuals, HSCT patients had increase fear of disease, anxiety, perfectionism, and sense of inadequacy. Mothers reported lower physical quality of life than fathers and children in multiple studies. It is hypothesized that mothers often assist more in the care of the transplanted children than fathers, and mothers may compare their child's physical well-being to an ideal well-being that the child may not have. Increase in anxiety with increase in age may be due to the awareness factor. Older children may be more aware with higher procedural anxiety than younger children who do not remember or dwell on the procedure. It would be important to look at sibling QoL scores as well. Siblings of WAS patients are lucky in the genetic draw. Siblings are also with the transplanted children on a more regular basis, and may have more insight on physical and psychological quality of life.

V. Conclusion

Larger retrospective and prospect studies of children with WAS undergoing the various treatment options can uncover the best treatment, most successful conditioning regimen, and donor choice. Pre and post- treatment immunological data can provide insight into factors that affect survival and reconstitution. The continuation of quality of life survey administration also tells the story of patients and their families dealing with the disease. Healthcare professionals must be aware of these social aspects of illness to provide a comprehensive care plan.

Quality of life scores in patients with WAS are significantly lower than those in healthy

patients. The Wiskott-Aldrich Foundation found that on average, patients and parents report similar QoL scores across all 4 domains, and that psychosocial QoL scores are significantly lower than physical QoL scores. We can also conclude that QoL in WAS is similar to QoL scores for other PIDs and chronic GvHD. When looking at treatment options, patients and families who had transplants reported higher QoL scores than those who did not. Because patients who are older at transplant report lower scores, it can be concluded that transplant at a younger age is beneficial on all domains. Ultimately, these results must be incorporated into psychosocial and emotional parts of care and treatment for all patients. Surveying must be administered at all annual visits to ensure patients and families are doing well emotionally and mentally apart from standard of care assessments. Support for siblings must be available, as they are affected with worry. After transplant, healthcare professionals should offer patient group support options and any emotional support possible to minimize worry in families. These groups are confronted with a rare condition that can be very isolating, and a community to understand their family function and perception of disease can ultimately improve quality of life and overall care of patient.

References

Aspesberro, F., Fesinmeyer, M.D., Zhou, C., Zimmerman, J.J., & Mangione-Smith, R. (2016). Construct validity and responsiveness of the Pediatric Quality of Life Inventory 4.0 Generic Core Scales and Infant Scales in the PICU. Pediatric Critical Care Medicine, 17(6), e272-e279.

Bosticardo M et al. Recent advances in understanding the pathophysiology of Wiskott-Aldrich syndrome. Blood. 2009; 113: 6288-6295.

Boztug K et al. Stem-cell gene therapy for the Wiskott-Aldrich Syndrome. New Engl J Med. 2010; 363: 1918-1927.

Buchbinder, D., Nugent, D., & Fillipovich, A. (2014). Wiskott–Aldrich syndrome: diagnosis, current management, and emerging treatments. The Application of Clinical Genetics, 55-64. doi:10.2147/tacg.s58444

Desai, A. D., Zhou, C., Stanford, S., Haaland, W., Varni, J.W., & Mangione-Smith, R.M. (2014). Validity and responsiveness of the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales in the pediatric inpatient setting. JAMA Pediatrics, 68, 1114-1121.

Imai K et al. Clinical course of patients with WASP gene mutations. Blood. 2004; 103: 456-464.

Lawitschka, A., Güclü, E.D., Varni, J.W., Putz, M., Wolff, D., Pavletic, S., Greinix, H., Peters, C., & Felder-Puig, R. (2014). Health-related quality of life in pediatric patients after allogeneic SCT: Development of the PedsQL™ Stem Cell Transplant Module and results of a pilot study. Bone Marrow Transplantation, 49, 1093–1097.

Notarangelo, LD, Miao CH, Ochs HD, Wiskott-Aldrich syndrome. Curr Opin Hematol, 2008; 15: 30-36.

Nuss, S. L., & Wilson, M. E. (2007). Health-Related Quality of Life Following Hematopoietic Stem Cell Transplant During Childhood. Journal of Pediatric Oncology Nursing, 24(2), 106-115. doi:10.1177/1043454206296033

Ochs HD, Notarangelo LD. Structure and function of the Wiskott-Aldrich syndrome protein. Curr Opin Hematol. 2005; 12: 284-291.

Ochs HD, Thrasher AJ. The Wiskott-Aldrich syndrome. J Allergy Clin Immunol, 2006. 117: 725-738; quiz 739.

Panepinto, J. A., Hoffmann, R. G., & Pajewski, N. M. (2009). A psychometric evaluation of the PedsQL™ Family Impact Module in parents of children with sickle cell disease. Health and Quality of Life Outcomes, 7(1), 32. doi:10.1186/1477-7525-7-32

Sullivan KE, et al., A multi-institutional survey of the Wiskott-Aldrich syndrome. J Pediatr. 1994; 125: 876-85.

Switzer, G.E., Bruce, J., Kiefer, D.M., Kobusingye, H., Drexler, R., Besser, R.M., Confer, D.L., Horowitz, M.M., King, R.J., Shaw, B., van Walraven, S.M., Wiener, L., Packman, W., Varni, J.W., & Pulsipher, M.A. (in press). Health-related quality of life among pediatric hematopoietic stem cell donors. Journal of Pediatrics.

Varni, J.W., Bendo, C.B., Shulman, R.J., Self, M.M., Nurko, S., Franciosi, J.P., Saps, M., Saeed, S., Zacur, G.M., Dark, C.V., & Pohl, J.F. (2015). Interpretability of the PedsQL™ Gastrointestinal Symptoms Scales and Gastrointestinal Worry Scales in pediatric patients

with functional and organic gastrointestinal diseases. Journal of Pediatric Psychology, 40, 591-601.

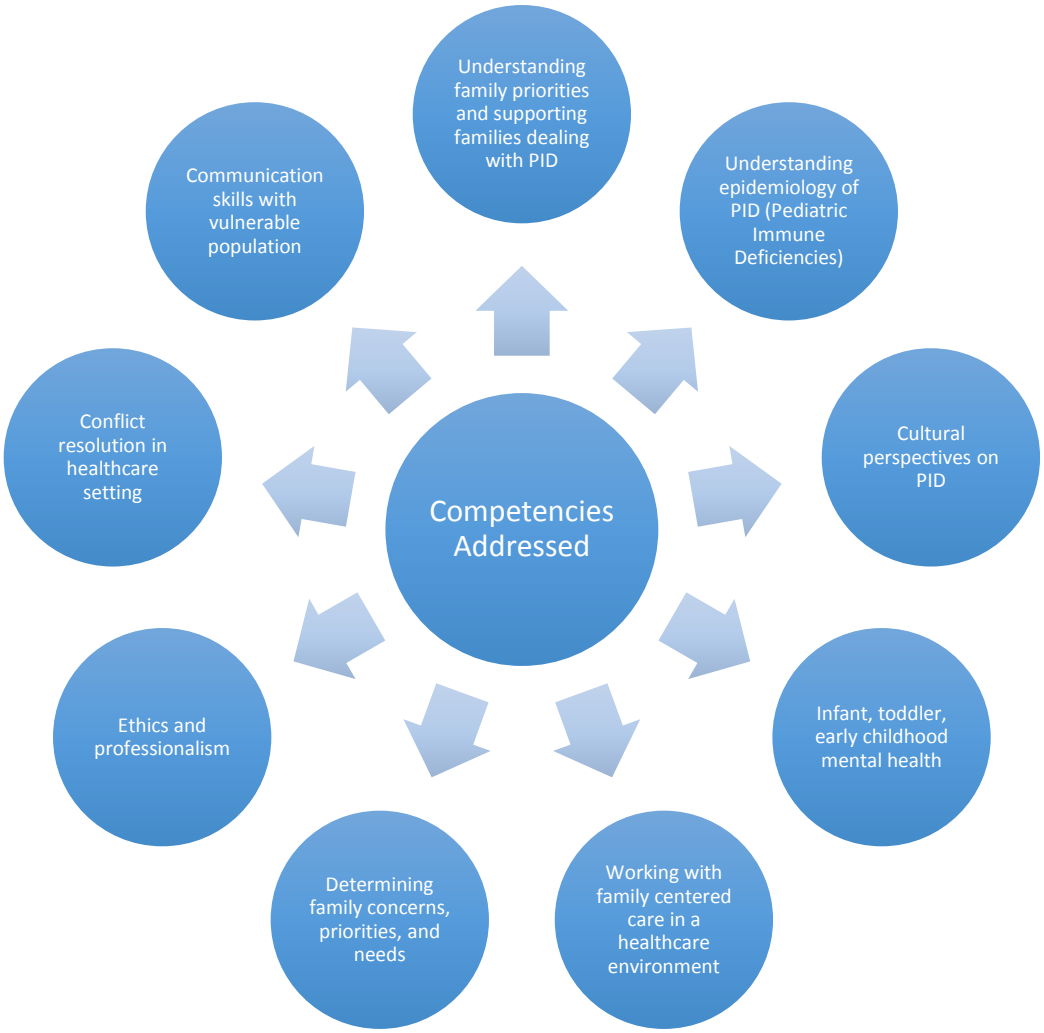
Varni, J.W., Franciosi, J.P., Shulman, R.J., Saeed, S., Nurko, S., Neigut, D.A., Bendo, C.B., Patel, A.S., Self, M.M., Saps, M., Zacur, G.M., Denham, J., Dark, C.V., & Pohl, J.F. (2015). PedsQL™ Gastrointestinal Symptoms Scales and Gastrointestinal Worry Scales in pediatric patients with inflammatory bowel disease in comparison to healthy controls. Inflammatory Bowel Diseases, 21, 1115-1124.

Varni, J.W., Limbers, C.A., Neighbors, K., Schulz, K., Lieu, J.E.C., Heffer, R.W., Tuzinkiewicz, K., Mangione-Smith, R., Zimmerman, J.J., & Alonso, E.M. (2011). The PedsQL™ Infant Scales: Feasibility, internal consistency reliability and validity in healthy and ill infants. Quality of Life Research, 20, 45-55.

Zhang, H., Wang, L., Quan, M., Huang, J., Wu, P., Lu, Q., & Fang, Y. (in press). Health-related quality of life in children with chronic immune thrombocytopenia in China. Health and Quality of Life Outcomes.

Appendices

Competencies Addressed



Fieldwork Reflection

My work at UCSF Benioff Children's Hospital involved the direct communication with patients and families with WAS. Patients that came in for diagnosis or follow-up treatment would have 10-minutes set aside for me to consent them to a part of a PIDTC (Primary Immune Deficiency

Treatment Consortium) cross-sectional study where QoL surveys would be administered and evaluated. I had to get IRB approval and consent training which really opened my eyes to patient care settings – especially with vulnerable populations. I felt honored to be a part of such an inspiring team of healthcare professionals who dedicated their lives to immunology. The physicians I worked with on a daily basis were some of the leading researchers in the field, and have helped patients with WAS live close-to-normal lives with innovative therapies. I had the opportunity to sit in on meetings where they discussed every child who came into either inpatient or outpatient clinic, and evaluated every small part of their treatment down to their emotional experience to make sure the patient and their families were comfortable. I was so impressed that these brilliant minds knew every detail about every patient down to the kind of meals they wanted to have that day.

The administration of the surveys was not always easy. There were some instances where families were overwhelmed, and thinking about signing various consent forms and learning about a research study was too much to handle at a vulnerable time. I never, however, experienced denial of participation or difficult communication with families. I believe a large part of this has to do with the close-knit community of PID families, and The Wiskott-Aldrich Foundation contributes to this. Because PID is rare, families are much more willing to participate in research to really uncover treatment options and unknowns behind the diseases. PIDTC is the largest multi-center consortium dedicated to PID, with one protocol for WAS. These patients and families seemed excited about the study because of the physicians behind the work and the patient advocacy groups they were a part of. It really felt like a family and team that helped each other out. I walked away from this experience believing that the heart is not the center of the body as most believe, but rather, it's the immune system. The University of San Francisco's

healthcare graduate program aims to prepare students to be leaders and problem solvers in an evolving healthcare realm, and I feel that my courses supplemented my fieldwork experience to deliver just that. I hope to extend my research and work to get vulnerable patients the emotional care they need.

Final Learning Objectives

Goal 1: To estimate survival for patients with Wiskott-Aldrich Syndrome (WAS) at 6 months and 1, 2, 3, 5, 10, and 15 years post-HCT (hematopoietic stem cell transplantation), and to study risk factors for overall survival in this patient population				
Objectives (S)	Activities	Start/End Date	Who is Responsible	Tracking Measures
Evaluate patient, donor, and transplant factors	Use EMR for UCSF patients to enter longitudinal data into data management site (DMCC)	September 1 – December 31, 2016	Tara Bani-Hashemi	Number of completed case report forms (CRFs) in DMCC database for UCSF WAS patients entered
Determine proportion of subjects having successful immunologic and hematologic reconstitution, including T cell function, B cell function, and platelet numbers at 100 days, 6 months and 1, 2, 3-5, 6-10, 11-15, and > 15 years after HCT for WAS	Use EMR for UCSF patients to enter longitudinal data into data management site (DMCC)	September 1 – December 31, 2016	Tara Bani-Hashemi and PIDTC statistician	Number of completed case report forms (CRFs) in DMCC database for UCSF WAS patients entered
Evaluate engraftment and quality of immune reconstitution as contributors to clinical outcome, including occurrence of post-transplant infections, bleeding episodes, and/or new malignancies, GVHD, autoimmunity, growth and development, and quality of life.	Use EMR for UCSF patients to enter longitudinal data into data management site (DMCC)	September 1 – December 31, 2016	Tara Bani-Hashemi and PIDTC statistician	Number of completed case report forms (CRFs) in DMCC database for UCSF WAS patients entered

Evaluate current survivors of HCT for WAS as to the effects of patient, donor and transplant-related factors on the degree of immune reconstitution of T, B, and NK cells, and normalization of peripheral blood platelet counts.	Consent WAS patients to Cross-Sectional portion of study in the UCSF BMT unit clinic	September 1 – December 31, 2016	Tara Bani-Hashemi	Number of UCSF WAS patients who came into BMT clinic for the follow-up/cross-sectional visit. Number of consents collected
Evaluate cross-sectional visits showing current survivors of HCT for WAS as to the effects of patient, donor, and transplant-related factors on current health	Administer Quality of Life surveys, collect Karnofsky or Lansky functional scores from physician notes	September 1 – December 31, 2016	Tara Bani-Hashemi	Number of UCSF WAS patients who came into BMT clinic for the follow-up/cross-sectional visit. Number of surveys and data points collected
Maintain IRB approvals and modifications for UCSF's 6904 WAS study	Submit modification forms, change in study personnel, protocol changes, and annual renewals to UCSF IRB	September 1 – December 31, 2016	Tara Bani-Hashemi	Compliance with IRB and maintenance of renewal terms

Goal 2: To improve the quality of life for patients and families of patients diagnosed with Wiskott-Aldrich syndrome through raising awareness of the effects of WAS and encouragement of questioning QoL through surveying.				
Objectives (S)	Activities	Start/End Date	Who is Responsible	
Research past QoL studies and effectiveness	Tara to conduct research on previous studies involving importance of QoL surveying and outcomes	September 1 – October 1, 2016	Tara Bani-Hashemi	Good understanding of QoL studies and their implications through past studies
Familiarize self with	Research PedsQL™ and differences to QoL	September 1 – October 1,	Tara Bani-Hashemi	Good understanding of PedsQL™ format and

PedsQL™	surveys administered to adult patients	2016		differences to adult quality of life surveys
Understand scoring of QoL surveys	Research QoL scoring options and research survey study outcomes from previous studies	September 1 – October 1, 2016	Tara Bani-Hashemi	Good understanding of scoring of quality of life surveys and how overall scores generated
Maintain IRB consents and QoL surveys through UCSF IRB	Submit consent forms and QoL surveys as need be	September 1 – December 31, 2016	Tara Bani-Hashemi	Compliance with IRB and maintenance of renewal terms
Create QoL surveys in various languages	Draft, finalize, and submit QoL surveys in various languages	September 1 – December 31, 2016	Tara Bani-Hashemi	Submission of various language QoLs to IRB and wider distribution at UCSF due to larger reach
Administer QoL surveys to UCSF WAS patients at cross-sectional visits	Tara to attend cross-sectional visits for WAS patients in BMT clinic to consent and administer surveys for PIDTC study	September 1 – December 31, 2016	Tara Bani-Hashemi	Number of UCSF WAS patients who came into BMT clinic for the follow-up/cross-sectional visit. Number of surveys and data points collected
Data entry of QoL results	Enter collected cross-sectional data into DMCC database for analysis	September 1 – December 31, 2016	Tara Bani-Hashemi & PIDTC statistician	Number of completed case report forms (CRFs) in DMCC database for UCSF WAS patients entered

Master of Public Health Program FIELDWORK TIME LOG

Student Information	
Student's Name: Tara Bani-Hashemi	Campus ID # 20377211
Student's Phone: (925) 262-7817	Student's Email: tbanihashemi@usfca.dons.edu
Preceptor Information	
Preceptor's Name: Sumathi Iyengar M.D.	Preceptor's Title: Executive Director
Preceptor's Phone: 919-641-7134	Preceptor's Email: sumathi.iyengar@wiskott.org
Organization: Wiskott-Aldrich Foundation	
Student's Start Date: September 1st, 2016	Student's End Date: 20hrs/wk through December 31st, 2016

Time Log for (Check One):

_____ **Summer 2016** _____**X**_____**Fall 2016**

_____ **Summer 2017** _____**Fall 2017**

Master of Public Health Program Student Time Sheet

Week	Total # of Hours for Week	Preceptor Initials
Sep 1-8, 2016	20	SI
Sep 8-15, 2016	20	SI
Sep 15-22, 2016	20	SI
Sep 22-29, 2016	20	SI
Sep 29-Oct 6, 2016	20	SI
Oct 6-13, 2016	20	SI
Oct 13-20, 2016	20	SI
Oct 20-27, 2016	20	SI
Oct 27-Nov 3, 2016	20	SI
Nov 3-10, 2016	20	SI
Nov 10-17, 2016	20	SI
Nov 17-24, 2016	0	SI
Nov 24-Dec 1, 2016	20	SI
Dec 1-8, 2016	20	SI
Dec 8-15, 2016	20	SI
Dec 15-22, 2016	20	SI
Dec 22-29, 2016	0	SI
Total	300	

Student Evaluation of Field Experience

Student Information	
Student's Name: Tara Bani-Hashemi	Campus ID # 20377211
Student's Phone: (925) 262-7817	Student's Email: tbanihashemi@usfca.dons.edu
Preceptor Information	
Preceptor's Name: Sumathi Iyengar M.D.	Preceptor's Title: Executive Director
Preceptor's Phone: 919-641-7134	Preceptor's Email: sumathi.iyengar@wiskott.org
Organization: Wiskott-Aldrich Foundation	
Student's Start Date: September 1st, 2016	Student's End Date: 20hrs/wk through December 31st, 2016

Please use the following key to respond to the statements listed below.

SA = Strongly Agree A = Agree D = Disagree SD = Strongly Disagree N/A = Not Applicable					
My Field Experience…					
Contributed to the development of my specific career interests	SA	A	D	SD	N/A
Provided me with the opportunity to carry out my field learning objective activities	SA	A	D	SD	N/A
Provided the opportunity to use skills obtained in MPH classes	SA	A	D	SD	N/A
Required skills I did not have Please list: Patient- interaction in a professional healthcare setting	SA	A	D	SD	N/A
Required skills I have but did not gain in the MPH program Please list: Acquired professional research skills not gained during program	SA	A	D	SD	N/A
Added new information and/or skills to my graduate education Please list: Work experience, time-management, independent learning, research analysis	SA	A	D	SD	N/A
Challenged me to work at my highest level	SA	A	D	SD	N/A
Served as a valuable learning experience in public health practice	SA	A	D	SD	N/A
I would recommend this agency to others for future field experiences.	Yes			NO	
My preceptor…					
Was valuable in enabling me to achieve my field learning objectives	SA	A	D	SD	N/A
Was accessible to me	SA	A	D	SD	N/A
Initiated communication relevant to my special assignment that he/she considered of interest to me	SA	A	D	SD	N/A
Initiated communication with me relevant to general functions of the agency	SA	A	D	SD	N/A

2. Would you recommend this preceptor for future field experiences? Please explain.

X Yes _____No _____Unsure

Dr. Iyengar was eager to help at all times, and was able to give me access to many valuable resources and publications that I would not come across on my own. She is a very valued member in the PID community and I feel very fortunate to have worked with her on a professional level.

3. Please provide additional comments explaining any of your responses.

I would strongly recommend any future students to work with and help the Wiskott-Aldrich Foundation. I believe as public health professionals, it is our duty to better understand populations in need and do whatever we can to support the patients and their families financially, emotionally, and using any resources we may have.

4. **Summary Report**: All students are required to prepare a written summary of the field work to be submitted with this evaluation form.

Student Signature Date

Master of Public Health Program

Preceptor Evaluation of Student in Fieldwork Experience

The purpose of this form is to provide the preceptor with an opportunity to evaluate the student's performance in the Field Experience. The preceptor and student should review and discuss this evaluation together before it is submitted.

Student's Name: Tara Bani-Hashemi

Preceptor's Name: Sumathi Iyengar M.D.

Preceptor's Title: Executive Director

Preceptor's Email: sumathi.iyengar@wiskott.org

Please rate the student's performance during the field experience based on the following criteria:

N/A – Not applicable

1 = Unacceptable at this point in training

2 = Somewhat below expectations

3 = Met expectations

4 = Consistently exceeded expectations

COURSE REQUIREMENTS:					
Achieved Field Experience Learning Objectives (see Field Learning Agreement)					
Completed defined project in Public Health Practice					
Worked effectively with Preceptor					
Worked effectively within Organization					
Integrated public health theory into public health practice					
Demonstrated an appropriate level of public health skills and knowledge in field experience					

PUBLIC HEALTH SKILLS AND KNOWLEDGE:					
Able to apply the core function of assessment in the analysis of public health problems. (Assessment)					
Demonstrated an understanding of the structure, process, and outcomes of health services including costs, financing, organization, outcomes, and accessibility. (Systems)					
Able to plan for the design, development, implementation, and evaluation of strategies to improve individual and community health. (Program Planning)					
Able to use the basic concepts and skills involved in culturally appropriate community engagement and empowerment with diverse populations. (Cultural Competency)					
Able to prepare a program budget with justification. (Financial Planning/Budgets)					
Demonstrated an ability to use collaborative methods to achieve community and organizational goals. (Leadership)					
WORK HABITS:					
Reliable					
Took initiative in work					
Efficient					
INTERPERSONAL SKILLS:					
Professional demeanor					
Interactions with co-workers					
Interactions with community partners					

2. Did the student bring the appropriate knowledge and skills needed to complete the projects (s) in your organization? If no, what additional knowledge and skills were needed?

3. What was the student's work helpful or useful to you and your agency/organization? Please explain.

4. Please provide additional comments regarding the student's performance.

Final Grade Assigned for Field Experience	(Check One)
A= Outstanding	
AB= Very Good	
B= Good	
BC= Satisfactory, but below expectations	
C=Marginal Pass	
F=No Credit	

Preceptor's Signature:_____Date: _____

Student's Signature:_____Date:_____

MPH Program Competency Inventory

USF MPH Competencies	Notes
1. Assess, monitor, and review the health status of populations and their related determinants of health and illness.	
2. Demonstrate the ability to utilize the proper statistical and epidemiologic tools to assess community needs and program outcomes.	
3. Identify and prioritize the key dimensions of a public health problem by critically assessing public health literature utilizing both quantitative and qualitative sources.	
4. Specify approaches for assessing, preventing, and controlling environmental hazards that pose risks to human health and safety.	
5. Apply theoretical constructs of social change, health behavior and social justice in planning community interventions.	
6. Articulate the relationship between health care delivery and financing, public health systems, and public policy.	
7. Apply evidence-based principles to the process of program planning, development, budgeting, management, and evaluation in public health organizations and initiatives.	
8. Demonstrate leadership abilities as collaborators and coordinators of evidence based public health projects.	
9. Identify and apply ethical, moral, and legal principles in all aspects of public health practice.	
10. Develop public health programs and strategies responsive to the diverse cultural values and traditions of the communities being served.	
11. Effectively communicate public health messages to a variety of audiences from professionals to the general public.	
12. Advance the mission and core values of the University of San Francisco.	