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Pushing the Boundaries of Healing

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Pushing the Boundaries of Healing

Cover Page Footnote

Thank you to my supervisors at RMHC-Madison, the Shepherd Program Faculty, and the families I worked with over the summer!

I believe healing can be viewed as a result of cooperation between biological and social components. The term “social determinants of health” has developed much traction in the world of medicine, and rightfully so, in my opinion. To illustrate, take a look at the table (Kaiser Family Foundation, 2018) below, and try to imagine what your life would be like if even one of the listed items were exacerbated. Granted, a change in some of these conditions will have a more substantial affect than others, but hopefully it is clear that we take these factors for granted when we are not experiencing stressors related to these items. Now consider the process of becoming ill. Social determinants of health (SDH) will not only shape your experience of illness, but also your healing process, especially for those who tend to lack the elements listed below, such as people of low socioeconomic status (SES; Weiss and Lonnquist, 2016). Taken together, these findings suggest healing can be aided through supplementing the social determinants of health.

Figure 1

Categorized social determinants of health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds	Higher education		Stress	
Support	Walkability				
	Zip code / geography				

Health Outcomes
 Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations



(Artiga & Hinton, 2018)

During the summer of 2019 I volunteered at the Ronald McDonald House (RMHC) in Madison, WI and gained a substantial amount of insight into the influence of social conditions on the health and coping of families with a child who has a serious medical condition. RMHC is an international nonprofit organization with the overall mission to enable access to the best pediatric care possible while keeping families in close proximity to their children undergoing medical treatment. During my time volunteering there, I observed the impact of this organization on the lives of families staying there. My interactions were mostly with parents and siblings of the patient, but occasionally I was able to meet the kids themselves, when they were discharged from the hospital or in stable enough condition to spend the night with their families. In this article, I will make the case that SDH-targeted support of patients improves the healing process for low-SES patients. There is evidence for the improvement of medical outcomes based on SDH support outright; for example, homeless HIV positive patients were better able to complete their course of medication when provided housing and food (Bangsberg et al., 2000). Through my own experiences at RMHC, I have identified SDH pathways through which patients and their families found support in times of medical need, and will seek to show how each strengthens the healing process for patients.

The Ronald McDonald Charity supports families with a child undergoing medical treatment. The charity itself is divided into three subcategories: the House (serves as a home base for out-of-town families), which is where I was based, the Family Room (an area of the hospital meant to serve as a mental break from the fast pace of the NICU), and the Mobile Care Station (an examination room on wheels providing physicals, primary care, vaccines, dental care, and treatment for chronic conditions). The first ever Ronald McDonald House was opened in 1974 as

a nonprofit organization, after a child with leukemia's father realized the need for a "home away from home" during hospitalization. Local McDonald's franchisees raised the money to create the House in Philadelphia (Ronald McDonald House Charities, 2017).

For a family to stay in the House, their pediatric patient must have a referral from a social worker or representative at one of Madison's healthcare or hospital facilities. The rooms in the House are meant for people who come to seek medical treatment in the capital of Wisconsin, (since some care is unavailable in rural northern areas) who are not from Madison and would otherwise be unable to afford the stay in a hotel. Since the House only suggests a donation of \$10 per night, and is in no way required, it removes the financial burden of otherwise staying in a hotel. Consider how accommodations in the city for low socioeconomic status families not only alleviates the cost of a hotel room, but also allows patients to obtain services (e.g. having MRI scans done) that may not be provided elsewhere.

Needs Met by RMHC Services

Most psychologists agree that humans have a basic need for physiological and social well-being (Maslow, 1943). The basic need for biological well-being refers to access to food and shelter. One of my duties as a volunteer at RMHC was working with a team to address basic needs of resident families; one such duty was providing meals. Along with three meals being made and served free of charge, meal service also centers around packing lunches to send to the hospital while families visit their children in the Pediatrics ward or take them to appointments. The program, called Lunches with Love, collects orders from RMHC residents as well as the NICU (due to a high volume of RMHC residents with babies in this ward) every morning and evening. These lunches typically consist of a sandwich (with meat and cheese), fruit, chips, and a cookie.

The House is supported by many partners coming together to provide other basic needs for families. An independent sales consulting firm purchases and donates hygiene handbags with toiletries. Various volunteer groups will visit the kitchen and prepare full meals for residents. The local girl scout troops participate in a Cookie Share with the House, which allows customers to purchase cookies that will be donated to RMHC, which in turn supplies these cookies to the NICU and other pediatric wards where RMHC resident families who requested sack lunches wait in doctor's offices. RMHC also receives a weekly donation of sandwich buns, cinnamon rolls, and other pastry goods from local bakeries.

Since I had just taken a course on nutrition in the spring semester, my first glance at the processed foods present in the delivered lunches felt like a missed opportunity to enhance the health of residents at the House. When I took a look at the RMHC Facebook page and saw comments about how helpful it was to have food delivered for free so parents did not have to leave to bring food, I realized the provision of any type of food is the number one concern. Managing so many meals based on contributions and donations is a daunting task. I do still hope that some healthy elements can be incorporated in the future; for example, adding another healthy item, lowering sugar content, or replacing existing foods with healthy alternatives.

Beyond biological needs, RMHC's mission is to keep families together during pediatric medical need. This is because it provides social support to the patient. The definition of social support is "a network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help" (National Cancer Institute, n.d., S Section). Social support has also been shown to be one of the key psychosocial factors which build resilience to stress and depression (Southwick et al., 2005) At the RMHC, not only are children kept in close connection with their parents, but their parents are connected with

other residents sharing similar situations. For instance, I remember listening to a mother comfort another new mom, since their babies were experiencing the same illness.

Keeping parents linked to these resources allows them to help their children cope with their anxieties, pain, and road to recovery. That the parents are with them is critical to the children's medical outcome. When the body fights disease, or recovers from invasive medical treatment, inflammatory responses activate a response from the immune system. Certain products of white blood cells, however, have been shown to correlate with perceived stress and a shift towards negative affect when present in high amounts. In the same study that established this correlation, it was also shown that people judged the amount of social support they could rely on to be less and less as their condition worsened (Marsland et al., 2007).

Unfortunately, low SES correlates with poor health (Weiss & Lonnquist, 2017). Research has shown the lasting effects of chronic stress (usually from types of work available), chronic exposure to pollutants (from living conditions or personal health behaviors), and their lasting effects on the body. However, social support can act as a protective agent from some of these adverse effects. One such factor measured in adults who had grown up in low SES households was maternal warmth. Bioindicators of inflammation were greatly reduced in those who reported experiencing healthy, loving relationships with their mothers compared to those who reported a lesser developed mother-child relationship (Chen et al., 2011). A sibling of a patient once told me, upon hearing her brother begin to sniffle after what had been a long day of being fitted for and adjusting to a hearing aid, "My mom says baby brother just needs love. You just have to give him lots of kisses-- like this-- and talk to him to make sure he knows you're here."

Finally, I want to mention that the community RMHC cultivates also provides a form of support. I have observed that once people who have stayed in the House reach a better point in their lives, they often show their thanks through fundraising efforts for the House. For example, I remember one family, who had stayed at the House years ago, brought in 300 pounds of aluminum pull-tabs from cans, to send in for rebate and fund supplies for the House. Looking at the sheer volume of those tabs really proved just how committed these families are to the concept of paying it forward. Donations like this, as well as the fundraising events I helped with, brought in thousands of dollars which go towards providing necessities for the House and its residents.

Additional Needs of Pediatric Patients

Once biological and social well-being needs are met, one can strive to meet needs such as self-expression (Maslow, 1943). During my summer at RMHC, I had the additional opportunity to create and implement music sessions. I knew from previous clinical shadowing experiences that I wanted to implement some sort of emotional outlet. I was introduced to the need for such programs when we went over a case with doctors of a teenager who had developed depression over the course of their illness. She was heard repeatedly calling herself a burden on her family, and even asking questions such as “Wouldn’t it be better if I were dead?”

The teenager in question met with a psychiatrist weekly for the rest of her stay in the hospital to improve her outlook on being bedridden. I could not help feeling, though, that this dark place in her life could have been avoided altogether through an emotional outlet. I felt that something to get a child’s mind off their hospitalization and refocus on what they enjoy. In a study of music therapy’s effect on improving mood, statistically significant reductions in depression levels were found over time in music intervention group compared to a control and

comparison group (Leubner & Hinterberger, 2017). Induction of positive mood by way of music was also shown to make stress responses healthier (Koelsch et al., 2016).

The reason I was inclined to choose music therapy for my time at RMHC was that I have experienced singing with others in the context of choir. I wholeheartedly believe that it helps the mind and soul for all ages: Even though choir is my last class of the day and I often arrive out of breath from the run across campus, singing with other puts me more in touch with my emotions and tends to improve my mood even on the toughest days. A choir also integrates feelings of social connection, which was hard to create for groups of kids at RMHC due to various schedules of doctors' appointments. I held my sessions during dinner, when most families have returned from the hospital. Due to the variability of participant age, I knew coordinating a choir would not be possible, so my hope was that they at least felt connected to me, if not others their age, during sessions of musical play. This opportunity to build a positive relationship would mean they have someone with whom they can discuss and express their feelings.

Introducing a passion or appreciation for music early on in life provides children with a tool to express themselves and allow emotional and mental stimulation, which is paramount in a hospital setting. Of course, working with young children is not always easy. Over time, I became quick to improvise and incorporate requests from the kids. Some days at the beginning were difficult, simply because younger kids love noisy instruments and repetition, and adult ears do not. I learned how to navigate those situations without making anyone cry. One day, I indulged their loud playing for a few minutes, then created a 'game' in which you can only win by playing as softly as possible.

More often than the challenges, I was met with sweetness and gratitude from both children and their parents. I will never forget some of the moments I observed and aided,

including watching a crying child with cognitive dysfunction go absolutely awe-struck watching a rainstick, a girl who attended multiple sessions shyly presenting me with a popsicle-stick craft she made for me earlier that day, and a very amusing two-year-old deciding to “read” me the same story I had read to her earlier, complete with sound effects. In a survey done by Barrera et al. (2002), pre-school aged pediatric cancer patients also rated their feelings as more positive after musical play, so music has a conscious affect even at early ages.

As I worked with the kids of the House more often, I found myself wanting to help them in other ways as well. The staff was able to allow me that chance when it came time to move in all the donations for the new kid-centered rooms. After helping bring the toys into storage, it became my job to create a new area within the House called the Toy Depot. All children, whether patients or siblings, are allowed a toy and blanket of their choice from this room. The design of this room was very colorful. I made sure the layout of toys was eye-level with kids based on age and approximate height. I was very pleased with the number of books that had been donated for the Toy Depot. I noticed, during the first week of its opening, that kids tended to prefer toys that were cool; larger, franchise-associated, and with multiple features. Outdoor sports equipment, puzzles, and science kits were not as in-demand. Additionally, I noticed that kids rarely took items from the back of shelves, and were more likely to take books if their titles were facing outward (as opposed to just the book spines facing outward). Both of these phenomena can be remedied; books could be displayed in a special shelf to display book covers, and to make other toys more appealing, one could be placed in the adjoining play-room for kids to try out. It is also possible, however, that toys representing familiar entities provide comfort that pediatric patients seek. Koukourikos (2015) shows that during hospitalization, toys can

provide mental stimulation and comfort during times of high anxiety. This study even suggests that doctors should be using creative play to work with their younger patients!

Bridging the Gaps Between Provider and Patient

Perhaps the most revealing indicator of family health were the conversations I had with parents. In one particular conversation I had about schooling for medically complex children, I realized something very important: the existence of a program to help does not necessarily mean it is effective. The mother of a child with autism and bipolar disorder explained to me how she homeschools her daughter using online resources because she believes her daughter would not thrive in a small school with only one special education teacher. This single mother also explained to me how she was making arrangements, despite a precarious financial situation, to move to the city in order to be closer to the mental health services her daughter needs.

Care outside the hospital needs coordination between school special education programs and doctors, as well as proper health literacy and education for the parents from pharmacists and doctors. Many schools have working special education programs, but how do we know they are effective for medically complex children? Such children benefit from constant attention that they can receive from a parent, but may be less likely to get in a more formal school environment. Since all children have a right to an education, there exists a theoretical responsibility to consider a shift in how special education programs are administered, or at least to assess their efficacy.

RMHC itself does not deal with these issues, but their intermediary could. For example, all families residing at the RMHC must be referred by a social worker. Research on the impact of communication with social workers has shown they are an invaluable resource. When patients are discharged from the hospital, they face issues such as “lack of communication with the primary care physician (PCP), low availability of PCPs, incomplete or inaccurate information

transfer to the next provider, and patient non-compliance with prescribed medications” (Barber et al., 2015, p. 2). This leads to greater use of emergency services. Social workers are described as “trained to link patients with community and home-based services, reduce fragmented health and social service systems, and address both the medical and psychosocial needs of the patient” (Barber et al., 2015, p. 3).

Along with observing this need for intermediary communication, I heard a lot about what parents were confused about in providing care for their children. Although they had a firm understanding of which medicines needed to be administered and when, they often had many related questions that were not answered during the brief time with the doctor. These included the development of the disease, complications to expect, and related symptoms. This led to using the internet as a primary source of information, which often contributed to parental anxiety about the severity of their child’s illness. I should note that in some cultures, asking questions during a doctor’s appointment is not considered respectful, which may add to this phenomenon (Coolen, 2012).

Additionally, the parents may not have a background sufficient for understanding biomedical explanations given by the doctor. Research has shown a significant proportional relationship between parental health literacy (the familiarity with terminology and practices used while discussing illnesses) and child health outcomes (DeWalt & Hink, 2009). Especially in more serious cases like the patients with families at RMHC, it is important to bridge any gap between what the medical providers explain and what is understood in terms of patient care planning. Unfortunately, research shows a track record of “frequent dosing and other medication errors, missed follow-up appointments, and misunderstood instructions as to what to worry about and come back for” (Glick et al., 2017, p. 11). This study goes on to describe how language and

complexity of the discharge plan “all contribute to the problem in reducing adherence to instructions” (p. 8).

Reflections on Healing

Students gearing up to study medicine are required to spend time observing or engaging in a broad range of preparatory experiences. Clinical volunteering is one that comes highly recommended, because it is one of the places students can see patients undergoing real treatment and the setbacks, complications, and other harsh realities of healing after a medical need. I believe, however, this experience outside the hospital has given me even clearer direction in determining my personal beliefs about the goals of medical care.

This experience has shown me, without a doubt, that medical care extends past the examination room. Since healing is a process that occurs on multiple dimensions, I will take what I have seen this summer with me in my journey to becoming a medical care provider. Children benefit from the mental stimulation and emotional release from art activities such as music and drawing. Parents benefit from easy-access health education, as well as communication between doctors and their children’s school.

I think hospital staff have a responsibility to make sure parents understand and can access the resources needed to care for their child. If a parent speaks another language, someone other than their child needs to communicate the doctor’s instructions. Many hospitals already have made strides with offering social worker consultations and referrals to places like the Ronald McDonald House. I hope to see work like that continue, and even foster such growth, in the future. I am glad to have seen and heard about these issues because I now know that professionally, I want to work in a clinic that truly feels like a care center.

With expenses in the medical sector increasing for inpatient care and being used less by low-income families (University of Washington, 2019), I think hospitals have remarkable potential for acting as care centers for such families. Families at the House have expressed how convenient it is to not need to worry about groceries or finding healthy food since volunteers cook free meals three times a day. Hospitals could partner with food pantries or volunteer kitchens, or adopt programs like Lunches with Love, in which food is delivered to wards by request. Furthermore, children could be scheduled to spend time outside of the hospital room (as their condition permits) with the opportunity to engage with activities or even other children.

While shadowing, I realized how vulnerable children are to the same feelings of uselessness and hopelessness that often accompany debilitating illnesses. To show them there are wonderful things they can do, and re-instill their hope for getting better, time spent reading, drawing, or making music is absolutely critical. Singing was what taught me that it's okay to feel sadness and fear deeply, but it also taught me you have to get back up once you have felt those things; you cannot let them disable you. That is what I intend to do as a medical provider, and my "why medicine?" will always be the children, like the ones I had the fortune of meeting this summer.

References

- Artiga, S., & Hinton, E. (2018, May 10). *Beyond health care: The role of social determinants in promoting health and health equity*. Kaiser Family Foundation.
<https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>
- Bangsberg, D. R., Hecht, F. M., Charlebois, E. D., Zolopa, A. R., Holodniy, M., Sheiner, L., Bamberger, J. D., Chesney, M. A., Moss, A., Bangsberg, D. R., Hecht, F. M., Charlebois, E. D., Zolopa, A. R., Holodniy, M., Sheiner, L., Bamberger, J. D., Chesney, M. A., & Moss, A. (2000). Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population. *AIDS, 14*(4), 357-366.
- Barber, R. D., Kogan, A. C., Riffenburgh, A., & Enguidanos, S. (2015). A role for social workers in improving care setting transitions: A case study. *Social Work in Health Care, 54*(3), 177-192. doi:10.1080/00981389.2015.1005273
- Barrera, M. E., Rykov, M. H., & Doyle, S. L. (2002). The effects of interactive music therapy on hospitalized children with cancer: A pilot study. *Psychooncology, 11*(5), 379-388.
<https://www.ncbi.nlm.nih.gov/pubmed/12228871>
- Chen, E., Miller, G. E., Kobor, M. S., & Cole, S. W. (2011). Maternal warmth buffers the effects of low early-life socioeconomic status on pro-inflammatory signaling in adulthood. *Molecular Psychiatry, 16*, 729-737. doi:10.1038/mp.2010.53
- Coolen P. R. (2012, May 1). Cultural relevance in end-of-life care. *EthnoMed*.
<https://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care>

- DeWalt, D. A., & Hink, A. (2009). Health literacy and child health outcomes: A systematic review of the literature. *Pediatrics*, *124*(S3), S265-S274.
https://pediatrics.aappublications.org/content/124/Supplement_3/S265
- Glick, A. F., Farkas, J. S., Nicholson, J., Dreyer, B. P., Fears, M., Bandera, C., Stolper, T., Gerber, N., & Yin, H. S. (2017). Parental management of discharge instructions: A systematic review. *Pediatrics*, *140*(2), 1-16. <https://doi.org/10.1542/peds.2016-4165>
- Koelsch, S., Boehlig, A., Hohenadel, M., Nitsche, I., Bauer, K., & Sack, U. (2016). The impact of acute stress on hormones and cytokines and how their recovery is affected by music-evoked positive mood. *Scientific Reports*, *6*, 1-11. doi:10.1038/srep23008
- Koukourikos, K., Tzeha, L., Pantelidou, P., & Tsaloglidou, A. (2015). The importance of play during hospitalization of children. *Materia socio-medica: Journal of the Academy of Medical Sciences of Bosnia and Herzegovina*, *27*(6), 438-441.
doi:10.5455/msm.2015.27.438-441
- Leubner, D., & Hinterberger, T. (2017). Reviewing the effectiveness of music interventions in treating depression. *Frontiers in psychology*, *8*. doi:10.3389/fpsyg.2017.01109
- Marsland, A. L., Sathanoori, R., Muldoon, M. F., & Manuck, S. B. (2007). Stimulated production of interleukin-8 covaries with psychosocial risk factors for inflammatory disease among middle-aged community volunteers. *Brain, Behavior, and Immunity*, *21*(2), 218-228. <https://doi.org/10.1016/j.bbi.2006.07.006>
- Maslow, A. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370-393.
<https://doi.org/10.1037/h0054346>
- National Cancer Institute. (n.d.). *NCI dictionary of cancer terms*. National Institutes of Health
<https://www.cancer.gov/publications/dictionaries/cancer-terms>

Ronald McDonald House Charities. (2017). *2017 Annual report: Keeping families close*.
Madison, WI.

Southwick, S. M., Vythilingam, M., & Charney, D. S. (2005). The psychobiology of depression and resilience to stress: Implications for prevention and treatment. *Annual Review of Clinical Psychology*, *1*(1), 255-291.
<https://www.annualreviews.org/doi/abs/10.1146/annurev.clinpsy.1.102803.143948>

University of Washington. (2019). *Tracking personal health care spending in the US*. Institute for Health Metrics and Evaluation. <https://vizhub.healthdata.org/dex/>.

Weiss, G. L., & Lonnquist, L. E. (2017). *Sociology of health, healing, and illness* (9th ed.).
Routledge.