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Narrative Storytelling for Social Change

Advocating through the Medical Literature: My Work in Hepatitis C Virus as a Narrative Review

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Sometimes advocacy needs to be directed towards physicians and other health care providers. When it is, advocating through the medical literature becomes a powerful tool to shape opinion on a topic and change the standard of care within health care. This narrative review highlights past articles about various topics within the field of Hepatitis C care and research that were written and published with the specific intent to advocate for practice changes, and outlines strategies that could be used by others to advocate through the medical literature.

Advocacy Focus and Impact on Health

How this work impacts health: This personal narrative focuses on how future authors can use the medical literature to advocate for changes in clinical practice to benefit patients and families, while also providing a history of how the field of Hepatitis C Virus (HCV) has advanced over the past 20 years and its challenges in getting there.
How this paper addresses advocacy/action: The author highlights specific published papers and discusses why and how they came together to advocate for practice and policy changes within health care.
What this work adds to the field: There are few prior published papers that describe the use of the medical literature for advocacy. A list of tips for how to get started and follow through to advocate through the medical literature is provided.
Next steps/needed action(s): Be bold with your ideas and intentions and get involved!

INTRODUCTION

When health care providers and educators think of engaging in advocacy and teaching advocacy to medical trainees, they usually focus on and discuss common processes for changing governmental and health care policy by participating in legislative hearings or influencing public opinion by writing newspaper columns and making media appearances (Agrawal et al. 2023; Earnest, Wong, and Federico 2010; Lichtenstein, Hoffman, and Moon 2017; Oberg 2003; Sagot and Flugrad 2024; Schwarz et al. 2015). However, to effectively advocate for health care policy or practice changes, sometimes that advocacy needs to be directed towards other physicians and health care providers. In this way, advocating though the medical literature becomes a powerful tool to shape provider opinion, fuel new research, update practice guidelines and change the standard of care within health care.

It is very ironic but perhaps not surprising that writing in the medical literature as a form of advocacy is not mentioned in any of the papers cited in the prior paragraph. However, there are many benefits of using this form of advocacy. For author(s), it can begin the process of change—the spark that initiates the self-reflection required to improve care for patients, populations, and communities. This is important because changes to clinical practice often come very slowly and frequently require some internal impetus to make real change. It can also align well with health care providers' own goals for career advancement in academic medicine. Outside of the academic setting, community health providers and other community members involved in supporting patients have a "front lines" perspective that can be shared, which can draw valuable attention to how current standards of care may not represent the best interests or unique needs of patients in their setting. Patients also can and do engage in and benefit from this type of advocacy; by sharing insights about their own health needs and the health of their communities, their advocacy helps lead to improved care and healthier communities.

In my career, I have written many articles with the specific intent to change the opinions and behaviors of physicians and other providers on Hepatitis C Virus (HCV) testing and treatment across all populations.

In this narrative review, I discuss some examples of advocating through the medical literature and highlight some key strategies that could be used by other health care providers in the future. The specific examples I share below also emphasize the unique perspective of a pediatrician in being able to discuss the health needs and priorities of my patients and their families, from the time of pregnancy

through to adolescence and young adulthood. The articles described below are presented in chronological order. The descriptions also provide some history from over the last 20 years about how the field of HCV has advanced and its challenges in getting there.

Jhaveri R, Grant W, Kauf TL, McHutchison J.
The burden of hepatitis C virus infection in children: estimated direct medical costs over a 10-year period
J Pediatr. 2006 Mar;148(3):353-8.
PMID: 16615966

Since it was first recognized in the 1970's, there was a prolonged period when HCV was exclusively discussed as an adult infection. From 1980 to 2003, there were very few papers published on HCV infection in children and even fewer on the topics of pregnancy and vertical transmission. As a trainee and early junior faculty member during those years, one of my goals was to increase attention to and awareness of the topic. My colleagues and I conducted this project and wrote this paper with the specific purpose to draw attention to the underappreciated burden of HCV in children (Jhaveri et al. 2006). Using the best available seroprevalence data in children and an appropriate methodology, we built a cost model to demonstrate that HCV in children was not only a growing health issue but was associated with significant economic costs that further burdened their families. The discussion of costs was coupled with a call to action that more work was needed to prevent and treat pediatric HCV infections.

What made this article an effective advocacy piece and what were the outcomes?

In writing this article, we brought attention to a topic that long went unrecognized beyond a small group of pediatric hepatologists. We knew we needed to make the topic relevant to others, so we drew parallels to conditions where costs were better appreciated. In the discussion, we called out that the estimated costs of treating HCV in children were comparable to caring for patients with biliary atresia and within range of care for neonatal Group B streptococcal and Hepatitis A infections. With this framing, we were able to make persuasive arguments and convince many pediatric providers why HCV was worthy of their attention. We also intentionally chose to submit the paper to a journal whose Editor-in-Chief was a member of that small group. As a result, the paper was not only published but was accompanied by a short introduction by the Editor-in-Chief highlighting the topic for readers and complimenting us for our efforts (Balistreri 2006). The article quickly became cited as a primary reference for pediatric HCV and is still cited almost 20 years later, largely because there are still relatively few papers on this topic.

Arshad M, El-Kamary SS, Jhaveri R.
Hepatitis C virus infection during pregnancy and the newborn period—are they opportunities for treatment?
J Viral Hepat. 2011 Apr;18(4):229-36.
PMID: 21392169

The standard of care for HCV treatment at the time this article was written was pegylated-interferon and ribavirin, each of which had a side effect profile that prohibited them as options for treatment during pregnancy (Manns et al. 2001). As a result, no one was thinking about treatment during pregnancy. With the first Direct-Acting Antivirals (DAAs) for HCV approaching FDA approval, I thought the time was right to introduce the concept to those less familiar with treatment of HCV during pregnancy (Jacobson et al. 2011; Poordad et al. 2011). Moreover, as an infectious disease specialist who trained during the era when treatment of HIV during pregnancy was widely implemented and ultimately led to the virtual elimination of perinatal transmission of HIV, I was very interested in HCV treatment during pregnancy as a future goal (Connor et al. 1994; Lampe et al. 2023). In the paper, while we focused on viremia as the primary contributor to vertical transmission, our discussion emphasized that resolution of viremia should have the theoretical benefit of preventing infants from getting infected (Arshad, El-Kamary, and Jhaveri 2011). As we moved away from interferon-based regimens, this option became more viable.

What made this article an effective advocacy piece and what were the outcomes?

First, the article was a comprehensive review of HCV in pregnancy and of what was known at the time about vertical transmission. The scientific content itself was an asset that drew attention to the topic.

Second, this paper outlined a vision that had not been described previously of how DAAs might open the door to HCV treatment during pregnancy. We drew parallels to the care of HIV to help readers appreciate the potential benefits while also being honest about the major differences between the two infections. While we did not yet appreciate just how powerful DAAs would be in curing patients with HCV, the article was still ahead of its time in describing a future that we are just now starting to realize. More than 10 years later, this paper continues to serve as a reference for people interested in HCV in pregnancy. It has been cited almost 200 times in total including almost 20 times since the beginning of 2023 (relevant to the increased interest in treatment during pregnancy discussed below).

Jhaveri R, Broder T, Bhattacharya D, Peters MG, Kim AY, Jonas MM.
Universal Screening of Pregnant Women for Hepatitis C: The Time Is Now
Clin Infect Dis. 2018 Oct 30;67(10):1493-1497.
PMID: 30215670

Since 2014, epidemiologic studies have shown that young adults with widespread injection drug use had become the peak age group for new HCV infections (Suryaprasad et al. 2014; Zibbell et al. 2015). At the time when we wrote this paper in 2018 (and before 2020 when official guidance was

changed), the HCV testing strategy endorsed in official U.S. guidelines was still focused on age-based universal testing for "Baby Boomers" and risk-based testing for all other age groups (Smith et al. 2012). While there were discussions at that time about how these age-based strategies were leading to under-testing in younger patients including those in pregnancy, no policy changes were being suggested or made. As members of the American Association for the Study of Liver Diseases/Infectious Diseases Society of America HCV guidance panel, we wrote this opinion piece to advocate for universal screening during pregnancy and changed our panel recommendations to emphasize universal screening during pregnancy (Jhaveri et al. 2018). We argued that pregnancy was a window when patients who were clearly in a high-prevalence group for HCV were already engaged in regular care and screened for other conditions including other infectious diseases, thus providing ample opportunity and ease of application amongst a population of high interest. While treatment for HCV in pregnancy was not available as an option at the time we wrote the piece, we felt strongly that this would come with time and that promoting a "forward-looking" policy that emphasized notification of a positive antibody test and knowledge of infection status would provide patients with powerful information that could change behavior.

What made this article an effective advocacy piece and what were the outcomes?

As a group with established credentials in HCV research and care, we had the credibility and the platform to outline a vision for where HCV policy needed to go to meet the needs of patients and improve public health policy. While the paper did generate controversy and resistance from many groups, including the American College of Obstetricians and Gynecologists (ACOG), it helped to accelerate the conversation about policy change. It took two more years, but pregnant patients eventually were included in both the CDC and U.S. Preventive Services Task Force universal testing recommendations for HCV, which in 2020 became the standard of care (Schillie et al. 2020; Force USPST et al. 2020). While the field was still not ready to consider treatment during pregnancy, this paper discussed how this first policy change could ultimately help enable subsequent treatment during pregnancy as part of broader efforts to eliminate HCV infection.

Jhaveri R, Yee LM, Antala S, Murphy M, Grobman WA, Shah SK.
Responsible Inclusion of Pregnant Individuals in Eradicating HCV
Hepatology. 2021 Sep;74(3):1645-1651.
PMID: 33743550

Four years after publishing the previous paper to include pregnant patients in universal screening, we wrote this paper with the express purpose of drawing attention to the active exclusion of pregnant patients from HCV research and treatment programs (Jhaveri et al. 2021). We effectively combined two papers into one: a systematic literature review demonstrating the near absence of papers on HCV treatment in pregnancy paired with a discussion of the equity and justice issues surrounding the inclusion of pregnant patients in research. In addition to emphasizing the current scarcity of evidence and practice, we also included an outline of unmet needs for patients (more discussions with their doctors) and providers (more research and a clear rationale for treatment benefits) and a call to action for more research in pregnancy.

What made this article an effective advocacy piece and what were the outcomes?

This paper called for equity and inclusion in the timeframe that was post-COVID and after the killing of George Floyd, when broader society was already questioning longstanding policies excluding subpopulations from mainstream health policies and interventions. By understanding the political climate and framing pregnancy as a timeframe when people were also being discriminated against or excluded, we were able to change the conversation around treatment of HCV during pregnancy from solely a scientific imperative to something that was essential to ensure equity and representation in research as well as society. Our multidisciplinary author group (pediatric infectious diseases, obstetrics/maternal fetal medicine, bioethics) was an asset and helped bring a multifaceted approach to the argument we made. We found out later that our colleagues within the field circulated our paper amongst their leadership to help garner internal support for specific research initiatives to assess HCV treatment during pregnancy.

TIPS FOR ADVOCATING THROUGH THE MEDICAL LITERATURE

First, it is important to note that none of these papers were conceptualized or written alone; I have been very fortunate to have amazing practice and research partners for every initiative mentioned here and many more that could not be included. Some of these articles have been original research on a topic long neglected, while many have been commentaries or editorials with the specific goal of changing other clinicians' minds about an issue. Both approaches have been fruitful pathways to changing perspectives on HCV, ultimately leading to significant practice changes and advancing research that includes underserved populations. Based on these experiences, I want to share a few tips to consider that can help to advance your advocacy efforts and academic careers (Table 1).

LINE UP YOUR PARTNERS EARLY

Most people are familiar with the proverb, "If you want to go fast, go alone; if you want to go far, go together." While the origins of that proverb are often debated, the point made is highly relevant to advocacy (Whitby 2020). Every paper mentioned above started as conversations with colleagues during which we shared ideas and openly ques-

Table 1. Tips for Using the Medical Literature for Your Advocacy

Line up your partners early	Discuss your ideas with colleagues to refine your thinking and to find allies in the relevant disciplines
Aim for your ideal audience, but settle for a good audience	Any audience that can still access and distribute your message is a good audience
Get your facts right	Be comprehensive in your review of existing literature so your argument will stand up to scrutiny
Draw parallels to what people know	The more people can directly relate to the points you make, the easier change will be
Highlight inconsistencies in care	Recognizing vastly differing practices for the same or related conditions can be a powerful motivator
Be clear about the path for action	Readers should clearly see how the first step will lead to the 2nd and 3rd and so on
Be persistent in the face of rejection and opposition	Change is difficult in virtually any circumstance, so don't give up if you experience early resistance to your message
Use writing and publishing as a springboard to other forms of advocacy	Writing these papers can help connect you with other advocates with a similar vision for change

tioned the status quo and potential impact of proposed changes—long before any words were written. These discussions created allies across disciplines, helped to clarify thoughts and ideas, and engaged future co-authors in the mission of putting those ideas into print. For the HCV burden paper, vetting my ideas with John McHutchison, an internationally recognized leader in Adult HCV treatment, not only helped shape that work but connected me with the health care cost researchers who became my other co-authors. For the HCV screening in pregnancy paper, all the co-authors were colleagues on the HCV guidelines panel that was already an established multidisciplinary group and facilitated our collaboration. The HCV treatment in pregnancy paper began with separate conversations with Lynn Yee, a maternal fetal medicine specialist, and Seema Shah, a bioethicist, both of whom helped shape my ideas and the resulting product and much beyond it. All of them were experts and credible in their fields, so their partnership brought much more weight to the argument than if I was writing it alone. Actively seek these people out and be bold in sharing your ideas as you look for partners with the understanding that although many of these conversations will end there, a few will lead to fruitful collaborations.

AIM FOR YOUR IDEAL AUDIENCE, BUT SETTLE FOR A GOOD AUDIENCE

In an ideal world, all medical journals would have a dedicated category for articles that propose innovative ideas and/or question the accepted paradigms of care. In reality, health care is a very risk-averse field, and this often extends to health care journal editors and reviewers (Oussedik, Anderson, and Feldman 2017). As an author, you need to understand your message and then choose a journal that may be open to that message. As an advocate, you likely have a very good idea of the exact group or journal audience who should be the target of your message because they could help drive the most change. However, that same group may be the most resistant to hearing your message and journals aligned with that group may not be open to publishing your work. In that case, submitting your paper to a more receptive journal will still find an audience and can filter into the public discourse to ultimately find the people you want to reach. Our universal HCV screening in pregnancy paper is a great example of this lesson. We initially submitted that paper to obstetric journals and were desk rejected without review, which we hypothesized might have been due to the field's reluctance to adopt a new screening strategy in the absence of an available treatment. We ultimately published in an infectious disease journal knowing that this group was very open and supportive of universal HCV screening in pregnancy. Despite "preaching to the choir", the message appeared in a high-impact journal and the key points of our paper were ultimately shared by others.

GET YOUR FACTS RIGHT

While your message may have broad appeal, the underlying facts to support your argument need to stand up to scrutiny. If someone can easily dismiss a key attribute of your argument because you overlooked a key study or prematurely dismissed an opposing perspective, your credibility is lost, and the balance of your points will be ignored no matter how much merit they have. Be comprehensive in your review of the existing literature and balanced in your presentation of the facts. You can anticipate the counterpoints that detractors may try to make and preemptively disarm them with an evidence-based rebuttal. The burden of HCV in children and HCV treatment in pregnancy papers were important primarily because they represented the most comprehensive review of the literature at that time. The HCV screening in pregnancy and HCV treatment in pregnancy and ethics papers were very effective because we included a discussion of the opposing perspectives along with counterpoints for why they did not undermine our position. The systematic review component of the HCV treatment in pregnancy paper offered a structure and format that supported our findings and our argument.

DRAW PARALLELS TO WHAT PEOPLE KNOW

So much of the success of your message will hinge on how you frame your argument of the importance of your proposed change. Drawing parallels to what your audience knows well will help your argument resonate. Our HCV burden in children paper did this well. We framed the case estimates and costs of HCV in children with other more well-known conditions in pediatrics like biliary atresia and Hepatitis A. By showing that the costs were significant, we helped our pediatric provider audience see that HCV was a relevant condition for them—not just an infection that only impacted older adults. Similarly, it is well known in both obstetrics and pediatrics that the virtual elimination of perinatal HIV transmission with antiretroviral use during pregnancy was one of the greatest public health achievements of the last 30 years. By drawing parallels to HIV, our work on HCV resonated with a wider audience who saw the pregnancy time period as an opportunity for similar progress with a different virus.

HIGHLIGHT INCONSISTENCIES IN CARE

A very powerful tool to motivate practice change is to point out inconsistencies in how different conditions or groups are treated. If there is a clear rationale for treating one group of patients with condition X that everyone supports, highlighting a similar group with the same condition that is not being treated will provide not only a compelling argument for practice change but serve as an ethical obligation. Our HCV treatment in pregnancy justice paper is a great example of this. Amongst global efforts by clinicians and researchers to increase the number of patients who receive treatment for HCV, the omission of any pregnancy-related research or inclusion of pregnant people in research studies was glaring. Furthermore, by showing that other antiviral agents like oseltamivir and tenofovir were widely used off-label during pregnancy, the lack of off-label use of HCV antivirals presented a stark contrast that highlighted a key opportunity for and our responsibility to provide an ethics-based discussion of exclusion and inclusion of key populations in HCV treatment and research.

BE CLEAR ABOUT THE PATH FOR ACTION

While emphasizing the need for change is an important goal, advocacy is also about laying out the actions that are needed for change to occur. When writing your paper, make the next steps required very clear for your readers. If the next steps are not immediately clear or ultimately feasible, the increased awareness that you have generated will not likely lead to substantive or sustained change. Our universal HCV screening in pregnancy paper is a great example of this. By emphasizing that the first step of universal HCV screening occurs at the individual or practice level, we were able to accelerate policy change at the regional and national level. By linking universal screening with the option for treatment during or soon after pregnancy, we were able to increase the acceptance of this as a policy strategy going forward.

BE PERSISTENT IN THE FACE OF REJECTION AND OPPOSITION

Just like with every other form of advocacy, there will be detractors who are obstacles to change. Journal editors and society sponsored journals tend to have well-established beliefs and may be very resistant to publishing your manuscripts that describe your proposed practice changes. They have the option to review and publish your papers, or to quickly reject them without pursuing peer review. Getting your message of change out will take persistence in the face of this adversity. Every paper mentioned above was submitted multiple times to multiple journals before being published and finding its audience. Luckily, today more journals are more open to publishing advocacy work, and having a new journal that focuses solely on health advocacy is a huge advantage.

USE WRITING AND PUBLISHING AS A SPRINGBOARD TO OTHER FORMS OF ADVOCACY

While a well-written paper can be very persuasive and powerful and can inspire others to join you in a call for change, one paper alone will rarely be sufficient to change health care practice. Use the process of writing and publishing to network with other advocates in other disciplines to build a team of colleagues with a similar vision for change. Coordinating efforts with other advocates, writing follow-up papers, or providing testimonials to highlight the results of pilot initiatives that prove the feasibility of the changes you are recommending are key follow-up steps along the continuum to improving health care. Establish yourself as an expert and work to get invited to events where you can speak on the things you have written about. When done in this way, publishing in the scientific literature becomes a "springboard" to building a portfolio of advocacy that extends beyond what appears in PubMed—publishing your advocacy then becomes an action that calls for more action.

Writing and publishing papers in academic journals can be very effective ways to advocate for changes in care that influence opinion among physicians and other medical providers and that connect you to advocates in other disciplines, and ultimately positively impact your patients and families. However, it is also important to acknowledge some of the limitations of advocating in the medical literature, which include an exclusive focus on health care providers who read journal articles, and which may exclude providers who receive updates via third party summaries or excerpts and of course the general public. Therefore, publishing papers should be viewed as part of a health care provider's broader advocacy efforts, including participating in legislative hearings, making media appearances, and writing op-eds with a focus on changing governmental and health care policy, to ensure that your message reaches all the major stakeholders for a given issue.

I have been very fortunate to work with many partners across many disciplines over my career to help introduce and facilitate changes in HCV practice that have impacted patients in a meaningful way. This form of advocacy has opened doors to other opportunities in research and public

health policy development that went well beyond what I initially conceived. Careful curation of your message, strategic selection of the journal and audience and unyielding persistence will help your advocacy message drive positive change to beneficially impact patient care.

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