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World Medical & Health Policy is a quarterly, peer-reviewed journal that considers the many factors shaping global health. We publish articles employing overlapping disciplines that include health policy and politics, political science, health economics, medical ethics, and public health. The journal's approach is unified by a thoroughgoing concern with critically examining the contexts within which policy is made, as well as more traditional considerations of processes, outcomes, and influences.

In converting empirical evidence into policy, ***World Medical & Health Policy*** helps policymakers design and promote programs that improve health outcomes, particularly for vulnerable populations. By bringing a global policy perspective to medical practice, the journal navigates the often-tangled world of global economic imperatives, international diplomacy, international agreements, the law, natural and humanmade disasters, humanitarian interventions, the social determinants of health, and local and international standards of care. The journal is committed to publishing practitioners' opinions and case studies alongside academic research articles.

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World Medical and Health Policy

Shared Stigma: The Effect of LGBT Status on Attitudes About the Opioid Epidemic

Simon F. Haeder, Steven Sylvester, and Timothy Callaghan

Over the past decade, the United States has been ravaged by an unprecedented public health crisis. In 2017 alone, the Centers for Disease Control and Prevention identified more than 70,000 individuals who died from an overdose. The dominant culprit in these deaths are opioids, which accounted for two-thirds of cases. Scholars have worked diligently to provide a better understanding of the root causes, extent, implications, and possible solutions to the opioid epidemic. A group that is disproportionately affected by illicit drug use, substance abuse disorder, and mental health issues has received little attention in this growing body of research: people who identify as lesbian, gay, bisexual, or transgender (LGBT). We conducted a large national survey to study this issue in depth. Specifically, our analysis uses a national survey weighted to population benchmarks with an oversample of LGBT respondents to better understand attitudes about the opioid epidemic and whom the public blames for the crisis. Our analysis finds consistent evidence that LGBT individuals are less likely to blame individuals with addictions for the opioid epidemic. Simultaneously, we find that conservatism, high levels of religiosity, addiction status, and high levels of racial resentment all increase the likelihood that individuals blame addicts themselves.

KEY WORDS: opioid pandemic, LGBT, attribution, stigma

Introduction

The opioid epidemic in the United States has surged in recent years, with roughly three million Americans experiencing its effects (Schuckit, 2016). From 1999 to 2017, the epidemic claimed more than 700,000 deaths and wreaked havoc in communities across America (Center for Disease Control and Prevention, 2019). In 2017 alone, the Centers for Disease Control and Prevention noted that roughly 70,000 individuals died from drug overdoses, with opioids accounting for roughly two-thirds of those deaths (Center for Disease Control and Prevention, 2019). While the epidemic has changed over time, morphing from prescription drugs to heroin and now into synthetic opioids, the death toll remains staggering. Secondary and tertiary implications will continue to pose tremendous challenges to all levels of government for the foreseeable future. Not surprisingly, both federal and state governments are increasingly seeking policy solutions to combat the epidemic. Most notably, President Trump has declared the opioid epidemic a public health emergency and, in 2018, put forth an initiative to stop opioid abuse and reduce the supply and demand of illicit drugs (White House, 2018).[1]

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Who is to blame for the epidemic? Some narratives have focused on the individuals coping with opioid addiction by arguing that, in the vein of Nancy Reagan, "they could have just said no to drugs." President Trump has openly contributed to this narrative, stating that "If they don't start, they won't have a problem" (White House, 2017). This line of reasoning has been carried to local communities by some street-level bureaucrats like the tough law-and-order sheriff in Butler County, OH, who refused to let his deputies carry *Narcan* to reverse overdoses (Wootson, 2017).

Yet, there are alternative narratives. The stories presented in the Netflix documentary Heroin(e), which features the struggles of Huntington, WV, show "typical" Americans and how circumstances outside their control, including rural hopelessness and economic depression, have led, or at the very least contributed to, their addiction. More recently, public discussion has centered on the role that pharmaceutical companies have played in the opioid epidemic (Lopez, 2017). Media reports have highlighted stories about how several companies have eagerly sought to expand the use of prescription opioids, raking in massive profits along the way. The maker of oxycontin, Purdue Pharma, has featured most prominently in this discussion (Taddonio, 2019). This narrative has been amplified by dozens of state attorneys-general seeking restitution from opioid manufacturers and their owners for the damage the crisis has done to their states (Lopez, 2019). Another reporting has focused on individual medical providers operating the so-called "pill mills," some of which prescribed in excess 500,000 doses of opioids (Hassan, 2019) or received kickbacks from manufacturers (Lawrence & Feeley, 2018). Yet other narratives have focused on the role of pharmaceutical wholesalers and pharmacies in the epidemic (Eyre, 2016; Hakim, Rashbaum, & Rabin, 2019; McGreal, 2019).

To understand the unique role played by the attribution of blame in policy attitudes about the opioid epidemic, our study utilizes attribution theory as an explanatory framework. The attributional analysis involves an individual's examination of an outcome (in this case, the opioid epidemic) and seeks to determine the underlying cause of that outcome. Policy analysts often refer to this as an underlying causal model (Weimer & Vining, 2017) or belief system (Jenkins-Smith & Sabatier, 1994). Specifically, individuals try to determine whether the outcome of interest is caused by some internal disposition or instead emerges because of situational forces (Heider, 1944, 1958). Following prior research on attribution theory, we posit that this attribution depends on the causal stories that individuals develop or internalize to explain the events, behaviors, and conditions in the world around them, and that the narrative they select has important policy consequences (Stone, 2012). In the case of the opioid epidemic, we anticipate that individuals will attribute addiction to opioids to either *personal choices* (i.e., factors controllable by the addict) or *situational factors* like the behavior of drug companies or doctors overprescribing medication (i.e., factors outside the control of the addict).

Yet beliefs about attribution may be affected by a variety of factors, including a personal connection to someone coping with addiction by highlighting the personal struggle of addiction firsthand. Similarly, one's ability to empathize with individuals experiencing addiction may be increased if one is part of a group that is subject to extensive negative stereotyping and stigma. Individuals identifying as LGBT may particularly fit this bill because, as a group, they have experienced disproportionate rates of addiction and negative stigmatization. For that reason, our goal in this manuscript is to use original survey data to understand the attributions of blame for the opioid epidemic, and how those attributions vary across LGBT and non-LGBT individuals. Our analysis proceeds as follows. First, we introduce readers to attribution theory. We then lay out our expectations for what factors may shape respondents' attributions of the opioid epidemic, with a focus on shared stigma. We particularly focus on how identification as LGBT may shape perceptions about responsibility for addictions. Our analysis suggests that individuals who identify as LGBT are less likely to blame those addicted to opioids and instead find other factors, which are responsible for the addiction. Furthermore, we find that conservatism, high levels of religiosity, addiction status, and high levels of racial resentment all increase the likelihood that individuals blame addicts themselves. We conclude by discussing the implications of our findings for health policy and the LGBT population by noting directions for future research.

Attribution Theory

Attribution theory, developed by Fritz Heider (1944, 1958), examines the cognitive processes that individuals develop regarding causes and effects for behaviors. Specifically, Heider (1944, 1958) believed that individuals observe, explain, and analyze behaviors and events, that is, they make sense of the world around them, by grouping these into two categories of causal explanations: *external or situational* and *internal or dispositional* attributions. Internal attributions focus on the personal characteristics of the individual—such as personality, individual choices, or ability. Situational attributions focus on items outside the control of the individual, such as government policies, other individuals' actions, or luck. Since its creation, attribution theory has been tested in various policy areas, such as LGBT policy issues, gun policy, and the influence of the media (Haider-Markel & Joslyn, 2008).

Building on this early work, Weiner (1985, 1979) introduced a third dimension to the study of attribution, whether or not individuals are perceived to control their own situations and experiences. Weiner's (1995, 2006) controllability dimension also proposed that individuals are less willing to support (and more willing to punish) individuals when people perceive that the cause of a problem is internal. Likewise that they are more willing to support (and less willing to punish) individuals when people perceive the cause of the problem is beyond the control of the individual. The emphasis on controllability is especially useful when analyzing casual attributions related to stigmatized groups or individuals. That is, individual perceptions of societal problems (particularly for issues involving stigma) are influenced by the belief that actions are either controllable or uncontrollable (Schneider & Ingram, 1997). For example, Weiner, Perry, and Magnusson (1988) found that stigmas that were deemed to be controllable (such as child abuse or contracting AIDS) elicited greater anger than stigmas that were deemed to be uncontrollable (such as cancer and Alzheimer's disease). Similarly, Appelbaum (2001, 2002), in her study on aid to the poor, found that generous policies were more likely to be supported when individuals were perceived to be deserving of aid rather than underserving. Finally, Haider-Markel and Joslyn (2008) found that the perception that homosexuality was a personal choice or controllable was associated with negative attitudes toward homosexuality and reduced support for policies supporting homosexuality.

Attribution theory is particularly helpful in understanding public attitudes toward stigmatized topics, such as drug addiction (Barry, McGinty, Pescosolido, & Goldman, 2014; Corrigan, Kuwabara, & O'Shaughnessy, 2009). Individuals with drug addiction are often perceived to be personally to blame for their addiction, with many supporting the narrative that addicts lack the self-discipline to use drugs appropriately—particularly prescription opioids—without becoming addicted (Kennedy-Hendricks et al., 2017). Research shows that this attribution and stigma can even extend to health-care professionals who tend to have negative attitudes toward individuals with addiction, which contributes to a lower quality of care (Van Boekel, Brouwers, Weeghel, & Garretsen, 2013).

Factor Affecting Attribution

Ideology

Highlighting the importance of political measures to attributions of blame, a growing number of studies show that the way individuals perceive attributions can be influenced by political ideology. In the worldview of liberals, forces beyond an individual's control often influence their behavior and circumstances. For example, evidence suggests that liberals are more likely to emphasize the importance of structural causes of poverty, which are beyond an individual's control (Bullock, 1999; Bullock, Williams, & Limbert, 2003; Cozzarelli, Tagler, & Wilkinson, 2002; Furnham, 1982; Skitka, 1999; Williams, 1984). Conservatives, on the other hand, are more likely to point to individuals as responsible for their own circumstances. In the case of poverty, for example, many conservatives believe that economic circumstances are at least partially attributable to individuals themselves (Bullock, 1999; Bullock et al., 2003; Griffin & Oheneba-Sakyi, 1993; Hopkins, 2009; Pandey, Sinha, Prakash, & Tripathi, 1982). The way political ideology influences causal attributions, of course, extends beyond poverty. Prominently, it also includes perceptions about sexuality. For example, Haider-Markel and Joslyn (2008) found that liberals were much more likely to attribute homosexuality to genetics (and thus beyond the individual's control), while conservatives were much more likely to attribute homosexuality to personal choice. In short, for many issues, including opioids, capital punishment, and homelessness, conservatives tend to attribute blame to the individual and dispositional factors, whereas liberals are more likely to blame the environmental or situational factors (Barry et al., 2016; Cochran, Boots, & Chamlin, 2006; Pellegrini, Queirolo, Monarrez, & Valenzuela, 1997). Much as with poverty and homosexuality, we hypothesize that conservatives will be more likely to attribute addiction to opioids to the individual and their personal choices, while liberals will be likely to attribute addiction to uncontrollable outside factors, such as pharmaceutical company marketing or doctors overprescribing drugs (see Barry et al., 2016).

Religion

Beyond political ideology, another potentially important predictor of attributions of blame for the opioid epidemic is religious affiliation and participation. Similar to how citizens use messaging from political elites to reduce their political uncertainty (Lupia, 1994), religious individuals often look to clergy members for guidance on a host of issues from abortion to homosexuality, and most importantly for this study, alcohol and drug use. Indeed, a substantial amount of research supports the negative association between religiosity and the use of, and attitude toward, marijuana (Chu, 2007; Desmond, Soper, Purpura, & Smith, 2008; Klein, Elifson, & Sterk, 2006; Marsiglia, Kulis, Nieri, & Parsai, 2005; Steinman, Ferketich, & Sahr, 2008; Stylianou, 2004; Walker, Ainette, Wills, & Mendoza, 2007). The literature on morality politics provides further support for this argument by pointing how conservatives use their religious beliefs to establish their viewpoints on alcohol, drugs, and tobacco as a sin (Meier, 1994, 1999; Mooney, 1999). Because religiosity has been a significant predictor in other morality policy issues (Click & Hutchinson, 1999; Haider-Markel, 1999; Mooney & Lee, 1999; Norrander & Wilcox, 1999), we expect religiosity to influence how individuals make causal attributions about the opioid epidemic. Specifically, we hypothesize that religious individuals will be more likely to attribute the opioid epidemic to personal choices rather than situational factors.

Personal Connection

While the literature on the interaction of attribution and stigmatization is clear and consistent, more work is needed on other potential factors that may influence attributions. We argue that a personal connection to an individual with addiction may serve as one of those factors. A personal connection, offering firsthand insights into the struggle with addiction, may influence how causal attributions are made about opioid addiction (Addison & Thorpe, 2004; Corrigan et al., 2009; Sattler, Escande, Racine, & Göritz, 2017). Some literature suggests that the type of relationship with the individuals addicted to opioids can have an effect (Couture & Penn, 2003). For example, a parent of a child or a spouse may have different attitudes toward an opioid or heroin addict than someone the addict has a close friendship with or works with. However, other research has found no significant difference between the attitudes of those with a personal connection to opioid use disorder and those who do not (Kennedy-Hendricks et al., 2017). Nonetheless, we hypothesize that individuals who have a connection to an individual addicted to opioids is less likely to attribute that addiction to personal choice.

LGBT Status

Next, we argue that individuals identifying as LGBT might be particularly resistant to personal attributions of responsibility for addiction. This could be the result of the LGBT community recognizing the shared stigma status of the drug-addicted population. It could also result from the disproportionately high rates of substance abuse issues within the LGBT community, which are often attributed to the "stress caused by being a member of a stigmatized minority group" or the "feelings of rejection, shame, and low self-esteem" that result from discrimination (Capistrant & Nakash, 2019; Gonzales 2014; Gonzales, Przedworski, & Henning-Smith, 2016). Indeed, prior research has identified that LGBT individuals are more likely to engage in heavy drinking and smoking (Gonzales et al., 2016) and that nonheterosexual individuals are more likely to report the use and abuse of various drugs, including marijuana and cocaine (Cochran, Ackerman, Mays, & Ross, 2004; Gonzales, 2020; McCabe, Bostwick, Hughes, West, & Boyd, 2010; McKirnan & Peterson, 1989; Medley et al., 2016; Skinner, 1994). These findings are largely consistent across different sexual minority identities (gay men and women, bisexual men and women, and transgender individuals) as well as across adolescents and adults (Corliss et al., 2010; Gonzales et al., 2016; Jordan, 2000; Russell, Driscoll, & Truong, 2002). Critically, recent research suggests that this disparity in abuse between LGBT and non-LGBT individuals extends into the realm of opioids. Scholars have found that LGBT adults are significantly more likely than heterosexual adults to have used illicit opioids in the past 12 months (Capistrant & Nakash, 2019). Additionally, research has found that sexual orientation is a consistently significant risk factor for prescription opioid misuse, with higher rates of abuse among individuals not only attracted to the opposite sex (Duncan, Zweig, Hambrick, & Palamar, 2019).

With drug abuse closely tied to stress, stigma, and discrimination in the population, we hypothesize that LGBT individuals will be less willing to blame users themselves for the growing epidemic and instead blame situational factors. Critically, while we would expect this to be particularly true for LGBT individuals who have used or abused drugs themselves, we believe that this could extend to the LGBT population at large. LGBT individuals are likely to have strong personal connections to others in the LGBT community; even if they have not experienced drug abuse themselves, they might have friends and loved ones who have battled addiction, leading them to see the issue differently than the general public.

Racial Resentment

Finally, American politics are subject to distinct racial undertones (Banks, 2013; Gilens, 1996, 2009). These undertones, termed racial resentment by Kinder and Sanders (1996) or racial prejudice by Kinder and Kam (2010), affect the attitudes of White Americans for a wide range of policies, including school desegregation, equal employment opportunities, and public assistance programs (Kinder & Sanders, 1996). Indeed, African Americans suffer from pervasive misperceptions and negative stereotyping (Gilens, 1996, 2009; Snowden & Graaf, 2019). For example, Nielsen, Bonn, and Wilson (2010) found that white respondents who hold prejudicial attitudes toward African Americans and Latinos are less likely to say that too little money is spent on drug rehabilitation. The election of the nation's first African-American president further extended racial biases in public policymaking (Banks, 2013; Fording & Patton, 2019; Grogan & Park, 2017; Henderson & Hillygus, 2011; Lanford & Quadagno, 2016; Pasek et al., 2009; Segura & Valenzuela, 2010; Snowden & Graaf, 2019; Tesler, 2012). Resentment or prejudice particularly applies to issues surrounding drug policy (Crow & Kunselman, 2009; Santoro & Santoro, 2018). Indeed, while the overwhelming majority of opioid deaths have occurred among White Non-Hispanics (Kaiser Family Foundation, 2018), American attitudes toward drug addiction have long been tied to racial prejudice and the perception of drug users based on their racial and ethnic status (Santoro & Santoro, 2018). Much like social welfare policy (Haeder, Sylvester, & Callaghan, Forthcoming), we hypothesize that the attitudes of Non-Hispanic Whites toward policies meant to combat the opioid epidemic will be influenced by racial prejudice and preconceived perceptions of drug users as coming disproportionately from racial and ethnic minority groups even as the actual opioid epidemic disproportionately affects Whites.

Data and Methods

To test our hypotheses, we fielded an online survey in December 2018 administered through *Qualtrics*.[2] *Qualtrics* relies on large, online, opt-in panels to recruit respondents to take surveys. A total of 10,362 individuals were invited to take the survey, of which 2,131 did, for a completion rate of 21 percent. We weighted the data to reflect national population benchmarks on gender, race, income, and education, which we drew from the U.S. Census 2017 Current Population Survey. Importantly, our sample also included an oversample of 754 LGBT individuals.[3] Our reliance on a non-probability opt-in panel is appropriate for modeling relationships between variables (Baker et al., 2013; Coppock & McClellan, 2019; Kennedy et al., 2016; Levay, Freese, & Druckman, 2016). Moreover, work by Coppock and McClellan (2019) finds that data from Lucid—which Qualtrics used to select our participants, are close population benchmarks, much better than most convenience samples, and “suitable for evaluating many social scientific theories.”

To measure causal attributions of opioid addiction, we asked respondents whether the reason individuals become addicted to opioids was due to personal choice or because of some other factor. The full wording of the survey questions used in our analysis can be found in the supplemental materials. Whether respondents attribute addiction to opioids to personal choice serves as the binary-dependent variable for all our models presented below.

To examine how an individual's personal connection to opioids influenced their perceptions of the causes of the opioid epidemic, we asked respondents if they personally knew anyone who has ever been addicted to prescription opioids or heroin to create our measure of *Personal Connection*.[4] We expect that individuals who have a personal connection are more likely to attribute prescription opioid addiction to some situational factor than to personal choice. We also asked them whether they were personally experiencing addiction. *LGBT status* is included as an indicator variable. Our measure of *Ideology* was created using the standard approach of asking respondents to describe their political views on a 7-point scale ranging from "extremely liberal" to "extremely conservative." For *Religiosity*, we utilized a common question assessing respondent's level of church attendance. Respondents were asked to rank their level of involvement on a 5-point scale ranging from "very inactive" to "very active." Finally, *Racial Resentment* is measured in our analysis by using a scale created from questions created by Kinder and Sanders (1996) meant to tap into racial resentment and prejudice of individuals (see also Kinder & Kam, 2010). As the questions were developed to assess the racial resentment of Whites, we include this variable only in model estimates for Non-Hispanic Whites.

Several control variables that could also affect causal attributions about prescription opioid addiction were included. We included measures for gender (a dichotomous measure of whether the respondent is male or female), age and its square, education (indicator variables for those completing high school, some college, or having obtained at least a bachelor's degree, with the those completing less than a high school degree serving as the reference category),[5] income level (indicator variables for ranges of $5,000 to $14,999, $15,000 to $24,999, $25,000 to $34,999, $35,000 to $49,999, $50,000 to $74,900, $75,000 to $99,999 and more than $100,000, with individuals making less than $5,000 serving as the reference category),[6] minority status (dichotomous indicators each for whether respondents are African American or Hispanic), rurality (an indicator for respondents from rural or urban areas, with suburban areas serving as the excluded reference category), and political knowledge (interval measure based on responses to the standard political knowledge battery). While not the primary focus of our study, based on previous research on attitudes about opioid use, we expect that education, gender, income, race, and age will influence whether an individual believes that addiction to opioids is due to personal choices of the individual and not situational factors (Addison & Thorpe, 2004; Corrigan et al., 2009; Sattler et al., 2017).

Results

We estimated the number of standard logit models, where 1 indicates the perception that those dealing with opioid addiction are personally responsible for their addiction. As aforementioned, two sets of models were estimated, one set for all respondents and one for Non-Hispanic White respondents, only including the racial resentment variable. Models 1 and 2 include all respondents, while Models 3 and 4 were estimated for Non-Hispanic Whites only. The difference between Model 1 versus Model 2 (and Model 3 vs. Model 4, by extension) is the inclusion or exclusion of a binary variable, indicating whether the respondent has dealt with opioid addiction themselves (Table 1).

Table 1. Opioid Addiction as Personal Choice: Baseline Results From Logit Models for All Respondents and Non-Hispanic Whites

	All Respondents				Non-Hispanic Whites			
	(1)		(2)		(3)		(4)	
Variables	AME		AME		AME		AME	
Personal connection	−0.118		−0.019		−0.331		−0.227	
	(.407)		(.894)		(.054)		(.199)	
Suffering from Addiction			−0.972**	−0.201			−0.974*	−0.195
			(.003)	(.007)			(.014)	(.022)
LGBT	−0.523***	−0.103	−0.477***	−0.093	−0.534**	−0.103	−0.501**	−0.095
	(.000)	(.000)	(.001)	(.001)	(.001)	(.002)	(.002)	(.003)
Ideology	0.163***	0.028	0.161***	0.028	0.076		0.0683	
	(.000)	(.000)	(.000)	(.000)	(.148)		(.203)	
Religiosity	0.205***	0.038	0.213***	0.040	0.177**	0.032	0.186**	0.034
	(.000)	(.000)	(.000)	(.000)	(.004)	(.005)	(.003)	(.004)
Female	−0.351*	−0.063	−0.385*	−0.069	−0.338		−0.360	
	(.026)	(.025)	(.015)	(.014)	(.073)		(.057)	
Black	0.339		0.287					
	(.143)		(.213)					
Hispanic	0.047		0.027					
	(.844)		(.911)					
Political Knowledge	−0.540		−0.624*		−0.157		−0.235	
	(.080)		(.047)		(.664)		(.522)	
Rural Residence	0.264		0.256		0.363		0.336	
	(.160)		(.177)		(.101)		(.134)	
Urban Residence	0.0858		0.073		0.168		0.153	
	(.628)		(.681)		(.476)		(.518)	
Age	−0.028		−0.025		−0.052		−0.052	
	(.251)		(.323)		(.117)		(.126)	
Age^2	0.000		0.000		0.000		0.000	
	(.376)		(.480)		(.217)		(.239)	
Racial Resentment					2.185***	0.088	2.200***	0.088
					(.000)	(.000)	(.000)	(.000)
Constant	1.251		1.400*		0.631		0.970	
	(.076)		(.043)		(.504)		(.288)	
Education	Yes		Yes		Yes		Yes	
Income	Yes		Yes		Yes		Yes	
Average prediction		0.741		0.741		0.720		0.720
McKelvey and Zavoina	0.100		0.110		0.165		0.174	
Observations	2,044		2,044		1,346		1,346	

Note: Robust *p* values in parentheses. AME, average marginal effect.
*$p < .05$.
**$p < .01$.
***$p < .001$.

Due to their non-linear nature, logit coefficients cannot be directly interpreted. We therefore also present the average marginal effect (AME) for those cases where they are statistically significant at conventional levels next to the coefficients.[7] Relying on AME's facilitates the interpretation of effect size and valence (Long & Freese, 2014). They are particularly helpful for policy-relevant research because they illustrate how substantively and statistically significant effects are (Cameron & Trivedi, 2010). AMEs were calculated for changes from 0 to 1 for indicator variables, discrete changes by one unit for ordinal variables, and changes by one standard deviation for continuous variables.

Based on the estimates in Model 1, four variables are statistically significant at conventional levels, two of which are negatively signed. Identifying as LGBT is associated with a 0.103 reduction in the probability of attributing addiction to personal choice. The effect is statistically significant at the $p = .000$ level. The probability of believing addiction is a personal choice and is also reduced for women by 0.063 ($p = .025$). On the other hand, higher levels of conservatism and religiosity are associated with effects in the opposite direction. For each increase by one unit of conservatism, the probability of believing addiction is a personal choice and is increased by 0.028 ($p = .000$). For religiosity, the increase is 0.038 ($p = .000$). Notably, the average prediction for the respondents in the sample is 0.741, indicating that a significant majority of individuals assign responsibility for addiction to the individual's personal choices. We note that all other models exhibit similarly high levels of average predictions. When we introduce whether the respondent themselves has suffered from addiction to the estimation (Model 2), the probability of personal attribution is reduced by a substantive 0.201 ($p = .007$), while the effects remain analogous for the other variables. As previously mentioned, Models 3 and 4 are estimated for Non-Hispanic Whites only and introduce a variable gauging the racial resentment of the respondent. We note that effects remain consistent with those in Models 1 and 2, with two important exceptions. First, the ideology measure fails to exert an independent influence in these specifications. Second, the racial resentment variable is statistically significant: for each standard deviation increase in racial resentment, the probability of personal attribution increases by 0.088 ($p = .000$). Finally, we find no effect for personal connections across all models.

We provide further nuance of these results in Table 2. Specifically, we replace the ideology measure with two indicator variables, one for extreme liberals and one for extreme conservatives. This allows us to empirically ascertain whether our previous findings on ideology are driven by one or both sides of the ideological continuum. Analogously, we replace the religiosity measure with two indicators for individuals who are highly active in their religion and one for those who are highly inactive. Re-estimating the models (Models 5 and 6) indicates that extreme liberals and extreme conservatives are exerting independent and opposite effects. That is, being an extreme liberal reduces the probability of attributing responsibility to the individual, while the opposite holds for extreme conservatives. However, this is not true for our replacements of the religiosity measure. Here, the substantive effect is associated only with those who are extremely non-active in religious matters. Moreover, re-estimating the models for Non-Hispanic Whites only eliminates the independent effect of both ideology measures. However, the effect of extremely non-religious individuals persists. Again, racial resentment is highly significant and substantively important. Finally, we note that personal connections are only significant in Model 3, marginally so, while the effect of LGBT status is persistently

Table 2. Opioid Addiction as Personal Choice: Expanded Results From Logit Models for All Respondents and Non-Hispanic Whites

	All Respondents				Non-Hispanic Whites			
	(5)		(6)		(7)		(8)	
Varaiables		AME		AME		AME		AME
Personal Connection	−0.132		−0.039		−0.349*	−0.062	−0.248	
	(.352)		(.790)		(.0411)	(.040)	(.161)	
Suffering from Addiction			−0.933**	−0.192			−0.952*	−0.190
			(.006)	(.011)			(.019)	(.030)
LGBT	−0.523***	−0.103	−0.480***	−0.093	−0.543**	−0.104	−0.510**	−0.097
	(.000)	(.000)	(.001)	(.001)	(.001)	(.002)	(.002)	(.003)
Extreme Liberal	−0.343*	−0.064	−0.343*	−0.064	−0.048		−0.029	
	(.0363)	(.042)	(.039)	(.045)	(.822)		(.894)	
Extreme Conservative	0.513**	0.087	0.492*	0.083	0.364		0.337	
	(.010)	(.005)	(.013)	(.008)	(.113)		(.142)	
Extreme Non-Religious	−0.587***	−0.114	−0.605***	−0.117	−0.555**	−0.104	−0.570**	−0.106
	(.001)	(.001)	(.000)	(.001)	(.005)	(.007)	(.005)	(.007)
Extreme Religious	0.135		0.150		0.014		0.033	
	(.498)		(.457)		(.957)		(.896)	
Female	−0.374*	−0.067	−0.406*	−0.073	−0.349		−0.369	−0.064
	(.018)	(.017)	(.010)	(.010)	(.064)		(.051)	(.047)
Black	0.330		0.277					
	(.151)		(.227)					
Hispanic	0.008		−0.0126					
	(.974)		(.958)					
Political Knowledge	−0.560		−0.640*	−0.033	−0.160		−0.239	
	(.068)		(.040)	(.045)	(.657)		(.515)	
Rural Residence	0.295		0.287		0.376		0.348	
	(.118)		(.131)		(.091)		(.120)	
Urban Residence	0.098		0.087		0.172		0.157	
	(.580)		(.622)		(.466)		(.507)	
Age	−0.028		−0.025		−0.0515		−0.051	
	(.255)		(.324)		(.125)		(.135)	
Age^2	0.000		0.000		0.000		0.000	
	(.390)		(.490)		(.237)		(.258)	
Racial Resentment					2.236***	0.090	2.251***	0.089
					(.000)	(.000)	(.000)	(.000)
Constant	1.394*		1.503*		0.479		0.747	
	(.044)		(.024)		(.618)		(.413)	
Education	Yes		Yes		Yes		Yes	
Income	Yes		Yes		Yes		Yes	
Average prediction		0.739		0.739		0.720		0.720
McKelvey and Zavoina	0.101		0.110		0.169		0.178	
Observations	2,056		2,056		1,353		1,353	

Note: Robust p values in parentheses. AME, average marginal effect.
$^{*}p < .05$.
$^{**}p < .01$.
$^{***}p < .001$.

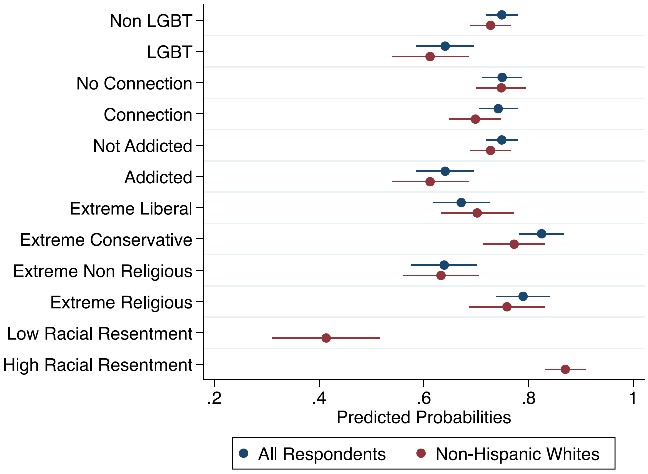

Figure 1 Opioid Addiction as Personal Choice: Predicted Probabilities for Select Covariates from Models Presented in Table 2.

strong. The predicted probabilities for statistically significant variables are presented in Figure 1 for Models 6 and 8 (Table 3).

Finally, we assess whether attribution might be mitigated, that is, whether LGBT respondents with personal connections to individuals coping with addiction are particularly susceptible to resist personal attribution over and above the independent effects of each variable independently. To assess whether the effect of a personal connection and LGBT status is multiplicative, we re−estimate the models from Table 2 but include an interaction between the two variables. Again, Models 9 and 10 were estimated for all respondents, while Models 11 and 12 are estimated for Non-Hispanics Whites. Due to the non-linear nature of logit models, interaction cannot be interpreted based on coefficients (Ai & Norton, 2003). To assess whether an interactive effect exists, we thus rely on differences between predicted probabilities presented in Figure 2. Specifically, we present four cases varying LGBT status and personal connection. For interactive effects to be present between LGBT status and personal connections, the predicted probabilities in row 4 ("LGBT & Connection") must be statistically different from the three other sets of predicted probabilities. And indeed, the predicted probabilities for those who identify as LGBT and who have a personal connection (row 4) are statistically different from those who do not identify as LGBT and have no personal connection (row 1) and those who do not identify as LGBT and have a personal connection (row 2). However, there are no statistically significant differences between individuals who identify as LGBT and who have no personal connection (row 3) and those who identify as LGBT and have a personal connection (row 4). While these results do not confirm the presence of interactive effects between the two variables, they do confirm our previous findings of a significant and independent effect of LGBT status on personal attribution. Again, differences are not present for all respondents nor for Non-Hispanic Whites only. We note that

Table 3. Opioid Addiction as Personal Choice: Results from Logit Models with Interactions for All Respondents and Non-Hispanic Whites

	All Respondents				Non-Hispanic Whites			
	(9)		(10)		(11)		(12)	
Variables		AME		AME		AME		AME
Personal Connection	−0.139		−0.048		−0.351*	−0.062	−0.252	
	(.340)		(.745)		(.046)	0.040	(.165)	
Personal Connection × LGBT	0.216		0.300		0.057		0.138	
	(.365)		(.231)		(.843)		(.632)	
Suffering from Addiction			−0.937**	−0.193			−0.954*	−0.190
			(.005)	0.011			(.019)	0.030
LGBT	−0.652***	−0.109	−0.657***	−0.101	−0.577*	−0.106	−0.593*	−0.100
	(.000)	0.000	(.000)	0.000	(.015)	0.002	(.012)	0.003
Extreme Liberal	−0.343*	−0.064	−0.343*	−0.064	−0.048		−0.0279	
	(.03)	0.042	(.039)	0.045	(.824)		(.898)	
Extreme Conservative	0.513**	0.087	0.493*	0.083	0.364		0.338	
	(.010)	0.005	(.013)	0.007	(.113)		(.142)	
Extreme Non-Religious	−0.587***	−0.114	−0.604***	−0.117	−0.555**	−0.104	−0.569**	−0.106
	(.001)	0.001	(.000)	0.001	(.005)	0.007	(.005)	0.007
Extreme Religious	0.133		0.147		0.013		0.032	
	(.505)		(.465)		(.958)		(.899)	
Female	−0.375*	−0.068	−0.407*	−0.073	−0.349		−0.369	−0.064
	(.018)	0.017	(.010)	0.009	(.064)		(.051)	0.047
Black	0.331		0.278					
	(.150)		(.226)					
Hispanic	0.006		−0.015					
	(.980)		(.950)					
Political Knowledge	−0.560		−0.640*	−0.033	−0.160		−0.238	
	(.068)		(.040)	0.045	(.658)		(.516)	
Rural Residence	0.296		0.288		0.376		0.348	
	(.117)		(.130)		(.091)		(.120)	
Urban Residence	0.098		0.087		0.172		0.157	
	(.579)		(.621)		(.465)		(.506)	
Age	−0.0282		−0.025		−0.052		−0.051	
	(.255)		(.324)		(.125)		(.135)	
Age^2	0.000		0.000		0.000		0.000	
	(.390)		(.490)		(.237)		(.258)	
Racial Resentment					2.236***	0.090	2.253***	0.090
					(.000)	0.000	(.000)	0.000
Constant	1.401*		1.513*		0.480		0.749	
	(.043)		(.024)		(.618)		(.412)	
Education	Yes		Yes		Yes		Yes	
Income	Yes		Yes		Yes		Yes	
Average Prediction		0.739		0.739		0.720		0.720
McKelvey and Zavoina	0.101		0.110		0.169		0.178	
Observations	2,056		2,056		1,353		1,353	

Note: Robust p values in parentheses. AME, average marginal effect.

$^{*}p < .05$.

$^{**}p < .01$.

$^{***}p < .001$.

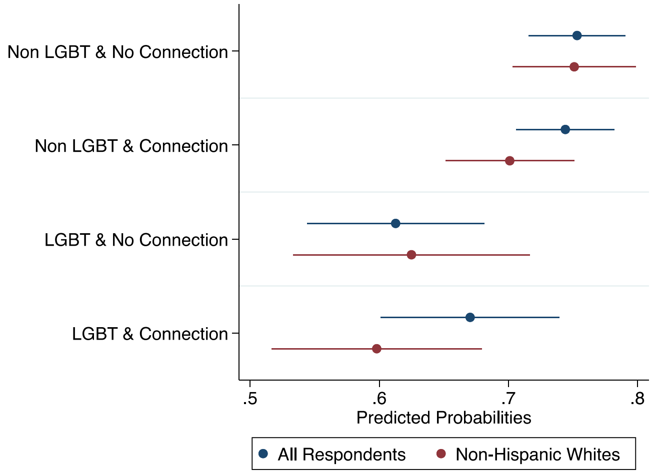

Figure 2 Opioid Addiction as Personal Choice: Predicted Probabilities for Personal Connection and LGBT Status Based on Models Presented in Table 3.

the effects of all other variables remain in line with the estimates presented in Table 2.

Discussion

Our research applies Weiner's attribution theory of controllability to individuals' attitudes about the causes of opioid addiction. According to attribution theory, the causes of addiction are perceived to be either controllable (driven by personal choice) or not controllable (driven by situational characteristics).

We posited that ideology and religiosity would be important predictors of respondents' perceptions. Our findings were generally consistent with these expectations. That is, liberals were more likely to assign responsibility to situational factors outside the individual, while the opposite held for conservatives. However, we also found that racial resentment plays a significant, if not overwhelming, role. When we estimated our models for a subset of Non-Hispanic Whites, ideology faded in importance, while racial biases became important predictors. These findings are in line with studies of other policy issues that have found similar effects. Moreover, we found that religiosity is also associated with perceptions of blame, but in a more nuanced way. Indeed, we only found associations for those who are highly inactive; that is, highly inactive individuals are much more likely to attribute blame to situational factors, while there is no difference between moderately and highly active churchgoers. This finding suggests that when individuals are not regularly exposed to religion and other religious individuals, they are less likely to blame individuals themselves for addiction.

Finally, we hypothesized that personal connections and shared stigma play an important role in attributions. These expectations were partially confirmed. That is, we found that LGBT status is an important and substantial negative predictor with regard to attribution opioid addiction to personal choice. We found no such effect for personal connections or the interaction of both factors. While growing bodies of research have started the important work of studying public opinion surrounding the opioid crisis (Barry et al., 2016; Gollust & Miller, 2020; Kennedy-Hendricks et al., 2017), little is known about American attitudes toward the epidemic in the context of sexual identity. To our knowledge, this is the first analysis to specifically focus on individuals identifying as LGBT. Importantly, we found significant and substantive effects of personal addiction and LGBT status but did not find consistent associations for other personal connections.

From a theoretical perspective, our findings match nicely with Weiner's theory of controllability within the study of attribution. Previous research has found that those who suffer from opioid use disorder face significant stigmatization from both society and those close to them (Addison & Thorpe, 2004; Corrigan et al., 2009; Kennedy-Hendricks et al., 2017; Sattler et al., 2017). The same holds for individuals identifying as LGBT, indicating a sense of empathy among stigmatized populations. Our research thus expands previous findings by focusing on shared connections and experiences while simultaneously highlighting the need to include political and religious variables in studies of opioid abuse attributions. Future research should extend these findings to other stigmatized groups and issues. Extensions of this work should also focus on how these factors may similarly affect perceptions of potential policy solutions.

Despite the importance of these findings, it is necessary to acknowledge several limitations of our analysis. First, our analysis does not account for differences across states in the severity of the opioid epidemic that could affect how individuals view attributions of blame. To the extent that respondents in particularly affected states like West Virginia or Ohio respond differently than respondents in other states, our dataset is not able to capture these distinctions. However, we note that the survey approximates important benchmarks for the United States as a whole. Second, we are not able to model changes in perception over time because we rely on a single survey for our estimations. Public opinion is dynamic and may change as the narratives about the opioid epidemic change in media and politics. Finally, all common limitations of survey research on sensitive subject matters apply to our work, as well.

Ultimately, even with these limitations, our research represents an important step forward for our understanding of public opinion about the opioid epidemic and policies to combat it as well for better understanding the interaction of a stigmatized group and personal connection to an important public health issue.

Conclusion and Policy Implications

Among the American public, there is a debate on whether the opioid crisis should be viewed as a criminal or a (public) health problem. The research found that the news media framed opioid use as a criminal justice issue rather than a public health crisis from 1998 to 2012 (McGinty et al., 2016). There is also evidence that the media differentiates their coverage between Whites and racial minorities

(Santoro & Santoro, 2018). Yet more recently, while opioid abuse has been viewed as a public health crisis, there are still elements of criminality, as evidenced by the U.S. Justice Department targeting prescription drug manufacturers and distributors for their role in the opioid crisis. American public opinion may be slower to adapt to these new perceptions as our analysis shows with average predictions for personal attributions exceeding 0.700 in all specifications. These perceptions may be particularly persistent, given the large amount of stigma associated with drug abuse.

Our findings with regard to LGBT individuals provide some important implications for addressing the opioid epidemic in particular and policymaking more generally. The significant effect of LGBT status on attribution may indicate the potential for policy entrepreneurs and policy solutions to the opioid epidemic to emerge from within the LGBT community, a population particularly affected by substance abuse. Given the scale of the problem, private entities might be needed to supplement the actions of governments, with the potential for successful private policy solutions to further inform the public policy response. More generally, the findings of shared stigma illustrated here may also be relevant for other stigmatized groups. Our findings suggest that members of other stigmatized groups might be less prone to blaming the opioid epidemic on users themselves because they understand what it means to be stigmatized. Critically, our findings point to the need for future research exploring whether stigmatized groups vary from the rest of the population when studying attribution on other policy issues.

The findings here make an important contribution to our understanding of the opioid epidemic in general. For one, getting a better grasp of public opinion on the opioid epidemic offers an important contribution to public and policy discourse. Our findings also hold value for policy advocates seeking to provide assistance to Americans affected by the opioid epidemic because they illustrate where Americans stand on the issue. While we have established key determinants of causal attributions about opioid addiction above, it is potentially even more critical to understand whether these attributions have policy consequences in the form of passing and implementing policy solutions that mitigate the epidemic. Here, attribution theory may again be helpful as it posits that the perceived cause of behavior should determine how individuals react toward stigmatized groups and related attitudes, including support for policies that either is designed to punish or aid those addicted to opioids. Specifically, we would expect that those who attribute the epidemic to personal choices will be less supportive of policies designed to provide assistance in order to rehabilitate those addicted to opioids and instead will support government policies meant to punish those addicted to opioids. That is, attributions of blame may significantly and substantively affect how Americans perceive certain policy solutions to the opioid epidemic like expanding access to Medicaid (Callaghan & Jacobs, 2013) or insurance marketplaces (Haeder & Weimer, 2013), a more supportive approach, or not exempting those with addiction from work requirements for Medicaid beneficiaries (Haeder, 2019; Haeder et al., Forthcoming), a more punitive approach. Exploring the possible relationship between attributions of blame and attitudes toward policies to combat the epidemic therefore is a critical direction for future research.

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Notes

Conflicts of interest: None declared.
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1. President Trump's plan included reducing the demand for prescription drugs by raising public awareness about the dangers of prescription opioids. The initiative also works to ensure that first responders are supplied with naloxone and provides federal funding to state and local jurisdiction to incentivize a nationwide overdose tracking system. For more information, see https://www.whitehouse.gov/briefings-statements/president-donald-j-trumps-initiative-stop-opioid-abuse-reduce-drug-supply-demand/
2. The institutional review boards at Texas A&M University, West Virginia University, The Pennsylvania State University, and Utah Valley University approved the study.
3. The LGBT oversample was weighted to LGBT population benchmarks relying on data from the UCLA Williams Institute (https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#density). Importantly, when the oversample is combined with the national sample, the LGBT oversample is down-weighted to reflect the proportion of the population that identifies as LGBT.
4. We conducted a robustness check to see if the results would change if we included a variable that examined the respondents' connection to the opioid crisis was within their immediate family and not some broad personal connection. None of the results were substantively different, so we opted for the more generalizable measure.
5. We note that we used various specifications for education with essentially identical results.
6. We note that we used various specifications for income with essentially identical results.
7. As described by Long and Freese (2014, p. 242), we obtain marginal effects by "comput[ing] the marginal effect of x_k for each observation at its observed values x_i, and the comput[ing] the average of these effects."

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State Medicaid and CHIP options and child insurance outcomes: An investigation of 83 state options with state-level panel data

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Abstract

Medicaid and the Children's Health Insurance Program (CHIP) both combine federal mandates to cover certain services and groups with state options in providing that coverage and in covering other services and groups. Using state-level panel data, we investigated the relationships of 83 state Medicaid and CHIP options with 2 child insurance outcomes from 2008 to 2018 using structural equation modeling, controlling for 10 possible demographic and economic variables, state fixed effects, and a quadratic year count variable. Our results suggest that eliminating asset tests for children's and parents' coverage, eliminating or reducing waiting periods for children's coverage, providing express and continuous eligibility for children's coverage, and eliminating face-to-face interview requirements for children's coverage may have been especially important in reducing child uninsurance rates and increasing the percentage of children covered by means-tested public insurance.

KEYWORDS

Children's Health Insurance Program, Medicaid, state options

Key points

- Eliminating asset tests for children's and parents' coverage may have been especially important in reducing child uninsurance rates in the United States from 2008 to 2018.
- Eliminating or reducing waiting periods for children's coverage may have been another important state option in reducing child uninsurance rates.
- Providing express and continuous eligibility for children's coverage may also have been important in reducing child uninsurance rates.
- Eliminating face-to-face interview requirements for children's coverage may also have helped to reduce child uninsurance rates.

BACKGROUND

When Congress created Medicaid in 1965, it required states that elected to participate to cover a core set of basic health services for public assistance recipients. However, it also gave states significant flexibility in designing their programs, both to cover additional services for public assistance recipients and to cover medically needy people who did not receive public assistance. The program has expanded far beyond public assistance recipients to include low-income families, pregnant women, people with disabilities, and people needing long-term care. But it continues to combine federal mandates to cover certain services for certain groups with state options in providing that coverage and in covering other services or groups. The federal government pays an average of about 57% of Medicaid coverage costs, but the federal share for most services and groups ranges from a minimum of 50% in high-income states to 74% in states with the lowest per-capita incomes (Centers for Medicare & Medicaid Services (CMS), n.d.b; Kaiser Family Foundation (KFF), 2012; Smith et al., 2005).

In 1997, Congress created the Children's Health Insurance Program (CHIP) to allow states to cover uninsured children in working families with incomes just above Medicaid eligibility levels. To encourage states to participate in CHIP, Congress provided states with enhanced federal financing and even greater flexibility in designing their programs as compared with Medicaid. States even have the option to provide CHIP coverage through Medicaid, a separate CHIP program, or a combination of the two. The federal government pays an average of 70% of CHIP coverage costs, which varies from a minimum of 65% to a high of 82% based on state per-capita income. Because CHIP is not an entitlement program like Medicaid, federal CHIP payments are subject to both national and state-specific funding limits (KFF, 2012; Lambrew, 2007; Medicaid and CHIP Payment and Access Commission, 2019).

In 2010, Congress passed the Affordable Care Act (ACA), which was primarily intended to reduce uninsurance rates among low-income adults, but also affected children's coverage. It required states to transition coverage to Medicaid for all children in families earning up to 138% of the Federal poverty level (FPL); previously, states were required to cover children under Medicaid up to that level only through age 5 and were required to cover older children only up to 100% of the FPL. The ACA also required states to maintain their income eligibility limits for children at least equal to the pre-ACA levels through 2019. And the ACA limited the length of waiting periods for CHIP coverage to a maximum of 90 days; previously, states required children to be uninsured for as long as 12 months before receiving coverage. Finally, the ACA provided subsidies for children in families below 400% of the FPL who were not eligible for Medicaid or CHIP and did not have access to employer-sponsored health insurance to purchase insurance in the new marketplaces; it also allowed children in families above 400% of the FPL to purchase unsubsidized insurance in those marketplaces (Rudowitz et al., 2014).

The research on the effects of state options on child insurance outcomes is extensive and we do not attempt to fully review it here. Instead, we focus on research that has taken advantage of a particularly valuable source of data on those state options: surveys of state Medicaid and CHIP program officials regarding eligibility, enrollment, renewal, and cost sharing policies that have been conducted by the Kaiser Family Foundation (KFF) annually since 2000 (Brooks et al., 2015, 2016, 2017, 2018, 2019; Cohen Ross & Cox, 2000, 2002, 2003, 2004, 2005; Cohen Ross & Marks, 2009; Cohen Ross et al., 2007; 2008, 2009; Heberlein et al., 2011, 2012, 2013). Among the dozens of articles that have cited one or more of the KFF surveys, we identified eight articles that used data from those surveys to estimate relationships between one or more state options and child insurance outcomes, although those articles varied in whether they considered Medicaid, CHIP, Medicaid and

CHIP combined, public insurance generally, or any public or private insurance (Abdus et al., 2014; Bansak & Raphael, 2007; Blavin et al., 2014; Kronebusch & Elbel, 2004; Ku et al., 2013; Sommers, 2005; Wolfe & Scrivner, 2005; Yu & Dick, 2009).

Most of the state options considered were not related to the child insurance outcomes in those eight prior studies. For the state options that were related, most relationships were in the expected direction, but there were some unexpected results. In one study, having continuous eligibility for Medicaid was related to a lower Medicaid enrollment rate for children, having continuous eligibility for CHIP was related to a lower CHIP enrollment rate for children, and having presumptive eligibility for Medicaid or CHIP was related to a higher uninsurance rate for children (Kronebusch & Elbel, 2004). In another study, having an asset test and requiring a face-to-face interview at enrollment were each related to a higher Medicaid take-up rate for Medicaid-eligible children and having a family-oriented Web site was related to a lower CHIP take-up rate for CHIP-eligible children (Wolfe & Scrivner, 2005). And not requiring documentation for a child's date of birth was related to a lower public insurance rate for children in another study (Bansak & Raphael, 2007).

Five of those eight prior studies considered relationships of child insurance outcomes with several different state options simultaneously. Doing so is important, because if state options omitted from the study are correlated with options included in the study, the results may overstate the importance of the included options. Bansak and Raphael (2007) considered 16 different state options, while Blavin et al. (2014) considered 14, Kronebusch and Elbel (2004) considered 11, Wolfe and Scrivner (2005) considered 10, and Yu and Dick (2009) considered 8.

All eight prior studies were multilevel studies that combined individual-level insurance data with state-level state options data. That approach allowed the authors to have greater confidence in the validity of any relationships that were found, but it also limited the number of years of state option data that could be included and, as a result, the number of different state options that could be simultaneously considered. We used only state-level data in this study, so that we could use state options data from all 20 years of KFF surveys to analyze the relationships of our child insurance outcomes with 83 different state options. Our two child insurance outcomes were the percentage of children who were uninsured at any point during the year and the percentage of children who were covered by Medicaid, CHIP, or other means-tested public insurance at any point during the year. We sought to identify state options that may be related to each child insurance outcome.

MATERIALS AND METHODS

Data

We used three different types of variables in our analyses. Our independent variables were derived from the state options data in the annual KFF surveys and represented either an individual state option, a variable combining data on the same state option for Medicaid and for CHIP, or an index comprising two or more closely related and highly correlated state option variables. Our control variables were state-level demographic and economic variables from the annual American Community Survey (ACS). And our dependent variables were the child insurance outcomes described above, using state-level data from the ACS.

For the independent variables, we first prepared a database from the annual KFF surveys for 83 state options that had multiple years of data available and that seemed most likely to be related to child insurance outcomes. Next, we combined data for the same state option reported separately for Medicaid and for CHIP in the same year into a single variable by averaging the Medicaid and CHIP data. Thus, for example, we combined separate data

TABLE 1 Descriptive statistics for variables included in final structural equation models

Variable	Number of state-years	Years covered	Mean	*SD*	Min.	Max.
Independent variables						
Income eligibility limit for children for Medicaid or CHIP as %of FPL	969	2000–2018	236.0	53.8	133	405
Asset test for children for Medicaid and/or CHIP	886	2000–2018	0.05	0.20	0	1
Waiting period in months for children for CHIP	890	2001–2018	2.3	2.4	0	12
5-year waiting period for legal immigrant children for Medicaid and/or CHIP	966	2000–2018	0.73	0.45	0	1
Express eligibility for children for Medicaid and/or CHIP	863	2000–2016	0.06	0.21	0	1
Continuous eligibility for children for Medicaid and/or CHIP	964	2000–2018	0.49	0.45	0	1
Child premium index	814	2003–2018	0.22	14.4	−9.4	79.4
Child premium at 101% of FPL	806	2003–2018	9.3	30.6	0	240
Child premium at 151% of FPL	788	2003–2018	62.0	104.3	0	480
Child premium at 201% of FPL	756	2003–2018	142.2	209.9	0	1500
12-month renewal period for children for Medicaid and/or CHIP	904	2000–2018	0.92	0.24	0	1
Face-to-face interview requirement for children index:	887	2000–2018	0.0	0.20	−0.05	0.95
Face-to-face interview required for child enrollment in Medicaid and/or CHIP	885	2000–2018	0.05	0.20	0	1
Face-to-face interview required for child renewal in Medicaid and/or CHIP	886	2000–2018	0.03	0.15	0	1
No income documentation index	961	2000–2018	0.0	0.33	−0.13	0.87
No income documentation required at enrollment for Medicaid and/or CHIP	961	2000–2018	0.13	0.33	0	1
No income documentation required at renewal for Medicaid and/or CHIP	347	2006–2012	0.32	0.45	0	1
Asset test for pregnant women for Medicaid and/or CHIP	717	2003–2018	0.09	0.28	0	1
5-year waiting period for legal immigrant pregnant women for Medicaid and/or CHIP	966	2000–2018	0.79	0.41	0	1
Income eligibility limit for parents as % of FPL	866	2002–2018	94.3	56.6	16	275
Asset test for parents	765	2002–2018	0.40	0.49	0	1
Parent copay index	814	2003–2018	0.0	0.99	−1.35	4.96
Copay for doctor visit	452	2010–2018	1.35	1.81	0	10
Copay for ER visit	691	2003–2018	1.44	7.30	0	100
Copay for nonemergency ER visit	805	2003–2018	9.24	78.8	0	1000
Copay for hospital visit	810	2003–2018	25.5	51.6	0	400

(Continues)

TABLE 1 (Continued)

Variable	Number of state-years	Years covered	Mean	*SD*	Min.	Max.
Copay for generic prescriptions	810	2003–2018	1.22	1.12	0	5
Copay for brand name prescriptions	809	2003–2018	1.91	1.44	0	10
12-month renewal period for parents	860	2002–2018	0.88	0.33	0	1
Telephone accessibility index:	491	2009–2018	−0.01	0.33	−0.79	0.21
Telephone application for Medicaid and/or CHIP	325	2012–2018	0.84	0.37	0	1
Telephone renewal for Medicaid and/or CHIP	460	2009–2018	0.57	0.48	0	1
Same eligibility system for Medicaid and nonhealth programs	434	2010–2018	0.60	0.49	0	1
Control variables						
Child poverty rate	714	2005–2018	19.0	5.2	7.9	34.7
Unemployment rate	714	2005–2018	7.0	2.3	2.6	15.1
% of children who are Hispanic	714	2005–2018	15.4	12.8	0.9	60.5
% of children who were born in the United States	714	2005–2018	97.2	1.5	92.7	99.8
% of children who live with a parent	714	2005–2018	88.8	3.0	75.5	94.5
% of children whose families receive public assistance	714	2005–2018	24.1	6.9	9.7	42.2
% of adults with a bachelor's degree or higher	714	2005–2018	28.9	6.1	16.5	60.4
Dependent variables						
% of children who were uninsured	561	2008–2018	6.4	3.2	1.0	20.0
% of children who were covered by means-tested public insurance	561	2008–2018	35.2	7.9	14.7	56.6

Abbreviations: CHIP, Children's Health Insurance Program; FPL, Federal poverty level.

on whether the state required a face-to-face interview at Medicaid enrollment (coded as 0 or 1) and whether the state required a face-to-face interview at CHIP enrollment (coded as 0 or 1) into a single variable, with possible values of 0, 0.5, or 1. (We considered averaging this variable differently to weigh the Medicaid value more because that program is much larger than CHIP, but there were relatively few cases in which the Medicaid and CHIP values were different for a given state in a given year.) This process reduced the number of state option variables to 62. Finally, we combined closely related and highly correlated variables into indices; we used structural equation modeling (SEM) to construct these indices, because we were also using SEM for our analyses. This process reduced the number of state option variables to 33. From those 33 state option variables and 10 possible demographic and economic control variables, we selected variables using both backward and forward stepwise selection, retaining only variables that were at least 80% likely to be related to the relevant dependent variable. Table 1 presents descriptive data for the variables included in either of our final structural equation models; for the independent variables, it includes both the indices included in the final models and the individual variables comprising each index.

TABLE 2 State option variables not included in final structural equation models

- Presumed eligibility for children for Medicaid and/or CHIP
- Child copay index
  - Copay for doctor visit at 151% of FPL
  - Copay for ER visit at 151% of FPL
  - Copay for nonemergency ER visit at 151% of FPL
  - Copay for hospital visit at 151% of FPL
  - Copay for generic prescriptions at 151% of FPL
  - Copay for brand name prescriptions at 151% of FPL
  - Copay for doctor visit at 201% of FPL
  - Copay for ER visit at 201% of FPL
  - Copay for nonemergency ER visit at 201% of FPL
  - Copay for hospital visit at 201% of FPL
  - Copay for generic prescriptions at 201% of FPL
  - Copay for brand name prescriptions at 201% of FPL
- Buy-in program for children
- No other documentation index
  - No documentation of child's age required for Medicaid and/or CHIP
  - No documentation of state residency required for Medicaid and/or CHIP
  - No documentation of household composition required
- Income eligibility limit for pregnant women for Medicaid or CHIP as % of FPL
- Presumed eligibility for pregnant women for Medicaid and/or CHIP
- Presumed eligibility for parents
- Face-to-face interview requirement for parents index:
  - Face-to-face interview required for parent enrollment
  - Face-to-face interview required for parent renewal
- Family application for Medicaid
- Automatic renewals for Medicaid
- Online accessibility index
  - Online application for Medicaid and/or CHIP
  - Online renewal for Medicaid and/or CHIP
  - Online account for Medicaid and/or CHIP
- Mobile accessibility index:
  - Mobile application
  - Mobile account

(Continues)

TABLE 2 (Continued)

Integration of Medicaid and CHIP index:
Joint application for Medicaid and CHIP
Joint renewal for Medicaid and CHIP
Same eligibility system for Medicaid and CHIP
Type of ACA marketplace
Expanded Medicaid under the ACA

Abbreviations: ACA, Affordable Care Act; CHIP, Children's Health Insurance Program; FPL, Federal poverty level.

Table 2 lists the additional variables that we considered, but that were not included in either of our final structural equation models, because they were not at least 80% likely to be related to either of our child insurance outcomes.

Data analysis

As shown in Table 1, the annual KFF surveys include data on different state options for different years. Because of these temporal differences in data, it is difficult to estimate the relationships with many state options simultaneously using regression techniques. One would need to impute many years of data for some variables and, in some cases, those data may not even be applicable. For example, recent surveys include data on the type of health insurance marketplace used by the state, but that concept was created by the ACA.

To make maximum use of our data in light of these temporal differences, we used SEM with full information maximum likelihood estimation, which is implemented in Stata through its maximum likelihood missing values (*mlmv*) option. The *mlmv* option assumes that missing values are missing at random. Because this assumption may not be appropriate for some variables, we conducted robustness checks using standard maximum likelihood estimation, as discussed below. The *mlmv* option also assumes joint normality of the variables when used with the observed information matrix, but we used state-clustered standard errors in all of our analyses, which assume only that the clusters are independent of each other (Stata Press, 2019).

We considered several different estimation approaches to make use of the panel structure of our data and take into account the fact that Medicaid and CHIP coverage in the current year may be affected not only by state policies in the current year, but also by policies in the prior year. Therefore, to estimate relationships with our child insurance outcomes in year t, we averaged the independent and control variables over years t and $t-1$. We considered different averaging approaches and determined to use time-weighted averages, with the current year (year t) receiving a relative weighting of 2 and the prior year (year $t-1$) receiving a relative weighting of 1. We also estimated models with unweighted averages of the independent and control variables over years t and $t-1$ as a robustness check, as discussed below.

Finally, we included state fixed effects and a quadratic year count variable to control for individual state effects and time trends. We considered models with year fixed effects instead of the quadratic year count variable, but it was difficult to get many of the models with year fixed effects to converge and the results with the quadratic year count variable were very similar to the results with year fixed effects for the models that did converge with year fixed effects.

TABLE 3 Structural equation model estimates of relationships with child insurance outcomes from 2008 to 2018

Model includes time-weighted averages from year *t* – 1 to year *t* of the following variables	**Dependent variable in year *t*** % of children who were uninsured	**Dependent variable in year *t*** % of children who were covered by means-tested public insurance
Independent variables		
Income eligibility limit for children for Medicaid or CHIP as % of FPL	0.010**	
Asset test for children for Medicaid and/or CHIP	1.61**	
Waiting period in months for children for CHIP	0.11*	–0.26**
5-year waiting period for legal immigrant children for Medicaid and/or CHIP		–1.57*
Express eligibility for children for Medicaid and/or CHIP	–0.68†	1.48*
Continuous eligibility for children for Medicaid and/or CHIP	–0.99†	2.13*
Child premium index	–0.014†	
12-month renewal period for children for Medicaid and/or CHIP	2.83†	
Face-to-face interview requirement for children index	0.84	–1.81*
No income documentation index	–0.52	
Asset test for pregnant women for Medicaid and/or CHIP	–0.63	
5-year waiting period for legal immigrant pregnant women for Medicaid and/or CHIP	–0.60**	1.39
Income eligibility limit for parents as % of FPL	–0.004	0.010
Asset test for parents	1.41***	–1.30**
Parent copay index		–0.65*
12-month renewal period for parents		–0.91
Telephone accessibility index	–0.40	
Same eligibility system for Medicaid and nonhealth programs	–0.43	
Control variables		
Child poverty rate	0.36***	
Unemployment rate	0.14*	
% of children who are Hispanic		0.32
% of children who were born in the United States	–0.88***	
% of children who live with a parent	–0.46***	
% of children whose families receive public assistance	–0.34***	0.59***
% of adults with a bachelor's degree or higher	0.42	–0.50*
Number of state-years	561	561

Note: Models use full information maximum likelihood estimation and include state fixed effects, a quadratic year count variable, and state-clustered standard errors.

Abbreviations: CHIP, Children's Health Insurance Program; FPL, Federal poverty level.

$^{***}p < 0.001$; $^{**}p < 0.01$; $^{*}p < 0.05$; $^{\dagger}p < 0.10$.

RESULTS

Main results

The results of our main structural equation models are presented in Table 3. Nine state option variables were related to the percentage of children who were uninsured: an asset test for parents' coverage, an asset test for children's coverage, a higher income eligibility limit for children's coverage, a longer waiting period for children's coverage, and a 12-month renewal period for children's coverage were each related to a higher child uninsurance rate; and a 5-year waiting period for coverage of legal immigrant pregnant women, higher premiums for children's coverage, express eligibility for children's coverage, and continuous eligibility for children's coverage were each related to a lower child uninsurance rate. Seven state option variables were related to the percentage of children covered by means-tested public insurance: continuous eligibility for children's coverage and express eligibility for children's coverage were each related to a higher child public insurance rate; and a longer waiting period for children's coverage, an asset test for parents' coverage, face-to-face interview requirements for children's coverage, higher copays for parents' coverage, and a 5-year waiting period for coverage of legal immigrant children were each related to a lower child public insurance rate.

Robustness checks

We conducted two robustness checks of our main structural equation models. First, we used unweighted averages of the independent and control variables over years *t* and *t* – 1 instead of the time-weighted averages described above. Second, we considered different estimation methods for the structural equation models. We used the full information maximum likelihood (*mlmv*) method for our main analyses, but as discussed above, that method assumes that missing values are missing at random, which may not be appropriate for some variables. We discuss here the results from models that used standard maximum likelihood estimation, which omits observations with missing values.

The results from the models that used unweighted averages of the independent and control variables were fully consistent with our main results. There were no cases in which a state option variable had a significant relationship with a dependent variable in our main analyses and was not at least 80% likely to be related to that variable in the models with unweighted averages. Moreover, all of the coefficients in the models with unweighted averages were within 20% of the corresponding coefficients in our main analyses.

The results from the models that used standard maximum likelihood estimation (using Stata's *ml* option) were also consistent with our main results. There was only one case in which a state option variable had a significant relationship with a dependent variable in the *mlmv* model and was not at least 80% likely to be related to that variable in the *ml* model: express eligibility for children's coverage was not significantly related to the child means-tested public insurance rate in the *ml* model, as it was in the *mlmv* model. And for the relationships that were significant in the *mlmv* models, all of the coefficients in the *ml* models were within 20% of the corresponding coefficients in the *mlmv* models, except for two: the coefficient for the relationship between express eligibility for children's coverage and the child uninsurance rate was 42% smaller in the *ml* model than in the *mlmv* model (but was still statistically significant), and the coefficient for the relationship between express eligibility for children's coverage and the child means-tested public insurance rate was 33% smaller in the *ml* model than in the *mlmv* model. We should note that, for the percentage of uninsured children, we estimated the models for this comparison over the period from 2010 to 2016, because some independent variables included in our final model for that outcome did not have data for the years 2008, 2009, 2017, or 2018.

DISCUSSION

First, our results suggest that eliminating asset tests for children's and parents' coverage may have helped to improve child insurance outcomes. The use of asset tests for both children's and parents' coverage decreased gradually from 2000 until 2013, when the ACA required all states to eliminate those tests. In our results, not having an asset test for parents' coverage was related to a 1.4% decrease in the child uninsurance rate and a 1.3% increase in the child means-tested insurance rate, and not having an asset test for children's coverage was related to a 1.6% decrease in the child uninsurance rate (but was not significantly related to the child means-tested public insurance rate). Most of the eight prior studies that considered asset tests also found that eliminating those tests was related to better child insurance outcomes, including higher Medicaid enrollment rates (Kronebusch & Elbel, 2004), higher combined Medicaid and CHIP enrollment rates (Kronebusch & Elbel, 2004), higher public insurance take-up rates (Bansak & Raphael, 2007), lower uninsurance rates (Kronebusch & Elbel, 2004), and lower uninsurance rates for children with special health-care needs (Yu & Dick, 2009). However, two of the prior studies did not find significant relationships between asset tests and the child insurance outcomes considered (Blavin et al., 2014; Wolfe & Scrivner, 2005) and, as mentioned above, one of those two studies found that asset tests were actually related to higher Medicaid take-up rates for Medicaid-eligible children (Wolfe & Scrivner, 2005).

Second, our results suggest that eliminating or reducing waiting periods for children's coverage may also have helped to improve child insurance outcomes. As discussed above, the ACA set a maximum waiting period for children's CHIP coverage of 90 days, which required many states to shorten their waiting periods. Overall, the average waiting period for children's coverage decreased from almost 90 days in 2001 to about 17 days in 2019. States may still require legal immigrant children to wait 5 years for coverage and almost one-third of states still have that requirement, but the percentage of states with that requirement has decreased consistently since 2009, when states were first allowed to eliminate that waiting period. In our results, reducing the waiting period for children's CHIP coverage by one month was related to a 0.11% decrease in the child uninsurance rate and a 0.26% increase in the child means-tested public insurance rate, and eliminating the 5-year waiting period for coverage of legal immigrant children was related to a 1.6% increase in the child means-tested public insurance rate (but was not significantly related to the child uninsurance rate). Our results are again consistent with most of the prior studies that had considered waiting periods, which found that shorter waiting periods were related to higher Medicaid enrollment rates (Kronebusch & Elbel, 2004), higher combined Medicaid and CHIP enrollment rates (Kronebusch & Elbel, 2004), higher CHIP take-up rates (Wolfe & Scrivner, 2005), and higher public insurance take-up rates (Bansak & Raphael, 2007; Wolfe & Scrivner, 2005). We note, however, that both prior studies that considered relationships between waiting periods and child uninsurance rates did not find a significant relationship between those variables (Kronebusch & Elbel, 2004; Wolfe & Scrivner, 2005).

Third, our results suggest that providing express and continuous eligibility for children's coverage may also have helped to improve child insurance outcomes. The Children's Health Insurance Program Reauthorization Act of 2009 created express eligibility by providing options for states to simplify and speed up the eligibility determination process. State use of expressed eligibility increased gradually from 2010 to 2012, but has decreased since then, with only eight states offering it in 2016; KFF has not even been tracking that option in its recent surveys. Since at least 1997, states have been able to provide continuous eligibility for children's coverage under Medicaid and CHIP, which allows children to maintain coverage for 12 months, even if their family income increases above the income eligibility limit during that period. State use of continuous eligibility increased slightly from 2000 to 2010, but has been relatively unchanged since then, with slightly more than half of states currently offering it. In our results, having express eligibility was related to a 0.7% decrease in the child uninsurance rate and a 1.5% increase in the child means-tested public insurance rate, and having continuous eligibility was related to a 1.0% decrease in the child uninsurance rate and a 2.1% increase in the child means-tested public insurance rate. The only one of the eight prior studies that considered express eligibility found that it was related to higher child Medicaid enrollments and higher combined Medicaid and CHIP enrollments (Blavin et al., 2014). And two of the prior studies that considered continuous eligibility found that it was related to some improved child insurance outcomes, including higher Medicaid enrollment rates (Kronebusch & Elbel, 2004), higher CHIP enrollment rates (Kronebusch & Elbel, 2004), and longer Medicaid enrollments (Ku et al., 2013). However, most of the prior studies that considered continuous eligibility found that it was not significantly related to the child insurance outcomes considered (Bansak & Raphael, 2007; Blavin et al., 2014; Yu & Dick, 2009).

Fourth, our results suggest that eliminating face-to-face interview requirements for children's coverage may also have helped to improve child insurance outcomes. In 2000, 11 states had face-to-face interview requirements for children's coverage at application or renewal. The number of states with those requirements decreased consistently over time until 2013, when those requirements were eliminated in all states under the ACA. In our results, not requiring face-to-face interviews was related a 1.8% increase in the child means-tested public insurance rate and may have been related to a 0.8% decrease in the child uninsurance rate; the relationship with the child uninsurance rate was not statistically significant, but the two variables were more than 80% likely to be related. Most of the prior studies found that face-to-face interview requirements for children's coverage were not related to the child insurance outcomes considered (Bansak & Raphael, 2007; Blavin et al., 2014; Kronebusch & Elbel, 2004; Yu & Dick, 2009); one study found that eliminating those requirements was related to a higher CHIP take-up rate for CHIP-eligible children, but that same study found that eliminating those requirements was actually related to a lower Medicaid take-up rate for Medicaid-eligible children (Wolfe & Scrivner, 2005).

Finally, our results suggest that public insurance expansions due to the state options discussed above may have crowded out private insurance coverage to some extent. For four of the five state options discussed above (waiting periods, express eligibility, continuous eligibility, and face-to-face interview requirements), the estimated relationship between the option and the percentage of children covered by means-tested public insurance was at least twice as large as the estimated relationship between the option and the child uninsurance rate. These results suggest that at least half of the increases in public insurance coverage for children related to these state options may have been offset by decreases in private insurance coverage. Among the prior studies, Bansak and Raphael (2007) found that between one-quarter and one-third of the increases in public insurance coverage associated with the state options that they considered were related to decreases in private insurance coverage. Kronebusch and Elbel (2004) found that crowd-out varied significantly by state option, as some state options were not related to any corresponding reductions in private insurance coverage, while for other options, any increases in public insurance coverage were fully offset by decreases in private insurance coverage. Wolfe and Scrivner (2005) did not find that any of the state options that they considered were related to reductions in private insurance coverage, at least not in their models with state fixed effects.

CONCLUSIONS AND POLICY IMPLICATIONS

Considering the number of different state options that are available to states under Medicaid and CHIP, it is not surprising that states continue to pursue very different approaches to covering children under those programs (Gifford et al., 2020). However, beyond merely pursuing different approaches, states often seem to have very different goals in covering children under those programs. It might be expected that all states would primarily consider expected long-term benefits and costs in making decisions about Medicaid and CHIP state options. Of course, those cost–benefit analyses are extraordinarily complicated, as they must estimate not only the direct costs and benefits of expanding coverage under Medicaid and CHIP and reducing public expenditures on uninsured children, but also indirect costs and benefits associated with issues such as the crowd out of private insurance coverage, increased usage of the health-care system by insured children, and improved health for insured children throughout their lives, including reduced health expenditures, increased productivity, longer life expectancies, and increased tax receipts (Brown et al., 2015). And those economic costs and benefits vary across states due to demographic and economic differences.

However, the political costs and benefits relating to decisions about Medicaid and CHIP state options likely vary even more across states than the economic costs and benefits, as many liberal voters are particularly concerned about reducing health-care costs and helping needy Americans, while many conservative voters are especially concerned about reducing budget deficits (Pew Research Center, 2020). And these political considerations often appear to be more important than long-term cost–benefit considerations. This fact is perhaps most clearly demonstrated by the fact that 12 states still have not elected to expand Medicaid under the ACA, despite the fact that the law requires the federal government to pay 90% of the expenditures for people enrolled under the expansion, as compared with the 50% to 74% federal share for other Medicaid enrollees. Most experts believe that policies that reduce uninsurance rates in the short term will also reduce net costs in the long term (Flores et al., 2017; Muenning et al., 2015; Price & Eibner, 2013). Therefore, for states that seek to minimize either long-term net costs or short-term uninsurance rates, analyses like ours can help to identify state options that may be effective.

In particular, our results suggest that states seeking to reduce child uninsurance rates should consider reducing or eliminating waiting periods for children's coverage and providing express and continuous eligibility for children's coverage. As of 2019, 13 states had waiting periods and 19 states did not have continuous eligibility. Although many of those states are relatively conservative politically, there are some surprising states that have not taken advantage of at least one of these options to reduce child uninsurance rates, including Connecticut, the District of Columbia, Illinois, Massachusetts, Maryland, New Jersey, and Rhode Island. As of 2016 (the last year the option was included in the KFF surveys), 43 states did not have express eligibility; the situation does not seem to have changed much since 2016 as the Medicaid website currently lists only 14 states that use express eligibility for either Medicaid or CHIP, including only four states that use it for both programs (CMS, n.d.a). So, that option remains available for most states as a possible approach to reduce child uninsurance rates.

Most states took advantage of increased federal matching funds under the ACA to move toward integrated eligibility systems and automated business rules engines for health and human services programs (Gjika et al., 2019; Shaw et al., 2015). These systems can make the eligibility and enrollment process more cost-efficient from the state's perspective and can shorten processing times for consumers. Because the increased matching funds expired in 2018 and, in light of the budget and public health pressures that states are experiencing due to the current coronavirus pandemic, states will need to be even more strategic going forward in managing their program rules and technology systems to continue making progress on reducing child uninsurance rates. Understanding specific state options that have helped to reduce uninsurance rates in the past can help states to prioritize their actions.

LIMITATIONS

The principal limitations of this study relate to the fact that it uses state-level data for the insurance outcomes, instead of combining state-level state options data with individual-level insurance data, as most prior studies did. We discussed our reasons for adopting this approach above. Nevertheless, as an ecological study, it is less reliable for drawing causal implications than a study using individual data would be. Therefore, our results that identified unexpected relationships between state options and our insurance outcomes, in particular, would require further investigation before reaching any conclusions about those relationships. Also, because this study used only state-level data with state fixed effects, it had less statistical power than most studies using individual data would have, which may have prevented it from detecting relationships that exist between some state options and our insurance outcomes. However, we believe that the fact that our study design allowed us to consider many more state options simultaneously than any prior study has done provided advantages that compensated for these limitations.

CONFLICT OF INTERESTS

The author declares that there are no conflict of interests.

ETHICS STATEMENT

The data, models, and methods used in this research are not proprietary.

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ORIGINAL ARTICLE

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Examining the effects of the Medicaid expansion on health outcomes

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Abstract

The study looks at the effects of the Medicaid expansion on health outcomes, healthcare utilization and access to healthcare through the Center of Disease Control's Behavioral Risk Factor Surveillance System. In particular, we looked into whether Medicaid Expansion has caused an increase in healthcare access, healthcare utilization, and positive health outcomes among newly insured Medicaid patients. We applied the difference-in difference models to cholesterol check, health plan, and medical cost. Our results indicated evidence a positive effect associated with state Medicaid expansions for adults and the utilization of preventive care increased in expansion states after the Medicaid expansion as more Medicaid recipients received blood pressure checks and regular primary care checkups relative to the non-expansion states.

KEYWORDS
access, cost, Medicaid

Key points

- There is an increase in individuals responses about the length of time since they last saw a doctor for a routine check up from expanded states compared to non-expanded states.
- Individuals from expanded states saw a decrease in cost being a factor when patients needed to see a doctor compared to non-expansion states.
- Individuals in expanded states had an increase in flu shots compared to individuals in non-expanded states.
- Medicaid expansion states saw an overall increase in healthcare utilization than nonexpansion states.

INTRODUCTION

Medicaid traditionally covers the poor, pregnant women, and persons with disabilities. There have been mixed results concerning whether Medicaid has benefits (Gruber, 2008). Research in the 1980s showed a reduction in mortality among infants and children. However, research has shown that Medicaid recipients are sicker than non-Medicaid recipients. Additionally, Medicaid recipients have a harder time accessing healthcare than non-Medicaid recipients. A randomized trial experiment in Oregon has shown improvements to health outcomes, access to health, and self-reported health. Previous research has shown that the expansion of Medicaid has reduced mortality and increase health utilization.

The first major healthcare reform in the United States has passed though the Affordable Care Act in 2010. It contains several provisions intended to increase health insurance coverage, including the 2014 Medicaid eligibility expansion to all nonelderly adults with family incomes of up to 138% of the Federal Poverty Level (FPL). This provision mandated all states to expand, but a 2012 Supreme Court decision made state Medicaid expansions optional. The Governors of each state were delegated the authority and given the choice to expand their Medicaid program. The supreme court decision allowed for a natural quasi-experiment to determine whether state expansions of Medicaid were associated with healthcare utilization. We hypothesize that Medicaid expansion would increase healthcare utilization among Medicaid populations.

We utilize a difference-in-differences method to compare measures of health care utilization and health outcomes between individuals in expansion states versus nonexpansion states. The assumption underlying this approach is that healthcare trends in expansion states should be different than nonexpansion states after 2014. Since the Medicaid expansion was a large increase in access for Medicaid eligible recipients, health utilization and health outcomes should improve (Finkelstein et al., 2015; Han et al., 2015).

LITERATURE REVIEW OF PUBLIC INSURANCE EXPANSION ON HEALTH

Government health insurance expansion and health has been closely researched to see the relation. Many factors affect health insurance status and health status in determining the impact of the two. Lacking health insurance can increase the risk of mortality (Franks et al., 1993). There is strong evidence that public insurance expansion increases healthcare utilization services which can improve health outcomes and access to health. The Massachusetts healthcare reform, or Romney Care, was a model for the Affordable Care Act. It was enacted in 2006 and signed under then Governor Mitt Romney. More than 7% of Massachusetts residents lacked health insurance before Romney care, and after the expansion, the percent of uninsured dropped to 2% (Long et al., 2012). Furthermore, preventable hospital rates decreased from 101 per 100,000 admissions to 83 per 100,000 (Joynt et al., 2013).

MEDICAID'S EFFECT ON HEALTH OUTCOMES

Several studies have been conducted on health outcomes and insurance. The research focuses on private, public (through Medicare or Medicaid), or no insurance. Sommers et al. (2013) found significant gains in access to Medicaid insurance for young adults. They found coverage gains for adult's ages 19–25. A Michigan study found Medicaid patients were twice as likely to after 1 month postsurgery than private insured patients (Waits et al., 2014).

Similarly, a University of Virginia Study found that Medicaid and uninsured patients were twice as likely to die than private insured patients (LePar et al., 2011).

The results of these studies have to be interpreted in proper context. Medicaid is coverage that people characteristically go on and off of compared to private insured patients. What was controlled in most studies, Medicaid patients were not likely to have coverage for a long time and have underlying complications. However, how well they were treated before cannot be controlled. The Medicaid population has different characteristics than privately insured patients. Medicaid patients have a number of characteristics that put them at a higher risk of mortality. Medicaid enrollees have greater poverty rates and have higher rates of mental and physical health problems, which are likely contributors to higher mortality rates (Bradley et al., 2002; DeMone et al., 2003; Watson, 1995). The facilities and treatment where Medicaid patients received care may have lacked quality of care or lacked resources.

Another interpretation is that Medicaid patients receive a lower quality of care than privately insured patients. It is difficult to make a conclusion whether Medicaid patients receive lower quality of care due to the reasons above. Without a random assignment of individuals into Medicaid, it is difficult to interpret which explanation is appropriate.

There is evidence from several studies that Medicaid patients increase health utilization when insured. Children were found to have an increase in the utilization of Medicaid's medical services. Medicaid insurance improved utilization of medical services (Fisher & Mascarenhas, 2007). Marquis and Long (1996) found that Medicaid beneficiaries use considerably more ambulatory care and inpatient care than they would if they remained uninsured. Lower cost sharing would enable Medicaid patients to utilize healthcare services. One study found that Medicaid adults and children had greater use of prescription drugs than the privately insured. Moreover, Medicaid patients utilize healthcare services at a lower expenditure compared to private insured patients (Ku, 2009). However, although increased access to Medicaid insurance causes higher utilization of healthcare services, Medicaid patients are significantly poorer, in worse health, and more likely to be members of racial and ethnic minority groups (Dor et al., 2008).

They also found a 60% increased likelihood of receiving recommended preventive care, a 25% decrease in the probability of having an unpaid medical bill sent to a collection agency, and a 35% probability of having any out-of-pocket medical expenditures.

Furthermore, Medicaid enrollees reported higher self-reported health and greater use of several preventive care services. This resulted in an increase in the number of prescription drugs received and office visits made in the previous year. There were increases in some preventive care and screening services, including cholesterol screening, and improved perceived access to care, including a usual place of care (Baicker et al., 2013). The study had significant limitations. The results are not generalizable because it took place in Oregon and in the Portland area. Also, because the study was conducted for only 2 years, the sample size of the population may not be powerful to have significance.

DATA

The Center Control for Disease (CDC) statistics is a national database composed of health service statistics. The CDC is a nationwide database that collects data for certain health outcomes. The Behavioral Risk Factor Surveillance System (BRFSS) is a nationwide database, through the CDC, that collects data on health outcomes such as mortality, access to care, self-health reports, and self-health utilization. There are numerous variables, but some utilization measures include: trends covering insurance coverage, regular doctor check-ups, prohibitively high medical costs, blood pressure and cholesterol checks, flu shots, self-reported health, and mortality rates.

We used six questions (dependent variables) from the BRFSS survey to measure health care access, utilization of health care services, and health outcomes. To measure health care access, we used individuals' self-report of health insurance and their responses to whether they needed to see a doctor in the past year but did not because of cost. To measure utilization of health care services, we used individuals' responses about the length of time since they last saw a doctor for a routine check-up, the length of time since they last took their blood pressure medicine, the length of time since they last had their cholesterol checked, and whether they received a flu shot during the past year. Our analysis controlled for variables that would not resemble the Medicaid population. This includes age and income level. All analyses used weighted data that was representative of each state that was provided by the BRFSS.

STUDY DESIGN

This study will use data from 2 years before the expansion (pre-ACA) and two after the expansion. The BRFSS data is a telephone survey compiled by the Centers for Disease Control. There are over 400,000 respondents each year. The BRFSS collects information on healthcare utilization, healthy behaviors, and preventive health. We compiled data from 2 years before the Medicaid expansion (2014) and 2 years after the Medicaid expansion. To ensure consistency in the questions over time, we limited the study to data after 2011. We analyzed data through 2016 to have an equal number of years before and after the Medicaid expansion. The years collected before the expansion are 2012 and 2013. The years collected after the expansion are 2015 and 2016. The more time that passes after the Medicaid expansion, the more other factors are responsible for healthcare utilization and across the states.

We excluded the year 2014 because of the new enrollees signing up for the Medicaid expansion that year. The data set consists of over 400,000 observations per year which represent the responses of nonelderly adults from expansion states versus nonexpansion states.

However, to keep consistency with my hypothesis, an analysis was conducted on the excluded year 2014. The excluded year is expected to be inconsistent with our hypothesis. Medicaid recipients will be signing up that year and the collection of data will not be stable compared to the years after 2014. There will be inconsistencies with the overall results.

STUDY SAMPLE

Fourteen States and the District of Columbia are excluded from this analysis owing to early or late ACA Medicaid expansions or the presence of pre-ACA Medicaid waiver covering childless adults up to 100% of the FPL. Our sample included 17 expansion states (AK, AZ, DE, HI, IL, KY, MD, MA, NY, NV, NM, ND, OH, OR, RI, WV, and VT) and 19 nonexpansion states (AL, FL, GA, ID, KS, ME, MS, MO, NE, NC, OK, SC, SD, TN, TX, UT, VA, WY, and WI). We limit our sample to expansions that occurred on January 1, 2014.

METHODS

We utilize a difference-in-differences approach to measure the impact of Medicaid expansion and nationwide compare the utilization of health care services and health outcomes. The Medicaid expansion fits the quasi-experimental model because there is both a treatment group (expansion states) and a control group (nonexpansion states). With the increase in access to care through the Medicaid expansion, expansion states should see a higher utilization of healthcare services.

A necessary component is the parallel trends assumption in the difference-in-difference from our dependent variables. We confirm that the variables trend similarly between expansion and nonexpansion states before 2014. Furthermore, we used an expansion dummy variable indicator variable for the pre-expansion years and find no significant difference.

One of the groups is exposed to a treatment in the second period but not in the first period. The second group is not exposed to the treatment during either period. In the case where the same units within a group are observed in each time period, the average gain in the second (control) group is subtracted from the average gain in the first (treatment) group.

We calculated a difference-in-difference to get a calculation of Medicaid expansions effect on health outcomes, access, and utilization. Difference in difference calculations were used to find the difference between expansion states and nonexpansion states. The first differences were the change over time in the average of the five measures for the expansion states and nonexpansion states. To calculate the difference, we subtracted the pre-Medicaid expansion period estimate (means for each of the five measures using 2011–2012 data) from the post-Medicaid expansion period (means for each of the five measures using 2015 and 2016 data). The two estimates produce an underlying result for expansion and nonexpansion states. The second difference is the result of the Medicaid expansion states subtracted by the result in nonexpansion states. This second difference is an estimate of the impact of the Medicaid Expansion. Due to the historic nature of a public insurance expansion nationwide, self-reports may have not been counted due to under reporting.

MODELING

The effect of the Medicaid expansion and its effects on health outcomes can be depicted with this difference-in-difference linear regression equation:

$$\mathrm{Yit} = \alpha \mathrm{i} + \lambda \mathrm{t} + \rho \mathrm{Dit} + \mathrm{X'it}\beta + \epsilon \mathrm{it} \text{ (DID Equation)}$$

$$\mathrm{Yist} = \alpha + \gamma \mathrm{EXPs} + \lambda \mathrm{dt} + \delta(\mathrm{EXP} \times \mathrm{dt}) + \varepsilon \mathrm{ist}. \tag{1}$$

Y is the continuous outcome variable for a BRFSS variable (*i*) in time period (*t*). Treatment is a dummy variable in the expansion state (treatment group) or nonexpansion state (control group). Expansion (EXP) is a dummy which is equal to 1 if the observation is from expansion. The coefficient on the difference-indifferences interaction, δ, is the difference estimator that identifies differential time trends in BRFSS variable between expansion states and nonexpansion states. We measured the effect of the expansion using a logistic regression model which contains a dummy variable indicating the effect of the Medicaid expansion in a given year.

RESULTS

Table 1 shows the difference-in-difference estimates of the Medicaid expansions impact on expansion states and nonexpansion States.

TABLE 1 Impact of Medicaid expansion

	HLTHPLN1	CHECKUP	BPMED	FLUSHOT	CHOCHECK	MEDCOST
Expansion states						
11–15 AVG	4.70%	1.70%	n/a	2.50%	n/a	–3%
12–16 AVG	5.10%	2%	–0.30%	1.30%	6.40%	–3%
Nonexpansion states						
11–15 AVG	4.10%	2%	n/a	3.60%	n/a	–2.60%
12–16 AVG	3.70%	2%	–1%	0.30%	5.80%	–2%
Diff (AVG)	1.10%**	–0.2%	0.70%**	0.00%	0.60%**	0.40%*

Note: The data come from the Behavioral Risk Factor Surveillance System. The 2011–2012 average is the average of the variables in the expansion states and nonexpansion states. The 2015–2016 average is the average after the Medicaid expansion. The first difference is the trend in Expansion states and nonexpansion states. The difference-in-difference is the trend in the nonexpansion states subtracted by the trend in expansion states. Appendix A includes the questions and responses from the BRFSS. Appendix A includes questions asked.

*$p < .001$.

**$p < .1.39E-12$.

The difference attributable to the Medicaid expansion is the gain in coverage (5%) minus the gain in coverage in the nonexpansion states (3.9%). Therefore, from estimates, I find the Medicaid expansion caused an added 1.1% of expansion state's population to report having health insurance coverage.

The difference attributable to the Medicaid expansion is the increase in individuals' responses about the length of time since they last saw a doctor for a routine check-up (1.8%) minus the gain in coverage in nonexpansion states (2%). Therefore, from the estimates, I find the Medicaid expansion caused an additional 0.20% decrease in the length of time since they saw a doctor for a routine checkup.

The difference attributable to the Medicaid expansion is the decrease when patients last took their blood pressure medicine (–0.3%) minus the decrease when patients' last took their blood pressure medicine in nonexpansion states (–1%). Therefore, from the estimates, I find the Medicaid expansion caused an additional 0.70% increase when the patients last took their blood pressure medication.

The difference attributable to the Medicaid expansion is the decrease in individuals' responses about cost being a factor if a patient needed to see a doctor (2.7%) minus the decrease in response to cost in nonexpansion states (2.3%). Therefore, from the estimates, I find the Medicaid expansion caused an additional 0.40% decrease in the percentage of individuals in the state who needed to see a doctor within the last 12 months, but did not because of cost.

The difference attributable to the Medicaid expansion is the increase when individuals last had their cholesterol checked (6.4%) minus the increase when individuals last had their cholesterol checked in nonexpansion states (5.8%). Therefore, from the estimates, I find the Medicaid expansion caused an additional 0.60% of expansion state's population to report having their cholesterol checked.

The difference attributable to the Medicaid expansion is the increase in flu shots (1.9%) minus the increase in flu shots in the nonexpansion states (1.9%). Therefore, from the estimates, I find the Medicaid expansion caused no change in percentage of expansion state's population flu shots.

TABLE 2 Analysis of 2011 versus 2014

Analysis of 2011 vs. 2014	MEDCOST	HLTHPLN1
2011		
Expansion states	11.9%	88.9%
Nonexpansion states	13.6%	87.1%
Difference	−1.7%	1.8%
2014		
Expansion states	12.1%	87%
Nonexpansion states	13.8%	89.2%
Difference	−1.7%	−2.2%
DID	0	−0.04
p value	<1E-16	<1E-16

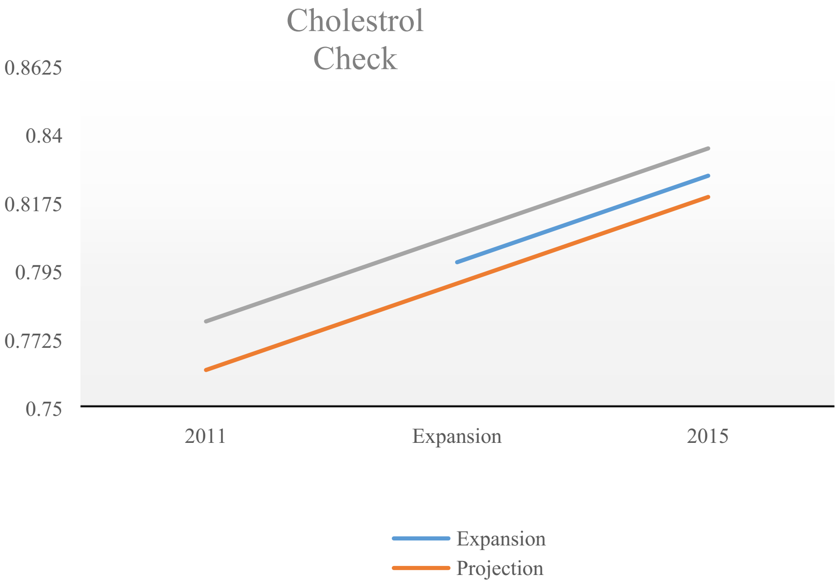

FIGURE 1 DID of cholesterol check

In the years after the Medicaid expansion's enactment, a greater number of expansion individuals increased access to health insurance, blood pressure medication and cholesterol checks ($p = 1.39E\text{-}12$) relative to individuals in nonexpansion states.

Expansion states experienced a decrease in the percentage of individuals in the state who needed to see a doctor in the last 12 months, but did not because of cost. ($p < 0.001$).

The results do suggest, however, that fewer individuals from expansion states received a regular doctor checkup relative to individuals in the control states. There was little, if any, change in the number of individuals in expansion states who had a flu shot within 12 months after the Medicaid expansion.

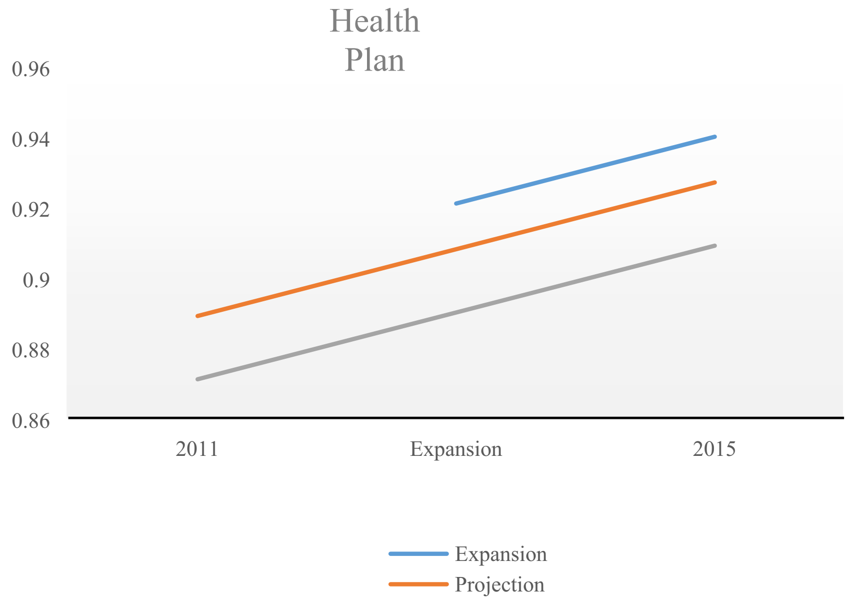

FIGURE 2 DID of health plan

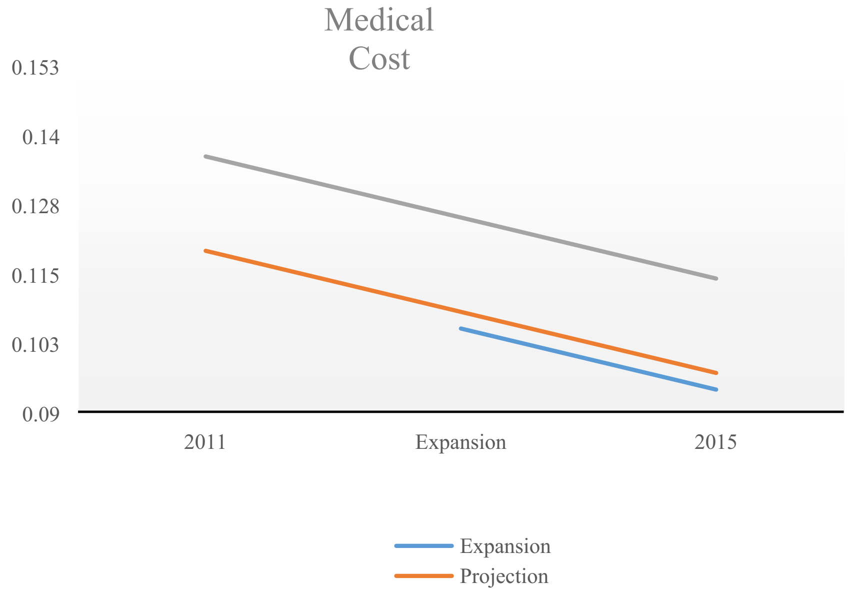

FIGURE 3 DID of medical cost

A separate analysis confirms my hypothesis that the year 2014 shows statistical significance showing no change in individuals' responses about cost being a factor if a patient needed to see a doctor but did not due to cost or a decrease in health coverage in expansion states. The difference attributable to the year 2011 and 2014 is the decrease in costs (−1.7%) minus the decrease in costs in the nonexpansion states (−1.7%). Therefore, from the estimates, I find the years 2011 and 2014 caused no change in percentage of expansion state's population response about cost being a factor if a patient needed to see a doctor but did not due to cost.

The difference attributable to the year 2011 and 2014 is the gain in coverage (1.8%) minus the decrease in coverage (2.2%). Therefore, from estimates, I find the years 2011 and 2015 caused a decrease of 1.1% of expansion state's population to report having health insurance coverage.

These results confirm my hypothesis and adjustment that the year 2014 will not show any significance due to the population signing up for healthcare and will not show any immediate results in the data.

LIMITATION

This study has several limitations. Using the Medicaid expansion as a natural quasi-experiment has disadvantages in mitigating outside influences. Confounding between exogenous variables such as insurance and demographics can hinder the results. I compared expansion states and nonexpansion states. My results may not be generalizable to other states because of demographic, political, and economic factors. The BRFSS data set did not allow us to control for individual-level characteristics other than race, sex, and age, and income levels. My results offer new evidence that the expansion of Medicaid increases health outcomes, healthcare access, and healthcare utilization. Federal and state policymakers should take notice that major changes in Medicaid, either the expansion or reduction in coverage, may have significant ramifications on the health of vulnerable populations. Interestingly, nonexpansion states have exhibited slight increases in healthcare access, health utilization, and health outcomes. This can be attributed to the ACA's mandate that everyone is required to have health insurance or pay a penalty. The health insurance exchange (HIX) is an explanation for the increase in health utilization and healthcare access. In conclusion, this study is supported by the difference-in-difference method that offers evidence that the expansion of Medicaid coverage increases healthcare utilization and access to healthcare compared to nonexpansion states. The BRFSS data set does not have specific data to control for confounding variables. For example, economic theory suggests the law of supply and demand where states may have more of supply of doctors to perform services to the increase of Medicaid patients. The reports may be due to the additional services doctors perform in expansion states compared to nonexpansion states. The BRFSS data analytics has limitations as a telephone survey than a face to face. Telephone survey populations are documented to be different than nontelephone populations (Groves & Kahn, 1979). Telephone surveys are known to have bias such as under reporting physical health diagnosis questions such as body weight. The potential for bias arises in self-reported survey studies and should account for misrepresentation of data.

DISCUSSION

Our study documents that the Medicaid expansion is significantly associated with increased healthcare outcomes, healthcare utilization, and access to healthcare, as compared to nonexpansion states.

These results build upon previous findings that Medicaid coverage is consistent with the preliminary results of the Oregon healthcare expansion, which showed increases in self-reported health (Baicker et al., 2013). The evidence suggests that utilization of preventive care increased in expansion states after the Medicaid expansion as more Medicaid recipients received blood pressure checks and regular primary care checkups relative to the nonexpansion states.

Exogenous variables may need to be explored for further research. Medicaid patients have worse health outcomes than private or uninsured patients. The social determinants of health with the Medicaid population contribute to poorer health outcomes (Bradley et al., 2002; DeMone et al., 2003; Watson, 1995). Moreover, research has shown that access to healthcare contributes relatively little, on average, to an individual's overall health. McGinnis et al. (2002) estimated that social circumstances, behavioral patterns, and genetic predispositions account for about 85% of early deaths.

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

ETHICS STATEMENT

No human participants were involved in this study.

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APPENDIX A: Variables utilized from BRFSS

Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, government plans such as Medicare, or Indian Health Service? (HLTHPLAN1)	1 = Yes 2 = No
Was there a time during the last 12 months when you needed to see a doctor, but could not because of the cost? (MEDCOST)	1 = Yes 0 = No
About how long has it been since you last had your blood cholesterol checked? (CHOLCHK)	1 = Within the past 2 years 2 = Longer than 2 years
Are you currently taking medicine for your high blood pressure? (BPMED)	1 = Yes 2 = No
Was there a time in the past 12 months when you needed to see a doctor but could not because of cost? (FLUSHOT)	1 = Yes 2 = No
About how long has it been since you last visited a doctor for a routine checkup? (CHECKUP)	1 = Within the past 2 years 0 = Longer than 2 years

World Medical and Health Policy

Exploring Factors Associated With Full Implementation of the Affordable Care Act's Medicaid Tobacco Cessation Provisions

Sara B. McMenamin and Sara W. Yoeun

Medicaid enrollees use tobacco at rates more than double that of the general population. To address this disparity, the Affordable Care Act (ACA) contained provisions to increase access to tobacco cessation treatments for Medicaid enrollees. There have been relatively low levels of implementation of these provisions by Medicaid programs. This research aims to evaluate the potential political, economic, and policy factors associated with implementation of each of the four tobacco-cessation-related ACA provisions. In 2017, UC San Diego researchers collected survey data from 51 Medicaid programs on tobacco cessation treatment policies and state-level variables from publicly available sources. Implementation of these provisions was associated with state-level variables such as having a budget shortfall during the recession years, Democratic control of the Governorship or legislature, and higher state cigarette taxes. Further guidance from the Centers for Medicare and Medicaid Services will be necessary to achieve full implementation of these ACA provisions.

KEY WORDS: tobacco cessation, Affordable Care Act, Medicaid

Introduction

Although great strides have been made in reducing cigarette smoking in the United States, tobacco use continues to be one of the largest contributors to adverse health outcomes among low-income populations (Centers for Medicare and Medicaid Services, 2019). Adults on Medicaid have smoking rates more than twice that of the general adult population (Ku et al., 2016). Guidelines developed by the United States Preventive Services Taskforce (USPSTF) recommend health insurance coverage of seven Food and Drug Administration (FDA)-approved drugs and three counseling modalities, including individual, group, and proactive telephone counseling, without cost-sharing to aid in smoking cessation (Fiore et al., 1996, 2000, 2008). Prior to the enactment of the Patient Protection and Affordable Care Act (ACA) in 2010, only seven Medicaid programs covered all of the USPSTF recommended treatments (McMenamin et al., 2010).

In 2010, four relevant provisions were introduced through the ACA to align state Medicaid program smoking-cessation treatment coverage with the USPSTF guidelines. These two mandatory provisions (Sections 4107 and 2502) and two voluntary provisions (Sections 4106 and 2001) are described below.

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- Section 4107 (Effective October 1, 2010) requires coverage for all FDA-approved pharmacotherapy and counseling modalities for pregnant Medicaid beneficiaries without cost-sharing (The Patient Protection and Affordable Care Act, 2010d).
- Section 2502 (Effective January 1, 2014) prohibits the exclusion of FDA-approved smoking-cessation pharmacotherapy from Medicaid formularies (The Patient Protection and Affordable Care Act, 2010b).
- Section 4106 (Effective January 1, 2013) offers a 1 percent increase in the Federal Medical Assistance Percentage (FMAP) to Medicaid programs that cover all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing (The Patient Protection and Affordable Care Act, 2010c).
- Section 2001 (Effective January 1, 2014) requires coverage of all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing or prior authorization requirements for beneficiaries enrolled in Medicaid expansion programs. Although the coverage is mandatory for the population enrolled in Medicaid expansion, the option to expand the Medicaid eligible population was voluntary (Centers for Medicare and Medicaid Services, 2014; The Patient Protection and Affordable Care Act, 2010a).

Previous research has documented that the ACA led to an expansion in Medicaid coverage for smoking cessation treatments in 47 states (McMenamin et al., 2018). In addition, the number of Medicaid programs offering coverage for all of the USPSTF recommended treatments increased from seven in 2009 to 28 in 2017 (McMenamin et al., 2018). Yet, nearly half of Medicaid programs were not in full compliance with the ACA provisions for benefit coverage for smoking cessation treatments. Therefore, this research aims to assess implementation of the ACA provisions and to identify factors associated with the extent to which Medicaid programs had either fully or partially implemented each of the four provisions.

Materials and Methods

Data Sources

We collected data for this analysis in 2017 with 51 state Medicaid programs (including the District of Columbia) via a web-based survey and submitted state benefits documentation (i.e., the UC San Diego Survey of Medicaid Smoking Policies). Survey respondents identified in each state (i.e., state Medicaid and tobacco control representatives) were asked to report their state's Medicaid coverage policies for smoking cessation treatments including coverage for nicotine replacement therapies, including gum, patch, nasal spray, inhaler, lozenge; bupropion; Chantix; individual, group, and telephone counseling. As telephone counseling is available in all states through state quitlines or state tobacco control programs and not typically paid for by Medicaid programs, coverage for telephone counseling was not considered in this study (North American Quitline Consortium, 2017). Additional questions were asked to ascertain implementation of all four ACA smoking cessation-related provisions. All 51 Medicaid programs replied for a 100 percent response rate. Additional details regarding study methodology are reported elsewhere (McMenamin et al., 2018).

Three variables were created to represent the outcomes of interest related to implementation of the ACA. Medicaid programs were categorized as either fully implemented (i.e., covered all required treatments without prohibited limitations such as cost-sharing or prior authorization requirements), partially implemented (i.e., covered some treatments, and/or imposed prohibited limitations such as cost-sharing or prior authorization), or no implementation (i.e., did not apply for FMAP or Medicaid expansion programs).

Previous research has examined the factors that are associated with the implementation of sections of the ACA (Lindley et al., 2014). This research identified political, economic, and policy factors that were important in predicting implementation of components of the ACA. We have adapted this conceptual model to study the factors related to implementation of ACA provisions related to tobacco cessation services.

There were two economic factors hypothesized to be associated with implementation of tobacco-related ACA provisions: state budget data specific to revenue shortfalls (average budget shortfall during 2010–13) and percentage of the state budget related to Medicaid spending (average Medicaid spending as a percentage of GDP 2011–17). State budget data specific to revenue shortfalls were taken from the Center on Budget and Policy Priorities (2012). State Medicaid spending data were taken from the National Association of State Budget Officers (SHADAC, 2019).

In this study, political factors that were hypothesized to be associated with implementation of tobacco-related provisions were the political party of the governor (democrat, republican, independent) and political state control (i.e., democrat if both the legislature and governor were democrat, mixed if they were not concordant, republican if both the legislature and governor were republican). The data were taken from the National Conference of State Legislatures (2017). For this analysis, variables were created to indicate a majority of years (i.e., 4–7 years during 2011–17) with a Democratic Governor (Yes/No) and a majority of years with Democratic control of both the Legislature and the Governorship (Yes/No).

Tobacco-specific policy factors were included to account for state-level tobacco-related policies. The four factors included in this analysis were (i) Medicaid program reporting "coordinating with the state tobacco control program" in 2017, (ii) average tobacco tax from 2011 to 2017, (iii) the percentage of Medicaid population that were current smokers in 2013, and (iv) percentage of total funding spent on tobacco control in 2013 as compared with the level of funding recommended by the Centers for Disease Control and Prevention (CDC). The first item was collected through our survey of state Medicaid programs to assess if they were coordinating—and thus receiving additional support and/or resources—with their state tobacco control program. The data on tobacco taxes were collected from the American Lung Association (2017); the smoking rate was taken from data published in Ku et al. (2016); and the percentage of funding for tobacco control as recommended by the CDC was taken from the CDC's State Tobacco Activities

Tracking and Evaluation (STATE) System (Centers for Disease Control and Prevention CDC, 2020).

Analysis

We conducted simple frequencies to evaluate states' full and partial implementation of the ACA provisions. Additionally, we conducted bivariate analyses using the CROSSTABS and MEANS function in SPSS version 24 to estimate potential associations between political, economic, and legal factors and the implementation of ACA smoking cessation-relevant provisions. Logistic regression models were run on each of the outcomes with the economic, political, and policy factors included. A bivariate correlation matrix was consulted to ensure that variables with high levels of correlation were not included in the logistic regression model together. Odds ratios and 95% confidence intervals were reported and statistical significance up to $p < .10$ was displayed. Finally, a principal components analysis was conducted to confirm that explanatory variables were making independent contributions to the regression models.

Results

There was great variability in the extent to which states have fully implemented these provisions (Table 1). As shown in Table 1, 19 states fully implemented just one provision, 17 fully implemented two provisions, eight fully implemented three provisions, and four fully implemented all provisions. Overall, only four Medicaid programs had fully implemented the two mandatory provisions directly related to coverage for tobacco cessation services (Sections 4107 and 2502), and the two optional provisions related to broader preventive services benefit impacting coverage for smoking cessation treatments (Sections 4106 and 2001).

Section 4107 of the ACA which required comprehensive coverage for smoking cessation treatments for pregnant Medicaid enrollees was the first provision to be enacted in October of 2010. As of June 2017, 28 Medicaid programs (55 percent) had fully implemented this provision (i.e., covered all seven FDA-approved drugs as well as group and individual counseling without cost-sharing), and 23 programs (45 percent) had partially implemented the provision (i.e., coverage for some treatments with or without cost-sharing) (Table 2). All 51 Medicaid programs had at least partially implemented this provision.

The second mandatory provision, Section 2502, prohibited the exclusion of smoking cessation drugs from Medicaid formularies. In 2017, 48 programs (94 percent) covered all seven FDA-approved drugs (i.e., fully implemented); three programs (6 percent) covered some but not all seven drugs (i.e., partially implemented); and zero programs excluded smoking cessation drugs from their formulary (Table 2). Overall, just over half of the Medicaid programs had fully implemented both of the mandatory tobacco-specific provisions (Sections 4107 and 2502). As all but three states (94 percent) had fully implemented Section 2502,

Table 1. Full Implementation of Smoking Cessation-Relevant ACA Provisions, 2017

State	Total Number of Provisions Fully Implemented
Alabama	1
Alaska	1
Arizona	1
Arkansas	2
California	3
Colorado	2
Connecticut	3
Delaware	3
Florida	0
Georgia	1
Hawaii	4
Idaho	1
Illinois	1
Indiana	2
Iowa	2
Kansas	1
Kentucky	2
Louisiana	1
Maine	2
Maryland	1
Massachusetts	2
Michigan	2
Minnesota	2
Mississippi	1
Missouri	2
Montana	3
Nebraska	1
Nevada	1
New Hampshire	3
New Jersey	3
New Mexico	3
New York	2
North Carolina	2
North Dakota	1
Ohio	4
Oklahoma	1
Oregon	4
Pennsylvania	2
Rhode Island	2
South Carolina	2
South Dakota	0
Tennessee	1
Texas	1
Utah	2
Vermont	2
Virginia	0
Washington	1
Washington, D.C.	4
West Virginia	1
Wisconsin	3
Wyoming	1

Total Number of Provisions Implemented	Total Number of States
0 Provisions	3
1 Provision	19

(*Continued*)

Total Number of Provisions Implemented	Total Number of States
2 Provisions	17
3 Provisions	8
4 Provisions	4

Note: ACA, Affordable Care Act.
Source: 2017 UC San Diego State Medicaid Tobacco Dependence Treatment Survey.

bivariate and multivariate analyses were not conducted on this section due to lack of variation.

There were two optional provisions (Sections 4106 and 2001) that related more broadly to incentivizing coverage for all recommended preventive services, including coverage for smoking cessation drugs and counseling. Section 4106 provided a financial incentive (i.e., a one percentage point increase in the FMAP payment) for Medicaid programs to implement coverage for all USPSTF A- and B-level recommended preventive services, including smoking cessation treatments, without cost-sharing. Fifteen Medicaid programs (30 percent) opted to submit a State Plan Amendment (SPA) to implement Section 4106 to be eligible for a one

Table 2. Implementation of Relevant ACA Provisions, 2017

Full Implementation of ACA Provisions	Fully Implemented	Partially Implemented	Not Implemented
Mandatory provisions			
Provision 4107a	28 (55%)	23 (45%)	0 (0%)
Provision 2502b	48 (94%)	3 (6%)	0 (0%)
Implemented both 4107 and 2502 ($n = 51$)	28 (55%)	23 (45%)	0 (0%)
Voluntary provisions			
Provision 4106c	9 (18%)	6 (12%)	36 (70%)
Provision 2001d	8 (16%)	24 (47%)	19 (37%)
Implemented both 4106 and 2001 ($n = 51$)	4 (8%)	10 (20%)	37 (73%)
Full implementation of all 4 provisions	4 (8%)	n/a	47 (92%)

Note: ACA, Affordable Care Act.

[a] Section 4107 (Effective October 1, 2010) requires coverage for all FDA-approved pharmacotherapy and counseling modalities for pregnant Medicaid beneficiaries without cost sharing.

[b] Section 2502 (Effective January 1, 2014) prohibits the exclusion of FDA-approved smoking-cessation pharmacotherapy from Medicaid formularies.

[c] Section 4106 (Effective January 1, 2013) offers a 1 percent increase in the Federal Medical Assistance Percentage (FMAP) to Medicaid programs that cover all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing.

[d] Section 2001 (Effective January 1, 2014) requires coverage of all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing or prior authorization requirements for beneficiaries enrolled in Medicaid expansion programs.

Source: 2017 UC San Diego State Medicaid Tobacco Dependence Treatment Survey and relevant state benefits documentation.

percent FMAP increase (Table 2). As of June 2017, nine Medicaid programs (18 percent) reported full implementation of Section 4106 to earn their one percent FMAP increase. The six remaining Medicaid programs had not yet modified their smoking cessation coverage to be fully compliant with Section 4106, as two reported coverage policies that excluded group counseling; three reported not yet implementing their SPAs and, therefore, were ineligible for the financial incentive; and one still required cost-sharing for some preventive services.

Section 2001 requires Medicaid expansion programs to cover all USPSTF recommended preventive services, including all seven FDA-approved drugs and three counseling modalities for smoking cessation treatment, without cost-sharing or prior authorization requirements. Of the 32 Medicaid programs that opted to participate in the Medicaid Expansion program, eight were identified as fully implementing the tobacco-related coverage aspects of Section 2001 (Table 2). The remaining 24 programs either did not completely cover all recommended smoking cessation treatments; required copayments for these treatments; or required prior authorization for smoking cessation medications.

Table 3 presents the bivariate analysis of the factors that are hypothesized to be associated with implementation of the mandatory provisions (Sections 4107 and 2502), 4106, and 2001. The two mandatory provisions were combined into one variable since provision 2502 was fully implemented in 94 percent of the states and thus lacked sufficient variation across states to be analyzed on its own. Factors positively associated with full implementation of the mandatory coverage provisions included states having a Democratic governor for a majority of 2011-2017 (77 percent) compared with states with a Republican governor for a majority of 2011–17 (38 percent). Similarly, states with both a Democratic governor and Democratic legislature (i.e., concordant political parties) for a majority of 2011-2017 were more likely to fully implement the mandatory provisions (89 percent) compared with states with a Republican/mixed political party government (48 percent). Additionally, states' average tobacco tax from 2011 to 2017 was positively associated with fully implementing the mandatory provisions—where states that fully implemented had an average state cigarette tax of $1.90 compared to $1.14 for the states that only partially or did not implement Sections 4107 and 2502.

As shown in Table 3, the state average budget shortfall during 2010–13—inclusive of peak recession and the three-year period in which the economy started to recover—was associated with implementation of Section 4106. Those who applied for the 1 percent FMAP increase and had compliant coverage for tobacco cessation services had an average budget shortfall of 15.9 percent; those who applied for the 1 percent FMAP but did not have smoking cessation compliant coverage had an average budget shortfall of 22.2 percent. In addition, state Medicaid programs were more likely to fully implement Section 4106 if they had a Democratic governor for a majority of 2011–17 or both a Democratic party and Democratic state legislature in session for a majority of 2011–17. Finally, there were also differences in average state cigarette tax between those who either partially ($2.38) or fully ($2.02) implemented Section 4106 compared to those states who did not implement at all ($1.30).

Table 3. Bivariate Analyses for Implementation of Smoking Cessation-Relevant ACA Provisions by Political, Economic, and Tobacco Policy Factors, 2011–17

	Implemented Mandatory Provisions (Tobacco Cov)			Implemented Section 4106 (FMAP Increase)				Implemented Section 2001 (Medicaid Expansion)			
Implementation status	Full	Partial		Full	Partial	None		Full	Partial	None	
Number of states	28	23		9	6	36		8	24	19	
Economic factors											
Budget shortfall 2010–13 (Avg %)	15.0%	14.0%		15.9%	22.2%	12.9%	*	15.3%	15.4%	13.1%	
Medicaid spending 2011–17 (Avg % of GDP)	25.3%	22.6%		21.9%	24.2%	24.6%		25.0%	23.9%	24.0%	
Political factors											
Political party of state governor (2011–17)											
Majority of years democrat ($n = 17$)	77%	23%	**	27%	23%	50%	*	23%	68%	9%	**
Republican/mixed party ($n = 34$)	38%	62%		10%	3%	86%		10%	31%	59%	
Political party of governor and legislature (2011–17)											
Majority of years democrat ($n = 9$)	89%	11%	*	56%	11%	33%	**	44%	56%	0%	**
Republican/mixed party ($n = 42$)	48%	52%		9%	12%	79%		10%	45%	45%	
Tobacco specific policy factors											
Coordinate with state tobacco control in 2017											
Yes ($n = 41$)	56%	44%		17%	12%	71%		12%	46%	42%	
No ($n = 10$)	50%	50%		20%	10%	70%		30%	50%	20%	

(*Continued*)

	Implemented Mandatory Provisions (Tobacco Cov)			Implemented Section 4106 (FMAP Increase)				Implemented Section 2001 (Medicaid Expansion)			
State cigarette tax (Avg $) YEAR	$1.90	$1.14	**	$2.02	$2.38	$1.30	*	$2.18	$1.83	$0.94	**
Funding for tobacco CDC Rec funding level (Avg %)	22.4%	26.6%		25.7%	14.8%	25.5%		18.5%	28.4%	21.5%	
Smoking rate among Medicaid pop (Avg %)	33.8%	33.7%		32.0%	32.5%	34.4%		33.9%	33.9%	33.5%	

Note: Section 4107 (Effective October 1, 2010) requires coverage for all FDA-approved pharmacotherapy and counseling modalities for pregnant Medicaid beneficiaries without cost sharing (The Patient Protection and Affordable Care Act, 2010d). Section 2502 (Effective January 1, 2014) prohibits the exclusion of FDA-approved smoking-cessation pharmacotherapy from Medicaid formularies (The Patient Protection and Affordable Care Act, 2010b). Section 4106 (Effective January 1, 2013) offers a one percent increase in the Federal Medical Assistance Percentage (FMAP) to Medicaid programs who cover all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing (The Patient Protection and Affordable Care Act, 2010C). Section 2001 (Effective January 1, 2014) requires coverage of all A- and B-level USPSTF preventive services, including smoking cessation treatments, without cost-sharing or prior authorization requirements for beneficiaries enrolled in Medicaid expansion programs. Source: 2017 UC San Diego State Medicaid Tobacco Dependence Treatment Survey (The Patient Protection and Affordable Care Act, 2010a). ACA, Affordable Care Act; Cov, Coverage; FMAP, Federal Medical Assistance Percentage; GDP, gross domestic product.

Source: 2017 UC San Diego State Medicaid Tobacco Dependence Treatment Survey.

*$p \leq .05$.

**$p \leq .01$.

Also shown in Table 3, the results of the bivariate analyses also found that 23 percent of states with a Democratic governor for a majority of 2011–17 fully implemented Section 2001 compared to 10 percent of states with a Republican governor for a majority of 2011–17. In addition, having both a Democratic governor and Democratic legislature in session for a majority of years (2011–17) was associated with higher levels of both full and partial implementation compared to having a Republican/mixed party in session during the same timeframe. In addition, the average state cigarette tax was associated with higher levels of implementation. The rate of smoking among Medicaid enrollees and the percentage of spending on tobacco control recommended by the CDC were not significantly associated with implementation of any of the tobacco-related policies.

Logistic regression models were run to predict the implementation of mandatory provisions (Sections 4107 and 2502) and voluntary provisions (Sections 4106 and 2001) using economic, political, and tobacco-specific policy factors previously described (Table 4). In the logistic regression model predicting full implementation of both mandatory provisions, three factors were significant. First, states with a higher percentage of their state GDP allocated for Medicaid expenses had higher adjusted odds of fully implementing the mandatory sections (odds ratio [OR] = 1.14; $p = .068$). Second, the political party of the state governor (majority years Democrat) was associated with higher adjusted odds (OR = 5.84; $p = .025$) of

Table 4. Multivariate Analyses for Implementation of Smoking Cessation-Relevant ACA Provisions by Political, Economic, and Tobacco Policy Factors, 2011–17 (Odds Ratios and 95% CI)

	Implemented Mandatory Provisions (Tobacco Cov)	Implemented Section 4106 (FMAP Increase)	Implemented Section 2001 (Medicaid Expansion)
Budget shortfall (2010–13 average %)	0.97 (0.89–1.07)	1.11 (0.99–1.24)*	1.02 (0.92–1.13)
Medicaid spending (2011–17 average % GDP)	1.14 (0.99–1.32)*	0.85 (0.71–1.02)*	1.07 (0.92–1.24)
Political party of state governor (2011–17) majority years democrat	5.84 (1.25–27.3)**	5.79 (0.99–33.9)*	12.9 (1.75–95.2)**
Coordinate with tobacco control program	2.59 (0.43–15.6)	2.55 (0.36–18.1)	0.57 (0.06–5.65)
State cigarette tax (2011–17 average $)	2.70 (0.98–7.43)*	1.57 (0.70–3.54)	4.28 (1.23–15.0)**
% Funding for tobacco CDC Rec funding level	1.003 (0.97–1.04)	0.99 (0.95–1.03)	1.03 (0.98–1.07)
Smoking rate among Medicaid Pop (%)	0.99 (0.89–1.10)	0.95 (0.83–1.09)	1.02 (0.90–1.15)

Note: ACA, Affordable Care Act; CI, confidence interval; Cov, Coverage; FMAP, Federal Medical Assistance Percentage; GDP, gross domestic product.

Source: 2017 UC San Diego State Medicaid Tobacco Dependence Treatment Survey.

*$p \leq .10$.

**$p \leq .05$.

fully implementing the mandatory sections of the ACA. And lastly, the average state cigarette tax was positively associated with full implementation of the mandatory sections (OR = 2.70; *p* = .054).

In the logistic regression model predicting implementation (either partial or full) of Section 4106 (applying for one percent FMAP increase for adding comprehensive preventive services coverage) three factors were significant. First, the average state budget shortfall from 2010 to 2013 was associated with higher adjusted odds of applying for FMAP funding (OR = 1.11; *p* = .068). In addition, with a higher percentage of their state GDP allocated for Medicaid expenses, there were lower adjusted odds of applying for FMAP funding (OR = 0.853; *p* = .089). In addition, the political party of the state governor (majority years Democrat) was associated with higher adjusted odds (OR = 5.79; *p* = .052) of fully applying for FMAP funding.

Two factors were significant in full or partial implementation of Section 2001 (i.e., optional expansion of their Medicaid program). Those with states that had a Democratic governor for a majority of years from 2011 to 2017 had higher adjusted odds of opting to expand their state Medicaid program (OR = 12.9; *p* = .012). In addition, the average state cigarette tax was positively associated with a full or partial implementation of Section 2001 of the ACA (OR = 4.28; *p* = .023).

Discussion

We found that 47 Medicaid programs have increased coverage for smoking cessation treatments post-implementation of the ACA by implementing one or more of the four relevant provisions. While this number indicates the promising practice of Medicaid programs' ability to align their coverage with the clinical practice guidelines, full compliance in the implementation of all four ACA provisions has yet to be realized in more than 90 percent of the Medicaid programs. In addition, voluntary provisions offering incentives to expand coverage for preventive services generally are less likely to be implemented than tobacco-specific provisions that are required of all Medicaid programs.

This research found that the mandatory provisions were implemented at higher rates than the voluntary provisions, where 55 percent of Medicaid programs had fully implemented both mandatory provisions compared to 16–18 percent of Medicaid programs implementing the two voluntary provisions. There was a large difference in the rates at which the two mandatory provisions were implemented. Section 2502—which prohibits the exclusion of tobacco dependence treatments from the Medicaid formulary—was fully implemented in nearly all Medicaid programs (94 percent), which was almost double the rate of full implementation for Section 4107, requiring full coverage of tobacco dependence medications and counseling for pregnant women. The Clinical Practice Guideline for Treating Tobacco Use and Dependence concludes that there is insufficient evidence to routinely offer pregnant women medications for tobacco use cessation, which may contribute to Medicaid programs' reluctance to provide full coverage (Fiore et al., 2008). This analysis did not find any consistent differences between the factors that predicted implementation of voluntary versus mandatory provisions, suggesting that the differences in implementation may have more to do with the content of the policies themselves than other external factors. The two voluntary policies addressing all preventive services were broader than the two mandatory policies limited to tobacco cessation benefits, and thus are likely to be more complex to implement.

Based on our assessment of potential associations between ACA implementation and various factors, potential facilitators might include (i) democratic political party affiliation of the state Governor; and (ii) higher taxes on cigarettes and tobacco products (American Lung Association, 2017). Implementation of the ACA has been political from the start. Opportunities may arise in the future to fully implement these provisions for states with a Republican Governor majority from 2011 to 2017 who have since elected Democratic Governors. In addition, increasing tobacco taxes may be one mechanism to offset costs for Medicaid programs that are concerned about the financial viability of adding more comprehensive coverage for smoking cessation treatments, but only if some of the revenue from such taxes are earmarked for redistribution to the Medicaid program.

Potential barriers to fully implementing the ACA provisions might include a Medicaid program's uncertainty regarding which smoking cessation treatments to cover. For example, a Medicaid program may assume they are in full compliance if they cover some but not all smoking cessation drugs or if they cover individual counseling as part of an office visit but do not cover group counseling. To assist Medicaid programs in this regard, the Centers for Medicare and Medicaid Services (CMS) has issued guidance regarding how to implement Sections 4106, 4107, and 2502, but additional, continued guidance may be needed (Centers for Medicare and Medicaid Services, 2011, 2013a, 2013b). Additionally, confusion may arise in states where the tobacco control program or state health department provides services in the community that are required to be covered by Medicaid programs under the ACA. In these instances, Medicaid should establish a contract to pay for services provided in the community to ensure that the availability of these resources for their members is not subject to continued funding of outside organizations.

Further guidance from CMS or stronger incentives may be warranted in an effort to achieve full implementation of tobacco-related ACA provisions. While independent evaluations, such as this one, can shed some light as to the degree to which Medicaid programs are implementing these provisions, an audit commissioned by CMS would be required to officially enforce and potentially penalize Medicaid programs that are not in compliance with the current law. To increase knowledge and awareness among Medicaid programs and the managed care plans they contract with to provide care to members, state regulators can issue additional guidance to improve implementation. For example, the California Department of Health Care Services (DHCS) issued an All Plan Letter to the 25 managed care organizations they contract with to provide care to their Medicaid enrollees detailing the requirements for a comprehensive tobacco cessation benefit (California Department of Health Care Services [DHCS], 2016). This letter detailed not only specific requirements from the ACA and additional state law but also provided guidance as to how these requirements could be implemented.

Limitations

This research is subject to a few limitations. First, although every effort was made to procure documentation to substantiate the survey responses, many of the items on the survey were not part of publicly available documents such as provider manuals, policies and procedures documents, or state Medicaid coverage documents. Therefore, it was not possible to confirm each survey response with Medicaid program documentation. In addition, the interpretation of Sections 4107, 4106, and 2001 used in this analysis was based on additional guidance issued from CMS and is stricter than what is specified in the text of the ACA (Centers for Medicare and Medicaid Services, 2014). If compliance is defined strictly in terms of the language in the ACA, without reference to the guidance from CMS, then these results would under-represent the extent to which Medicaid programs have fully implemented the ACA provisions.

Conclusions and Policy Implications

The four relevant ACA provisions were successful in improving and expanding state Medicaid coverage of effective evidence-based smoking cessation treatments. From 2009 through June 2017, 47 Medicaid programs (92 percent) added or expanded coverage in their state based on the ACA provisions. However, more than 90 percent of Medicaid programs have not fully implemented the ACA provisions as only four Medicaid programs fully implemented all four provisions as of 2017. Implementation of these provisions was associated with state-level variables such as having a budget shortfall during the recession years, Democratic control of the Governorship or legislature, and higher state cigarette taxes. CMS may need to have closer oversight to ensure full implementation of all provisions.

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Notes

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Identifying factors associated with the issuance of coronavirus-related stay-at-home orders in the Middle East and North Africa Region

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Abstract

The COVID-19 pandemic has not spared the Middle East and North Africa (MENA) Region. MENA is one of the most politically, socially, and economically heterogeneous regions in the world, a characteristic reflected in its governments' responses to COVID-19. About two-thirds of these governments issued coronavirus-related stay-at-home orders (SAHOs), one of the most effective tools public health officials have for slowing the spread of infectious diseases. While SAHOs are very effective in terms of countering infectious diseases, they are extremely disruptive in nonhealth domains. The objective of this study is to identify reliable factors related to health care policy making that shaped the decisions of MENA governments to issue a SAHO or not in response to COVID-19. The results identify specific political, social, and medical factors that played important roles and provide a look at early government responses to a global health crisis in a heterogeneous region of the world.

Key Points

- About two-thirds of MENA governments issued stay-at-home orders (SAHOs) in response to the early stages of the COVID-19 pandemic.
- While SAHOs are very effective in terms of countering infectious diseases, they are extremely disruptive in non-health domains.
- Among broad factors that typically affect public health policy making, the results suggest medical and political considerations as well as policy diffusion reliably influenced the issuance of SAHOs in MENA.

- This research gives policy makers and researchers a look at early government responses to a global health crisis in a heterogeneous region of the world.

KEYWORDS

coronavirus, COVID-19, lockdowns, MENA, pandemic, policy diffusion, public health, stay-at-home orders

INTRODUCTION

The COVID-19 pandemic has created turmoil around the world. Widespread infection and deaths have led governments to take a number of steps to contain the disease including running public awareness campaigns, limiting public gatherings and domestic travel, imposing curfews, changing prison policies, closing schools and borders, and issuing lockdowns and stay-at-home orders (SAHOs; ACAPS, 2020). The most restrictive health policies can dramatically limit the spread the disease (e.g., Kraemer et al., 2020), but in nonhealth domains the consequences have been severe (e.g., Coetzee & Kagee, 2020). For instance, UNESCO (2020) reports that nationwide school closures have affected more than 60% of the world's student population with localized closures affecting millions of additional students, and, according to some, these closures being among the most disruptive consequences of this pandemic (Hoffman & Miller, 2020). Further, locking down businesses has led to severe economic consequences across a wide range of countries (UNIDO, 2020; World Bank, 2020b). The contraction of economic activity has been substantial, and millions of workers around the world have been furloughed (Jones et al., 2020), including more than 40 million workers in Europe's six biggest economies (O'Brien & Schneeweiss, 2020).

The Middle East and North Africa (MENA) Region has suffered from the consequences of the disease with the rest of the world. Seven months into the pandemic, the United Nations (UN) Office for the Coordination of Humanitarian Affairs (OCHA) reported that the region had suffered almost 1 million confirmed cases and more than 17,000 deaths (OCHA, 2020). Shortly before that, the OECD reported that the pandemic is imposing a “dramatic economic cost” (OECD, 2020, p. 1) and “massive economic turmoil” (OECD, 2020, p. 6) in the region due to simultaneous shocks from large drops in oil prices, economic consumption, and trade.

MENA includes a population of about 550 million people who embody highly heterogeneous governmental, socioeconomic, cultural, linguistic, and religious characteristics. Strategically located between East and West, the MENA region garnered historic interest due to trading routes, but now is better known for having a large share of the world's petroleum reserves. A history of colonialism influenced a statist approach to governing, with a significant emphasis on domestic and national security. Government types include monarchies, theocracies, single-party authoritarian states, consociationalism, and parliamentary democracies. Economies range from some of the world's wealthiest to some of its poorest. Religious cleavages also influence domestic and international policy. The current war in Yemen serves as an example, with Shia Houthi rebels supported by Iran and Sunni former government officials supported by Saudi Arabia as both countries vie for regional hegemony. The MENA Region is complex and worth study under “normal” circumstances. During the COVID-19 pandemic, its varied and complex nature offers researchers and policy makers an important opportunity to evaluate public health decision making within the context of a worldwide health crisis. As Okma and Marmor (2013, p. 490) note, “relationships that hold over many very different national experiences are likely to be few in number but powerful and thus important."

As such, this study is designed to identify factors related to health care policy making that shaped the decisions of governments in the MENA Region to disrupt daily life in their countries by issuing a SAHO or not in response to COVID-19. With this objective in mind, the next section of this study presents previous research that provides potential explanations and expectations about MENA government responses and nine associated hypotheses. In particular, this review focuses on political, social, economic, and scientific/medical factors often present in health care policy making. The following section details the method of analysis used, event history analysis (EHA), and the data collected, which come from a wide variety of sources including the World Bank, UN, World Health Organization, and Oxford University. The results section presents several analyses and robustness checks of the findings showing that decisions by MENA governments regarding SAHOs in response to COVID-19 were reliably influenced by two political issues, the policies of other governments, and the extent of the threat of the disease to citizens. Lastly, the discussion summarizes the results, addresses the study's limitations, and places the findings in a larger context about government decision making during major public health crises.

LITERATURE AND HYPOTHESES

Public policy scholars have identified two broad categories of factors that influence the adoption of policies (e.g., Berry & Berry, 2018; Mooney & Lee, 1995). Internal factors include the characteristics of a country that make a policy more or less appropriate for that country and attractive to its policymakers. This factor includes political, social, and economic characteristics, and, specifically regarding public health policy, medical characteristics (Brownson et al., 2009). External factors include policy adoption in other countries that may influence a country's policymakers, such as geographically proximate neighbors or social learning from similar governments (e.g., Berry & Berry, 2018; Mooney & Lee, 1995; Shipan & Volden, 2012).

Starting with political factors, Blank et al. (2018, p. 6) note that health policy is, "at its base…a political matter," and Spasoff (1999) extends that by arguing that political actors play the principal role in public health decisions. The government processes that shape public health policy are difficult and can occur both formally and informally due to the profound impact, cost, and complexity (e.g., issues regarding provision, financing, and regulation) involved. Irrespective of the policy under consideration, issues regarding the concentration of power (Blank et al., 2018) are important. Making policy becomes easier as fewer actors play a role. In autocratic governments, policy making is centrally concentrated, while in democratic governments it is widely dispersed both within governmental institutions and with voters. Blank et al. (2018, p. 99) argue that one of the primary tenets of democracy is to maximize the choices of patients. This suggests, on one hand, that autocratic governments face fewer constraints on their decisions to issue SAHOs, although it is not clear if they are more or less likely to lock down their societies for public health reasons. On the other hand, democratic societies face more constraints on policy making, and they philosophically tend to prefer to maximize citizen choice. Therefore, limiting citizens' choices by issuing a SAHO may be harder to enact and contrary to their approach to personal freedoms. Overall, this suggests:

H1a: *The probability that a government will issue a SAHO will decrease when it is a democratic versus autocratic government.*

Another political factor related to concentration of power is a government's administrative ability to make and implement policy, regardless of the type of government. A government that cannot function or implement adopted policy has, in practical terms, not made policy. In the case of issuing a coronavirus-related SAHO, government authorities may recognize that they cannot implement or enforce such an order and, in lieu of angering some citizens by restricting their activities, may forgo that intervention. On the other hand, more efficacious governments may be more inclined to issue a SAHO given their abilities to implement them. As such:

H1b: *The probability a government will issue a SAHO will increase when it has greater administrative capacity.*

Social factors also play an important role in health policy. While this policy domain is complex, several clear social dimensions are pertinent: social arrangements, historic legacies, and policies of similar countries. The first social factor captures differing population vulnerability. The populations of some countries may be more vulnerable to an infectious disease than other countries. For instance, living arrangements can be important. Urban populations can be especially vulnerable to pandemics (Kawashima et al., 2016), as a virus is more likely to spread when large concentrations of people live and work in close physical proximity to each other. As a result, governments with more vulnerable populations may be more likely to take aggressive steps to intervene against the disease.

H2a: *The probability a government will issue a SAHO will increase when residents are more vulnerable to the disease.*

Another social factor is countries' historic legacies, which may capture long-term effects on how their health care systems were created and how their health-related cultural and philosophical expectations evolved (Blank et al., 2018). The British and French together colonized more than half of the MENA countries, while several others were never colonized at all. Further, many of the countries did not gain their independence from their colonizers until the 20th Century (Wolfe, 2013). Research suggests British and French colonial legacies are reflected in the current political order in Africa due to more direct French administration of their colonies, which promoted more centralized rule (Müller-Crepon, 2020). As a result, countries with French colonial legacies may be more likely to issue a SAHO. As such:

H2b: *The probability a government will issue a SAHO will increase when the country was a French versus of British colony.*

The final social dimension is the only external factor addressed in this study. A country's policies may be affected by the policy choices of other countries, a process known as policy diffusion (e.g., Berry & Berry, 2018). A policy may diffuse from one country to the next, including health care policy (Linos, 2013), in a process that is often considered forms of competition, coercion, or learning (e.g., Dobbin et al., 2007; Mooney & Lee, 1995). First, policies may diffuse to geographically proximate or neighboring countries (Berry & Berry, 2018; Chamberlain & Haider-Markel, 2005). This may particularly be the case due to concerns about the physical spread of a disease across country borders as demonstrated, for instance, by the diffusion of impaired driving laws from neighboring states in the United States (Macinko & Silver, 2015). Although diffusion has classically been assessed in terms of geographically proximate neighbors, other factors such as political, economic, and demographic similarities may be the actual influence (Shipan & Volden, 2012) and may be reflected in temporal patterns. For example, Mooney and Lee (1995) find that countries learn from the policy successes and failures of similar countries leading to common patterns of policy adoption over time. They describe one frequent, S-shaped curve or pattern that involves one or two regional leaders implementing a new policy while other countries observe the outcomes. Learning from the leaders and adjusting as appropriate for national conditions, several observing countries adopt the policy and it picks up momentum. As momentum picks up, nonadopting countries feel pressure to adopt and a small number do adopt. Finally, a limited number of other governments resist adoption. These two bodies of literature suggest:

H2c: *The probability a government will issue a SAHO will increase when geographically proximate governments have issued a SAHO.*

H2d: *The probability a government will issue a SAHO will vary over time in response to similar governments issuing a SAHO.*

Economic factors also play a role in health care policy making. Many studies have identified wealth, in the form of GDP per capita, as one of the most important predictors of health care expenditures (e.g., Ke et al., 2011). Simply put, countries with greater wealth have more disposable income to spend on health care. On a broader scale, citizen satisfaction with government plays a large role in government sustainability, even in autocracies, and research suggests that economic prosperity plays a meaningful role in citizen satisfaction with democratic (e.g., Jung & Oh, 2019) and authoritarian (e.g., Klymenko & Gherghina, 2012) government. SAHOs, which affect employment and consumption patterns, have the potential to substantially disrupt economic systems and, therefore, wealth and economic prosperity. Governments with stronger economies may be more likely to estimate that they can afford to disrupt their economies than those with weaker economies. As such:

H3: *The probability a government will issue a SAHO will increase as the strength of its economy increases.*

The previous literature outlines expectations regarding political, social, and economic factors that may influence governments' decisions to issue SAHOs. Researchers have argued that scientific/medical factors also influence public health policy (e.g., Brownson et al., 2009). One scientific/medical factor is type of health care system, which Blank et al. (2018) broadly categorize as health care provision based on a national health service, social insurance, or private insurance. This generally indicates systems' macro-institutional characteristics, which range from government monopoly to free market. Specifically, on one extreme are national health services, which are characterized by universal health care coverage financed by taxes on the general public and which imply health care is viewed more as a public good. On the other extreme is private insurance, which is characterized by individual responsibility for health care acquisition financed by personal or employer contributions and which implies health care is viewed more as a private good. In many countries this would be considered a social factor related to societal values and more specifically to important citizen expectations (Blank et al., 2018) related to collectivism versus individualism (e.g., Triandis, 1988). But in the heavily nondemocratic region of MENA where 12 of the 21 governments are categorized as authoritarian (Marshall & Elzinga-Marshall, 2017), this is more reasonably classified as a medical factor because it reflects the preferences of the high-level leaders and not specifically the people. Otherwise, a government with a monopoly on health care services may be more likely to issue a SAHO as their responsibility to their citizens, while leaders with free market systems may be less likely to treat this as a government responsibility. As such:

H4a: *The probability a government will issue a SAHO will be greater in countries in which health care is viewed more as a public than private responsibility.*

Another scientific/medical factor that may affect leaders' decisions regarding SAHOs is the threat or prevalence of the disease. When a disease spreads too quickly, a health care system may have insufficient capacity in the form of staff, equipment, or other medical resources to care for patients. In epidemiology, taking steps to slow disease transmission to reduce the likelihood that a health care system will become overwhelmed with patients is known as "flattening the curve" (Centers for Disease Control, 2007). SAHOs force social distancing and slow transmission, therefore, helping to flatten the curve. Leaders in countries with a greater presence of the disease may be more concerned about their country's health care system becoming overwhelmed and, therefore, be more aggressive in issuing a SAHO. This suggests:

H4b: *The likelihood that a government will issue a SAHO will increase as the prevalence of the disease increases.*

DATA AND METHODS

There is no definitive list of MENA countries,[1] so this study takes a geographic focus by including the 19 countries and one territory (Palestine) that constitute the World Bank MENA region plus Israel, which results in a total of 21 governments. The data include 61 days of observations starting on January 31 and ending March 31, 2020. January 31 is the day following the World Health Organization's declaration of a "public health emergency of international concern" related to COVID-19 (World Health Organization, 2020), and March 31 follows shortly after the last MENA government issued a SAHO during the initial wave of the disease. While many dates could have been used to start and end data collection, these are the dates of fairly unambiguous events that offer reasonable justifications.

We construct the dependent variable of the issuance of a SAHO (coded 1) or not (coded 0) from data provided by the Oxford COVID-19 Government Response Tracker (Hale et al., 2020). This study employs EHA to assess the effects of political, social, economic, and scientific/medical factors on the government issuance of SAHOs in response to COVID-19 in MENA. EHA is a statistical technique commonly used in policy adoption research to analyze time-series data to investigate rare or one-time events and factors that affect them (Berry & Berry, 1992). As with survival analysis, in EHA a subject drops out of the analysis once it is no longer at "risk" of adopting the policy (once the government has issued a SAHO). For example, Jordan issued a SAHO on March 18. It was coded 0 for the 45 observations from January 31 to March 17, then 1 on the one observation on March 18, the day on which the order was issued, and subsequently omitted from the data from March 19 to March 31. As a result of this coding, Iraq, the first country in which a SAHO went into effect (March 13), contributes 43 observations to the data set and Egypt, the last country in which a SAHO went into effect (March 25), contributes 55 observations. The six governments that did not issue a SAHO contribute 61 observations each. The data set includes 1134 country-day observations when capturing all 21 governments. See Appendix A for details on all variables.

The following independent variables are used in the theoretically strongest model. We collected the data from sources such as the World Bank, UN, and World Health

Organization. Two measures are used to capture the political factor: regime type (H1a) and government effectiveness (H1b). Regime type is indicated by Polity scores, a widely used measure of countries' levels of autocracy versus democracy as estimated by The Center for Systemic Peace (Marshall & Gurr, 2020). This continuous measure ranges from a score of −10 (strong autocracy) to 10 (strong democracy). The hypothesis indicates the relationship will be negative. Government effectiveness is a measure from the World Bank indicating the quality and credibility of each country's policy processes and public services as rated in 2018. This continuous measure ranges from −2.5 (low effectiveness) to 2.5 (high effectiveness). The hypothesis indicates the relationship will be positive.

The social factors include percent urban population, colonial legacy, and geographic and temporal diffusion. The first reflects population vulnerability based on living arrangements (H2a). Urban populations can be especially vulnerable to pandemics (Kawashima et al., 2016) due to residents' close living conditions and large numbers of people. Its effect is captured in the percentage of a country's population that lives in urbanized areas as reported by the UN. The hypothesis indicates the relationship will be positive.

The second social factor indicates historic ties between countries (H2b), which may suggest similarities in healthcare systems that were created in countries with common colonizers and how they relate to cultural and philosophical expectations regarding health and healthcare. This measure captures colonial legacy and categorizes the countries as colonized by Britain (coded 0), France (coded 1), or not colonized by Britain or France (coded 2). This last category includes the six remaining MENA countries that were never colonized by Britain or France and the one country, Libya, that was colonized by Italy. This variable is entered into the regression models as two indicator variables where the former British colonies serve as the comparison group. The hypothesis indicates the relationship regarding formerly French colonies will be positive.

The final social factor captures geographic and temporal policy diffusion from other countries. Policies may diffuse geographically (H2c; Berry & Berry, 2018; Chamberlain & Haider-Markel, 2005), which is captured here as the proportion of a country's bordering countries with a SAHO in effect by country-day. The hypothesis indicates the relationship will be positive. They may also diffuse temporally (H2d) following an S-shaped curve in which one or two regional leaders implement a new policy after which several other countries quickly adopt with a remaining few laggards that resist adoption over a longer period of time. In technical terms, this process represents a policy's hazard rate; that is, the probability a government will adopt a policy given that it has not adopted it yet (Mooney & Lee, 1995). Table 1 presents data pertinent to the hazard rate in the form of a life table. It shows the S-curve pattern of regional leaders issuing SAHOs followed by an acceleration of SAHOs going into March 20 with the peak on March 23 then the deceleration. The temporal diffusion measure is calculated by taking the square root of the number of days between a given day and the day with the highest hazard rate, which for this study is March 23. The hypothesis indicates the relationship will be negative as the S-curve learning pattern suggests the probability of a SAHO rises toward the day of peak adoption then falls after that.

Following substantial evidence of the effect of wealth on government health care spending and, in particular, GDP per capita (e.g., Ke et al., 2011), the economic factor (H3) is captured by GDP per capita in 2017 from the *UN Statistical Yearbook*. A higher GDP per capita indicates a stronger economy. The hypothesis indicates the relationship will be positive.

Finally, the scientific/medical factor is captured by two measures: type of health care system (H4a) and extent of coronavirus threat (H4b). Type of health care system reflects a country's macro-institutional health care arrangements ranging from government monopoly to free market. One fundamental measure of this is government health care spending as a proportion of total health care spending (Blank et al., 2018), which is used to assess H4a.

TABLE 1 Life table and temporal diffusion

Day	SAHOs implemented	Risk set	Hazard rate
12-March	0	21	0.00
13-March	1	21	0.05
18-March	2	20	0.10
20-March	3	18	0.17
22-March	3	15	0.20
23-March	5	12	0.42
25-March	1	7	0.14

Note: Day indicates day and month a SAHO took effect. SAHOs implemented indicates the number of SAHOs taking effect that day and month. Risk set indicates the number of governments that have not yet implemented a SAHO. Hazard rate is the proportion of countries that implemented a SAHO that could have implemented a SAHO.

In countries in which the government contributes a very large proportion the system is closer to a government monopoly, while in countries where the government contribution is very small the system is closer to a free market system. A greater contribution indicates a greater government responsibility for health care. The hypothesis indicates the relationship will be positive.

The next measure captures that extent to which COVID-19 is threatening the country (H4b). It indicates the number of cases in the country per 100,000 residents. A higher number of cases per capita would signal greater threat. The hypothesis indicates the relationship will be positive.

RESULTS

This section presents an overview of the data followed by fundamental relationships based on bivariate analyses then relationships based on multivariate analyses that account for the full set of predictors. Table 2 presents descriptions of the variables used in the analyses. It shows that 15 of the 21 MENA governments issued a SAHO at some point during the period under consideration, with Iraq issuing the first order on March 13 and Egypt issuing the last on March 25. Politically, based on Polity scores, 12 of the governments are authoritarian, seven democratic, and two are failed states. Freedom House categorizes 14 of the countries as “not free,” four as “partially free,” and three as “free.” Government effectiveness ranges from a low of −2.5 to a high of 2.5 with a mean score in MENA of a bit less than zero.

There are many other indications of the heterogeneity of this region. Socially, in Qatar and Kuwait nearly everyone lives in an urban setting, while in Egypt and Yemen only about four in 10 do. It is also worth noting that the largest country (Egypt, 98.4 million) is more than 200 times the size of the smallest (Malta, 0.5 million). Britain has the largest colonial legacy in the region (eight), but France follows closely behind (six). Economically, MENA's largest GDP per capita (Qatar) is 76 times its smallest (Syria). The World Bank classifies the MENA region as “high income” (World Bank, 2020a), which may be at least partly attributable to the fact that MENA countries account for seven of the 13 members of the Organization of the Petroleum Exporting Countries (OPEC). It categorizes seven countries as “high income” and two as “low income” with the remaining not quite evenly split between “low-” and “upper-middle” income (not reported in the table). UN data indicate unemployment ranges widely from around 1% (Qatar) to more than 25% (Palestine). Finally, medically and in terms of

TABLE 2 Variable descriptions

		Political				Social			Economic		Medical/scientific	
Country	SAHO date	Polity/ (regime)	FH status	Govt Eff	Fragility	Urban (%)	Pop Den	Colonial legacy	GDPpc	Inflation	Govt Hlth spend (%)	Service coverage
Algeria	23-March	2 (D)	*NF*	–0.44	*11*	73.2	*17.7*	France	4055	*2.0*	66.0	*78*
Bahrain	Never	–10 (A)	*NF*	0.18	*9*	89.4	*2107.3*	Never	23,668	*1.0*	58.0	*77*
Djibouti	23-March	3 (D)	*NF*	–0.90	*12*	77.9	*41.4*	France	1928	*3.3*	47.0	*47*
Egypt	25-March	–4 (A)	*NF*	–0.58	*10*	42.7	*98.9*	Britain	2000	*13.9*	33.0	*68*
Iran	Never	–7 (A)	*NF*	–0.43	*9*	75.4	*50.2*	Never	5680	*41.1*	51.2	*72*
Iraq	13-March	6 (D)	*NF*	–1.32	*18*	70.7	*88.5*	Britain	4756	*–0.2*	41.9	*61*
Israel	20-March	6 (D)	*F*	1.21	*7*	92.5	*410.5*	Britain	42,452	*0.8*	63.6	*82*
Jordan	18-March	–3 (A)	*PF*	0.11	*6*	91.2	*112.1*	Britain	4196	*0.3*	44.8	*76*
Kuwait	22-March	–7 (A)	*PF*	–0.09	*4*	100.0	*232.2*	Never	28,897	*1.1*	87.4	*76*
Lebanon	18-March	6 (D)	*PF*	–0.64	*5*	88.8	*669.5*	France	8778	*2.9*	50.0	*73*
Libya	22-March	0 (F)	*NF*	–1.85	*14*	80.4	*3.8*	Italy	3942	*4.6*	63.3	*64*
Malta	23-March	5[a] (D)	*F*	0.97	*7*[a]	94.7	*1514.5*	Britain	29,137	*1.5*	63.1	*82*
Morocco	20-March	–4 (A)	*PF*	–0.21	*7*	63.0	*80.7*	France	3070	*0.0*	42.9	*70*
Oman	Never	–8 (A)	*NF*	0.19	*5*	85.4	*15.6*	Britain	15,267	*0.1*	87.7	*69*
Palestine	22-March	–7[a] (A)	*NF*	–0.76	*4*[a]	76.4	*759.0*	Britain	2946	*1.6*	43.6	*59*[a]
Qatar	Never	–10 (A)	*NF*	0.63	*3*	99.2	*239.6*	Never	63,506	*–0.6*	80.7	*68*
Saudi Arabia	23-March	–10 (A)	*NF*	0.32	*8*	84.1	*15.7*	Never	20,761	*–1.2*	64.1	*74*
Syria	Never	–9 (A)	*NF*	–1.67	*14*	54.8	*92.1*	France	831	*14.4*	45.3	*60*

(Continues)

TABLE 2 (Continued)

Country	SAHO date	Political Polity/ (regime)				Social Urban (%)			Economic GDPpc		Medical/scientific Govt Hlth spend (%)	
			FH status	Govt Eff	Fragility		Pop Den	Colonial legacy		Inflation		Service coverage
Tunisia	20-March	7 (D)	*F*	−0.11	*4*	69.3	*74.4*	France	3475	*6.7*	57.1	*70*
UAE	23-March	−8 (A)	*NF*	1.43	*5*	86.8	*135.6*	Never	40,699	*−1.9*	72.0	*76*
Yemen	Never	0 (F)	*NF*	−2.24	*21*	37.3	*54.0*	Britain	990	*10.0*	10.2	*42*
Mean [mode]	[Never]	−2.5 [A]	*[NF]*	−0.30	*8.7*	77.8	*320.2*	[Britain]	14,811	*4.8*	55.9	*69*
SD		6.2		0.97	*4.8*	17.1	*528.8*		17,341	*9.5*	18.3	*10*

Note: Columns in italics indicate alternative measures. Polity: positive scores indicate a Democratic (D) government, negative scores an Authoritarian (A) government, and 0 a failed state (F).

Abbreviations: F, free; FH, Freedom House; NF, not free; PF, partially free.

[a] Imputed value.

health care systems, eight MENA governments spend less than half the total spent on health care and three governments spend more than 80%. In other data reported by WHO the most fully resourced country (Malta) has 17 times the number of physicians and more than six times the number of hospital beds per capita than the least resourced (Djibouti and Yemen, respectively).

Bivariate results

Appendix B reports bivariate correlations between the dependent variable and each independent variable as estimated using bivariate regression models. All regression results are based on probit models because the dependent variable is dichotomous. Diagnostic tests suggest the presence of heteroskedasticity, so the regression models use robust standard errors. All p values are based on two-tailed tests. The bivariate results demonstrate the complexity of the effects. Most of the relationships are statistically insignificant, although the multivariate results indicate a number of important relationships when confounding effects are controlled for. The two strongest bivariate effects are the external effects related to policy diffusion by social learning from other governments. In particular, the bivariate results suggest a government is more likely to issue a SAHO if bordering states have already issued one. Notably, though, the strongest single predictor by far is social learning through temporal diffusion. Its pseudo R^2 is significantly larger than that of the other independent variables, and its pseudo log likelihood and BIC are significantly smaller than that of the other independent variables.

Multivariate results

The multivariate results clarify the associations between the dependent variable and each independent variable by accounting for the effects of the other specified independent variables. Table 3 reports the relationships in terms of probit coefficients for each independent variable, which can be translated into marginal effects that indicate the probability that a government will issue a COVID-19-related SAHO on any given day. The marginal effects or estimated changes in that probability on any given day are reported in square brackets. Model 1 is the theoretically best model. The remaining models provide robustness checks in the form of alternative specifications for the relationships identified in Model 1, which will be reported in the next section. All of the multivariate models include at least one measure of each factor (i.e., political, social, economic, and scientific/medical).

Model 1 includes 1110 observations, as represented by country-days. Its overall model fit is statistically significant ($X^2 = 35.43$, $p < 0.05$), and it produces a McFadden's pseudo R^2 of 0.59 and BIC of 142.17. The results suggest that political factors play a meaningful role in the issuance of SAHOs. They show that as governments become more democratic, as indicated by Polity score, they become more likely to issue a SAHO. Although the substantive effect is small (i.e., two-tenths of 1% per day for each one-point increase in Polity score), it is statistically significant. This contradicts H1a, which suggests autocratic governments should be more likely to issue a SAHO than democratic governments. One interpretation of this result may be that democratic governments, which are subject to the preferences of their voters, may feel their voters want an aggressive public health response to the pandemic, while autocratic governments may feel they are free to protect their economies. The results provide limited support for H1b. That is, as governmental processes and services are higher in quality and credibility, MENA governments are more likely to issue a SAHO, but the effect is only marginally statistically significant (i.e., $p < 0.10$). Overall,

TABLE 3 Multivariate results

Factor and variable	Hyp/ Sign	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7	Model 8	Model 9
Political										
Government type	H1a/–	**0.153*** **(0.060)** **[0.002*****]**		0.161* (0.062) [0.003*]	0.146* (0.047) [0.003*]	0.179* (0.062) [0.004*]	0.156* (0.050) [0.002*]	0.143* (0.058) [0.002*]	0.142* (0.048) [0.002*]	
Freedom house										
2/Partially free	*H1a/–*		*0.980* *(0.629)* *[0.018]*							*0.915** *(0.411)* *[0.027*$^{+}$*]*
3/Free	*H1a/–*		*1.476*$^{+}$ *(0.832)* *[0.034]*$^{+}$							*0.947* *(0.597)* *[0.029]*
Govt effectiveness	H1b/+	**0.702**$^{+}$ **(0.375)** **[0.011*****]**	0.104 (0.358) [0.002]		0.736* (0.368) [0.013*]	1.155* (0.462) [0.023*]	0.169 (0.283) [0.003]	0.418 (0.420) [0.007]	0.709^{+} (0.372) [0.012*]	
State fragility	*H1b/–*			*–0.115* *(0.078)* *[–0.002*$^{+}$*]*						*0.067* *(0.064)* *[0.002]*
Social										
Urban population (%)	H2a/+	**0.054*** **(0.022)** **[0.001*****]**	0.047* (0.021) [0.001*]	0.046* (0.021) [0.001*]		0.061* (0.027) [0.001*]	0.028 (0.031) [0.000]	0.028 (0.018) [0.000^{+}]	0.042* (0.020) [0.001*]	
Population density	*H2a/+*				*0.000* *(0.000)* *[0.000]*					*–0.000* *(0.000)* *[–0.000]*

TABLE 3 (Continued)

Factor and variable	Hyp/ Sign	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7	Model 8	Model 9
Colonial legacy										
1/France	H2b/+	**−0.428** **(0.636)** **[−0.006]**	−0.121 (0.399) [−0.002]	−0.625 (0.608) [−0.008]	−0.473 (0.651) [−0.006]	−0.147 (0.539) [−0.002]	0.042 (0.490) [0.001]	−0.695 (0.620) [−0.010]	−0.164 (0.557) [−0.002]	*0.213* *(0.404)* *[0.006]*
2/Never	na	**1.002*** **(0.487)** **[0.025^{+}]**	0.289 (0.586) [0.006]	0.780 (0.516) [0.019]	1.031* (0.448) [0.030^{+}]	1.941* (0.767) [0.064*]	0.721^{+} (0.425) [0.014]	0.445 (0.491) [0.011]	1.301* (0.644) [0.035^{+}]	*−0.141* *(0.445)* *[−0.003]*
diff Never—France		**1.43^{+}**	0.41	1.41^{+}	1.50*	2.09*	0.68	1.14	1.47*	*0.35*
Geographic diffusion	H2c/+	**0.010** **(0.008)** **[0.000]**	0.004 (0.006) [0.000]	0.008 (0.007) [0.000]	0.005 (0.006) [0.000]	0.012 (0.009) [0.000]	0.019* (0.007) [0.000*]	0.006 (0.008) [0.000]	0.014^{+} (0.008) [0.000^{+}]	*0.000* *(0.007)* *[0.000]*
Temporal diffusion	H2d/−	**−1.244*** **(0.234)** **[−0.020*]**	−1.231* (0.343) [−0.022*]	−1.291* (0.293) [−0.021*]	−1.042* (0.171) [−0.018*]		−1.196* (0.203) [−0.018*]	−1.179* (0.207) [−0.020*]	−0.978* (0.160) [−0.016*]	
Temporal diffusion (linear)	*H2d/+*					*0.235** *(0.072)* *[0.005*]*				*0.126** *(0.039)* *[0.003*]*
Economic										
GDP per capita	H3/+	**−0.000*** **(0.000)** **[−0.000*]**	−0.000 (0.000) [−0.000]	−0.000 (0.000) [−0.000]	−0.000 (0.000) [−0.000]	−0.000* (0.000) [−0.000*]		−0.000^{+} (0.000) [−0.000*]	−0.000* (0.000) [−0.000*]	
Inflation	*H3/−*						*−0.167* *(0.112)* *[−0.003]*			*−0.080* *(0.073)* *[−0.002]*

(Continues)

TABLE 3 (Continued)

Factor and variable	Hyp/ Sign	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6	Model 7	Model 8	Model 9
Medical/scientific										
Govt Hlth spending (%)	H4a/+	**–0.038*** **(0.016)** **[–0.001*]**	–0.032^{+} (0.017) [–0.001*]	–0.039* (0.019) [–0.001*]	–0.003 (0.011) [–0.000]	–0.045* (0.020) [–0.001*]	–0.044* (0.019) [–0.001*]		–0.034^{+} (0.018) [–0.001*]	
Service coverage	*H4a/+*							*0.016* *(0.023)* *[0.000]*		*0.019* *(0.027)* *[0.000]*
Cumulative cases	H4b/+	**–0.131*** **(0.036)** **[–0.002]**	–0.118* (0.043) [–0.002*]	–0.125* (0.039) [–0.002*]	–0.102* (0.035) [–0.002*]	–0.125* (0.038) [–0.003*]	–0.106* (0.038) [–0.002*]	–0.112* (0.036) [–0.002*]		
Cumulative deaths	*H4b/+*								*–3.057^{+}* *(1.782)* *[–0.051^{+}]*	*–1.153* *(4.301)* *[–0.027]*
Constant		**0.960*** **(0.444)**	0.354 (0.408)	2.051* (0.963)	0.706^{+} (0.412)	–13.229* (3.855)	0.181 (0.479)	–0.045 (1.623)	–0.001 (0.396)	–8.366* (2.016)
N		**1110**	1110	1110	1110	1110	1110	1110	1110	1110
Pseudo Log likelihood		**–32.518**	–34.670	–32.278	–36.146	–40.031	–31.868	–34.254	–34.202	–49.622
X^2		**35.43***	26.98*	37.88*	46.03*	37.03*	56.37*	41.09*	52.58*	49.96*
Pseudo R^2		**0.591**	0.564	0. 594	0.545	0.496	0.599	0.569	0.570	0.376
BIC^{a}		**142.170**	153.485	141.688	149.425	157.195	140.869	145.642	145.537	183.390

Note: DV = SAHO. Numbers in parentheses indicate robust *SE*s; numbers in square brackets indicate the marginal effect or change in probability of the issuance of a SAHO on any given day given a one-unit increase in the independent variable. Bold values highlight Model 1, the theoretically best model. Italic values indicate results for alternative measures.

[a] BIC assesses model fit; smaller BIC is preferred/better model.

*Statistical significance at the 5% using two-tailed tests and robust *SE*s.

$^{+}$Statistical significance at the 10% using two-tailed tests and robust *SE*s.

the evidence contradicts H1a and somewhat supports H1b, but both results suggest political factors play a role in the issuance of SAHOs in MENA.

In terms of the social factors, living arrangements in the form of urbanicity are statistically related to the issuance of SAHOs as asserted by H2a. Each percentage-point increase in population living in an urban setting is associated with one-tenth of 1% increase in the probability a government will issue a SAHO. The results do not support H2b regarding colonial legacies, but the analyses uncover a related effect that is notable. The evidence suggests that governments with British and French colonial legacies do not differ in likelihood of issuing a SAHO. But governments with no colonial legacy do statistically differ from those with British legacies, and the substantive effect is about 2.5 percentage points per day, although it is only marginally statistically significant. Similarly, the governments with no colonial legacy also may differ from those with French legacies, but, again, the difference is only marginally statistically significant. Contrary to H2c, the results indicate that SAHOs did not diffuse geographically, but in support of H2d they did diffuse temporally. The negative coefficient for the measure of temporal diffusion indicates that the probability of a government issuing a SAHO order followed the S-curve learning pattern as proposed in H2d by rising toward the day of peak adoption then falling after that day. It is worth noting that the bivariate results showing a pseudo R^2 of 0.41 suggest temporal diffusion accounts for a large proportion of the variance in the dependent variable. The multiple regression results confirm this. Removing this measure from the model results in a drop in pseudo R^2 of 75% from 0.59 to 0.15. A likelihood-ratio test without robust standard errors indicates the difference between the two models is statistically significant ($X^2 = 70.04$; $p < 0.05$). Overall, the evidence suggests social factors play a meaningful role in the issuance of SAHOs, but it offers mixed support for the hypotheses.

Contrary to H3, economically stronger countries were not more likely to issue a SAHO; they were less likely. Specifically, as GDP per capita increases the likelihood of a SAHO decreases. This may suggest that instead of wealthy governments calculating that their economies can endure a public health shock, they simply want to protect their economies. While unexpected, this result is consistent with a report regarding the issuance of SAHOs in US states (Murray & Murray, 2020). Finally, the results indicate that medical factors played a role but not as hypothesized. Contrary to H4a, governments with a more nationalized health care system as indicated by greater government contribution to health care spending were less likely to issue a SAHO. One interpretation of this result is that these governments felt better able to handle a large number of patients given their greater coverage of the population and, therefore, they did not believe they needed to take drastic measures. Further, contrary to H4b, the results show the greater the number of coronavirus cases per capita the less likely a government was to issue a SAHO.

Overall, Model 1, the theoretically best model, suggests that political, social, economic, and scientific/medical considerations played a role in MENA governments issuing a SAHO or not in response to the coronavirus, but the effects are complicated.

Robustness check: Alternative variable specification

The next models specify alternative measures to test the robustness of the effects found in Model 1. Appendix A contains detailed descriptions of the alternative measures. Model 2 replaces the Polity measure with the Freedom House measure of regime type, which classifies countries as “not free,” “partially free,” or “free” based on civil liberties and political freedom. These measures are a bit more than moderately correlated (Spearman's $\rho = 0.55$, $p < 0.05$), but they are different enough to test whether the effect found in Model 1 is random. Model 2 indicates that partially free countries are not more likely to issue a SAHO than not free countries, but free countries may be, although the effect is only marginally statistically significant. The results also indicate that free countries are not statistically more likely to issue a SAHO than partially free countries. Overall, though, the marginal results are consistent with the results from Model 1 that government type affects the issuance of SAHOs and, therefore, the contrary evidence regarding H1a is at least somewhat robust.

Model 3 replaces the government effectiveness measure, the second measure of the political factors, with a measure of state fragility. The State Fragility Index measures a government's capacity and systemic resilience (Marshall & Elzinga-Marshall, 2017). Scores range from 0 (no fragility) to 25 (extreme fragility); therefore, the effect is expected to be negative. These measures are strongly correlated ($r = -0.75$, $p < 0.05$), but they are calculated differently and provided by different organizations, so they should provide a reasonable test of whether the effect found in Model 1 is random. In this case, as a MENA country's fragility increased its likelihood of issuing a SAHO decreased but only in terms of the marginal effect, and that effect does not achieve conventional levels of statistical significance. This is somewhat consistent with the results from Model 1. Overall, the results in support of H1b are robust but only weakly.

Model 4 replaces percent urban population with population density for the second test of H2a. These measures are a bit more than weakly correlated ($r = -0.36$, $p < 0.05$), but both provide reasonable indications of living conditions. The results do not confirm the significant effect of living arrangements found in Model 1. The results for colonial legacy and geographic diffusion are not tested due to the lack of satisfactory alternative measures. Model 5, then, tests the robustness of the temporal effect found in Model 1, but in this case using a linear versus S-curve pattern. The results confirm the robustness of the temporal effect, but the three model fit statistics indicate linear time is a much weaker predictor of a SAHO than the S-curve measure. Overall, these results confirm the Model 1 results for temporal diffusion and, therefore, the evidence in support in support of H2d is robust.

Model 6 replaces GDP per capita with inflation. Generally speaking, high or negative inflation is considered harmful to an economy. These measures are a bit more than weakly correlated ($r = -0.35$, $p < 0.05$), but both provide reasonable measures of the health of an economy. The MENA region includes both, with four countries being slightly negative and the remainder positive and ranging up to a very high 41.1%. Therefore, the expected direction of effect is expected to be negative. Regardless, Model 6 indicates the effect is not statistically significant, so the economic effect found in Model 1 regarding H3 is not robust. Model 7 starts the tests of the medical/scientific factors and replaces government spending as a percent of total health care spending with the World Health Organization Service Coverage Index, which indicates how widely essential health care services are provided in a country. This measure is considered an indication of universal health care coverage. These measures are a bit more than moderately strongly correlated ($r = 0.59$, $p < 0.05$), but they are different enough to test whether the effect found in Model 1 is random. The results are not statistically significant and, again, do not support H4a, although they are not contrary to expectations as found in Model 1. Model 8 provides an alternative measure of increased threat by replacing per capita cumulative cases with per capita cumulative deaths. These measures are a bit more than moderately strongly correlated ($r = 0.60$, $p < 0.05$), but they are different enough to test whether the effect found in Model 1 is random. Again, the results are contrary to H4b and, like in Model 1, they indicate that as threat of the disease increases MENA governments become less likely to issue a SAHO. In further confirmation of this unexpected finding, other results not detailed in the table similarly indicate that as the number of cases and deaths per available hospital bed go up the probability of a SAHO goes down.

Together, these nine robustness checks provide mixed results for the primary findings. They support findings that political factors matter (H1a and 1b). They confirm the findings for social factors related to temporal diffusion (H2d) but not living arrangements (H2a). They do not confirm the original and unexpected findings regarding economic considerations (H3) or regarding medical factors related to type of health care system (H4a). But, contrary to H4b, they confirm Model 1 results that increased disease threat is associated with a decreased probability of issuing a SAHO.

Robustness check: Effects across multiple models

There is another reasonable way to assess the hypotheses in terms of these results. There are nine multivariate models with all the variables except colonial history and geographic diffusion being replaced to test robustness. That is, there are at least eight different tests of the hypothesized relationships. The government-type measure was conventionally statistically significant in all of the models, and the measure used to test robustness also offered some statistical support for the effect. This provides relatively robustcontrary evidence for H1a, but indicates that government type affects the issuance of SAHOs in MENA. Support for government efficacy is moderate, with four of the models indicating a statistical relationship of some kind, and the alternative measure also offering at least some support. This provides moderate support for H1b.

Similarly, there is some support for an association based on living arrangements in six of the models and, therefore, H2a. In five of the models governments with no colonial legacy were at least marginally statistically more likely than former British colonies to issue SAHOs, and in five of the models they were statistically more likely to issue a SAHO than governments with a French legacy. Although these effects are not consistent with H2b, which focuses on a comparison of British and French colonies, they do uncover an important social effect. Although there is little support for H2c in regard to geographic diffusion, by far the results provide the strongest support for H2d in regard to S-curve temporal diffusion. All the models indicate that the probability a country will issue a SAHO followed an S-curve pattern. The results do not support H3, and they provide some indication that the economic effect is actually opposite the hypothesized effect. Lastly, the results provide no support for H4a regarding type of health care system, but six of the models indicate a statistically detectible effect that is contrary to the hypothesis suggesting this may be an important consideration for government leaders. The same can be said regarding the second scientific/medical hypothesis. The results show, contrary to H4b, that in all the models increased disease threat decreased likelihood of a SAHO.

Robustness check: Alternative specifications only

Finally, there is one more reasonable way to assess the robustness of the effects. Model 9 includes only the alternative specifications used to test each hypothesis. This model replaces seven of the nine measures in Model 1 with their alternative measures. It includes 1110 observations. Its overall fit is statistically significant ($X^2 = 49.96$, $p < 0.05$), and it produces a McFadden's pseudo R^2 of 0.38 and BIC of 183.390. Although its fit statistics indicate it does not capture the effects in the data as well as Model 1, which has a pseudo R^2 of 0.59, with a pseudo R^2 of 0.38 it still accounts for a reasonable level of the variance in the dependent variable. More importantly, its results continue to suggest that more democratic governments are more likely to issue SAHOs, offering additional evidence regarding H1a, and that temporal diffusion plays a powerful role, offering additional support of H2d.

DISCUSSION

The purpose of this paper is to gain an understanding of the decisions of MENA governments to take the disruptive step of closing their societies in response to the coronavirus pandemic. Following a general theoretical framework for health care policy making (Brownson et al., 2009), it examines political, social, economic, and scientific/medical factors in MENA that may be related to the issuance of SAHO orders or not in response to

COVID-19. Table 4 presents a summary of the findings in terms of the nine proposed hypotheses. It reports the expected relationships between the dependent variable and each measure (Column A); the statistical results for the measure from the primary model, Model 1, (Column B); and whether the Model 1 results support the hypothesis (Column C). The next column (Column D) indicates the model number for each alternative measure used to test the robustness of effects found in Model 1, the statistical significance of each alternative measure (Column E), and whether the results of the alternative measures support the pertinent hypothesis (Column F). The last column (Column G), indicates whether the results from the alternative models are consistent with the results from Model 1 to summarize robustness. Overall, it shows the findings give substantial support to certain political, social, and medical factors.

First, the results strongly indicate that MENA governments learned over time from other governments in the region following a classic social learning or innovation pattern (H2d; e.g., Mooney & Lee, 1995). As shown in Table 1, a small number of governments issued SAHOs in mid-March followed by a large group in the third week of the month then another one during the last week of the month. This is consistent with the policy adoption process in which countries learn from the policy successes and failures of similar countries and adjust the policy for national conditions.

The results provide consistent, but sometimes weak, evidence that the political factors mattered. Contrary to H1a, more democratic governments were more likely to issue a SAHO. It is notable that in this case democratic governments were more likely to restrict the actions of their citizens than autocratic governments. It may be they concluded that their citizens wanted that, that autocratic governments were more concerned about their economies than public health, or some combination of the two. The results also provide consistent but weak evidence of an effect for government capacity. Although this is consistent with H1b, the supporting evidence is not substantial.

The medical factor related to disease threat is the final reliable effect, but the relationship is opposite what was expected. Contrary to H4b, the results suggest that as the levels of coronavirus-related illness and death increase, the likelihood a government will issue a SAHO decreases. This might indicate that governments took proactive steps and issued SAHOs before the number of cases and deaths started to grow dramatically. This policy approach would likely be applauded by public health experts, but it clearly calls for further investigation.

Otherwise, there is nontrivial evidence that colonial legacy plays a role although not specifically as asserted in H2b. While the results did not demonstrate a difference between British and French colonies, they did provide nontrivial evidence that governments with no colonial legacy stood out from those with British or French legacies in their likelihood of issuing a SAHO. This result was not subject to a robustness check due to the lack of a reasonable alternative measure, though. There are a number of relationships that did not survive the robustness checks (e.g., the negative effect of wealth as represented by GDP per capita) but are worthy of further investigation.

This study is limited in several ways that should be noted and that will hopefully inform future research. In narrow terms, the study does not capture the effects of media on these governments' decisions. While research suggests the media can play an important role in policy making, in particular agenda setting (e.g., Sato, 2003), resource constraints prevented the collection of pertinent Arabic-language media data. This study does not consider related subnational policies, which may serve as an impetus or hindrance to national action (Quinton, 2017). More broadly, the SAHOs were issued over a two-week period, which is a very short period of time for policy research. That said, the urgent nature of the pandemic and the profound actions many governments were taking by shutting down their societies suggest the policy window on this issue was tightly compressed for good reason. This study

TABLE 4 Summary of predictors of MENA stay-at-home orders

Hypothesis	Factor	*Measure*	(A) Exp. Sign	(B) Model 1 *Stat sig*	(C) Hypotheses supported (Model 1)	(D) Alt. Model #	(E) Alt. model Stat sig	(F) Hypotheses supported (alt models)	(G) Model 1 and Alt Model consistent
H1a	Political	*Govt Type*	–	{*}	No	2	{+}	No	✓
H1b	Political	*Govt Eff*	+	+	Weakly	3	[+]	Weakly	✓
H2a	Social	*Live Arrange*	+	*	Yes	4	*NS*	No	
H2b	Social	*Col Legacy*	+	*NS*	No	NA	NA	NA	
H2c	Social	*Geo Diff*	+	*NS*	No	NA	*NA*	*NA*	
H2d	Social	*Temp Diff*	–	*	Yes	5	*	Yes	✓
H3	Economic	*GDP pc*	+	{*}	No	6	NS	No	
H4a	Med/Sci	*System*	+	{*}	No	7	NS	No	
H4b	Med/Sci	*Threat*	+	{*}	No	8	{+}	No	✓

Note: All variables defined in Appendix A.

Abbreviations: Alt., alternative; Exp. Sign, expected sign; NA, not applicable; NS, not significant.

*and + in columns B and E indicate statistical significance at the 5% and 10% levels, respectively, using two-tailed tests and robust standard errors. {} indicates statistically significant two-tailed test but in the wrong direction. [] indicates statistical significance of the marginal effect only.

only examines the MENA region, which includes an extremely heterogeneous set of governments and countries. One should generalize to other countries and regions with great caution, if at all. The results are based on analyses of publicly available quantitative data. Data such as these that come from autocratic governments, of which there are many in the MENA region, should be thoughtfully scrutinized in terms of integrity and validity. Finally, the data do not and cannot indicate the effects of nonpublic data to which government leaders had access or the leaders' personal motivations or fears.

In conclusion, This study gives policy makers and researchers a look at early government responses to a global health crisis in a heterogeneous region of the world. It strongly indicates that these governments learned from each other. It suggests that political institutions in the form of regime type and government capacity play an important role as do medical factors related to the threat of the disease. These results indicate the world has a great deal to learn about government responses to this and other dangerous infectious diseases. This study may offer a number of learning opportunities to those concerned about and responsible for addressing such matters.

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CONFLICT OF INTERESTS

The authors declare there are no conflicts of interest.

ENDNOTE

[1] The authors recognize that a territory is not a country, but for ease of communication this article sometimes refers to a territory as a country.

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APPENDIX A: VARIABLE DESCRIPTIONS

DEPENDENT VARIABLE

Stay-at-home order (SAHO). Coded 1 on the effective date of a SAHO in a country/territory and 0 on all days prior the effective date. Coded as missing on days after the effective date. A country-day is determined to have a SAHO when the government required “not leaving house with exceptions for daily exercise, grocery shopping, and ‘essential’ trips” (coded 2 in original data) or “not leaving house with minimal exceptions (eg allowed to leave once a week, or only one person can leave at a time, etc)” (coded 3 in original data).

Source: Oxford COVID-19 Government Response Tracker, Blavatnik School of Government (Hale et al., 2020).

INDEPENDENT VARIABLES

(alternative measures for robustness checks appear in italics)

Political factors

Polity

Polity 2 is a composite index of Autocracy/Democracy where a score of −10 indicates a strong autocracy and +10 a strong democracy.

Source: Center for Systemic Peace; see Marshall and Gurr (2020).

Freedom House regime type

Freedom House Status categorized as “not free,” partly free,” and “free” based on scores given to each country for political rights and civil liberties granted to its citizens in 2018 by Freedom House, a not-for-profit organization that researches issues related to political freedom around the world.

Source: Freedom in the World 2018: The Annual Survey of Political Rights and Civil Liberties.

Government effectiveness

According to the World Bank Data Catalog: This measure "captures perceptions of the quality of public services, the quality of the civil service and the degree of its independence from political pressures, the quality of policy formulation and implementation, and the credibility of the government's commitment to such policies. Estimate gives the country's score on the aggregate indicator, in units of a standard normal distribution, i.e. ranging from approximately −2.5 [low effectiveness] to 2.5 [high effectiveness]."

Source: World Bank variable GE.EST.

State Fragility Index

According to Marshall and Elzinga-Marshall (2017), "The State Fragility Index…combines scores on the eight indicators [of security, political, economic, and social effectiveness and legitimacy] and ranges from 0 'no fragility' to 25 'extreme fragility.' A country's fragility is closely associated with its state capacity to manage conflict, make and implement public policy, and deliver essential services, and its systemic resilience in maintaining system coherence, cohesion, and quality of life, responding effectively to challenges and crises, and sustaining progressive development."

Source: Center for Systemic Peace.

Social factors

Urban population

Urban population as percent of total population. Centered in the models.

Source: United Nations Statistics variable SYB082.

Population density

Population density in terms of people per km^2 of land area in 2018. Centered in the models.

Source: *World Bank variable EN.POP.DNST.*

Colonial legacy

Identifies the colonial history of each country as colonized by Britain (coded 0; eight countries/territories), colonized by France (coded 1; six countries), or not colonized by Britain or France (coded 2; seven countries/territories). This last category includes the six countries in MENA that were never colonized and the one country, Libya, that was colonized by Italy.

Source: Wolfe (2013).

Geographic diffusion

The proportion of bordering countries with a SAHO in effect by country-day.

Source: calculated by the authors.

Temporal diffusion—S-curve

A nonlinear trend variable that is constructed by taking the square root of the number of days between a given day and the day with the highest hazard rate, in this study March 23.

Source: calculated by the authors.

Temporal diffusion—Linear

A linear trend variable that is constructed by consecutively numbering the dates in the data set from 1 to 61.

Source: *calculated by the authors.*

Economic factors

GDP per capita

Gross Domestic Product per capita in 2017 in US dollars. Centered in the models.

Source: UN Stats variable SYB025.

Inflation

Inflation in terms of consumer prices (annual percent). Centered in the models.

Source: IMF variable FP.CPI.TOTL.ZG.

Scientific/medical factors

Percent government health care spending

Government health expenditure as a percent of total health expenditures. Centered in the models.

Source: World Health Organization variable SH.XPD.GHED.CH.ZS.

Service Coverage Index

A measure of provision of selected essential health services and indication of progress toward universal health coverage.

Source: World Health Organization report on "World Health Statistics 2020: Monitoring Health for SDGs," Annex 2.

Cumulative Cases (*Deaths*)

Daily cumulative COVID-19 cases (*deaths*) per 100,000 population in a country lagged one day.

Source: European Centre for Disease Prevention and Control (ECDC) at https://www.ecdc.europa.eu/en/publicationsdata/download-todays-data-geographic-distribution-covid-19-cases-worldwide.

APPENDIX B: BIVARIATE RELATIONSHIPS AS ESTIMATED BY PROBIT REGRESSIONS

Factor and variables	Hypo	Sign	H1a	H1b	H2a	H2b	H2c	H2d	H3	H4a	H4b
Political											
Government type	H1a	–	0.025 (0.016)								
Government effectiveness	H1b	+		0.049 (0.100)							
Social											
Urban population (%)	H2a	+			0.003 (0.005)						
Colonial legacy											
1/France	H2b	+				0.045 (0.238)					
2/never	na					–0.128 (0.246)					
Geographic diffusion	H2c	+					0.011* (0.003)				
Temporal diffusion	H2d	–						–0.722* (0.135)			
Economic											
GDP per capita	H3	+							–0.000 (0.000)		
Medical/scientific											
Govt heath spending (%)	H4a	+								–0.000 (0.004)	
Cumulative Cases	H4b	+									0.011 (0.012)

(Continues)

Factor and variables	Hypo	Sign	H1a	H1b	H2a	H2b	H2c	H2d	H3	H4a	H4b
Constant			−2.173* (0.103)	−2.206* (0.102)	−2.220* (0.100)	−2.192* (0.159)	−2.365* (0.112)	−0.290 (0.263)	−2.220* (0.100)	−2.218* (0.100)	−2.231* (0.128)
N			1131	1131	1131	1131	1131	1131	1131	1131	1110
Pseudo Log Likelihood			−78.640	−79.637	−79.636	−79.496	−74.119	−46.895	−79.664	−79.742	−79.244
X^2			2.38	0.24	0.26	0.48	17.90*	28.75*	0.19	0.00	0.95
Pseudo R^2			0.014	0.001	0.001	0.003	0.071	0.412	0.001	0.000	0.003
BIC[a]			171.342	173.335	173.334	180.085	162.300	107.852	173.390	173.546	172.512

Note: DV = SAHO. * and $^+$ indicate statistical significance at the 5% and 10% levels, respectively, using two-tailed tests and robust standard errors. Smaller BIC is preferred/better model.

[a] BIC assesses model fit.

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Accuracy of health-related information regarding COVID-19 on Twitter during a global pandemic

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Abstract

This study was performed to analyze the accuracy of health-related information on Twitter during the coronavirus disease 2019 (COVID-19) pandemic. Authors queried Twitter on three dates for information regarding COVID-19 and five terms (cure, emergency or emergency room, prevent or prevention, treat or treatments, vitamins or supplements) assessing the first 25 results with health-related information. Tweets were authoritative if written by governments, hospitals, or physicians. Two physicians assessed each tweet for accuracy. Metrics were compared between accurate and inaccurate tweets using χ^2 analysis and Mann–Whitney *U*. A total of 25.4% of tweets were inaccurate. Accurate tweets were more likely written by Twitter authenticated authors (49.8% vs. 20.9%, 28.9% difference, 95% confidence interval [CI]: 17.7–38.2) with accurate tweet authors having more followers (19,491 vs. 7346; 3446 difference, 95% CI: 234–14,054) versus inaccurate tweet authors. Likes, retweets, tweet length, botometer scores, writing grade level, and rank order did not differ between accurate and inaccurate tweets. We found 1/4 of health-related COVID-19 tweets inaccurate indicating that the public should not rely on COVID-19 health information written on Twitter. Ideally, improved government regulatory authority, public/private industry oversight, independent fact-checking, and artificial intelligence algorithms are needed to ensure inaccurate information on Twitter is removed.

KEYWORDS
COVID-19, pandemic, social media

Key points

- One quarter of COVID-19 health-related information on Twitter was found to be inaccurate.
- Accurate tweets were more likely to be written by Twitter authenticated authors and authoritative sources (i.e., government, hospitals, physicians).
- Accuracy was not associated with number of retweets, number of likes, tweet botometer scores, or tweet rank order.

INTRODUCTION

In December, 2019, a novel coronavirus was identified as the cause of pneumonia in a cluster of patients in Wuhan, China (Zhu et al., 2020). Since this initial outbreak, the identified virus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has spread across the globe with the World Health Organization (WHO) declaring a global pandemic on March 11, 2020 (World Health Organization, 2020a). As of April 13, 2021 there were over 136 million cases and 2.9 million deaths reported worldwide (World Health Organization, 2021). WHO control of this pandemic has involved public health measures including quarantine of exposed individuals, isolation of infected individuals, and social distancing with a heavy reliance on the public to follow recommendations from national and international experts and governments. Subsequently, the dissemination of information has become an important component of regulating behavior and guiding the worldwide response to this disease.

One of the many means of transmitting health information to the public is via social media. Twitter use rose 23% in 2020, largely due to the influence of social distancing and individuals seeking information regarding COVID-19 (Kafka, 2020). As Twitter use increased, questions have arisen about the spread of COVID-19-related misinformation on this platform (Frenkel et al., 2020). During previous infectious disease outbreaks (2012 Middle East respiratory syndrome coronavirus (MERS-CoV), 2013 H7N9, 2014 Ebola, and 2016 Zika), social media was used positively as an avenue for identifying and tracking infections, gauging a community's response to those outbreaks, and providing information to at-risk populations (Al-Surimi et al. 2017; Fung et al., 2016, 2013; Rudra et al., 2018) However, the spread of inaccurate information during past disease outbreaks occurred in 10%–60% of Ebola-related, 61% of yellow fever-related, 25% of diphtheria-related, and 5%–10% of H1NI-related tweets (Chew & Eysenbach, 2010; Ortiz-Martinez & Jimenez-Arcia, 2017; Oyeyemi et al., 2014; Pandey et al., 2010; Porat et al., 2019; Sell et al., 2020) More recently, tweets related to COVID-19 have contained misinformation in 25%–39% of cases and unverifiable information in 17% of tweets (Brennan et al. 2020; Kouzy et al., 2020).

The International Fact-Checking Network (IFCN) has labeled COVID-19 as “the biggest challenge fact-checkers have ever faced” (Suarez, 2020). Twitter is one of the most common means of spreading public health information with nearly 123 million COVID-19-related tweets posted between January 21 and May 15, 2020, the majority of which were posted in English (Chen et al., 2020). The WHO states that in addition to a global pandemic related to COVID-19, there is a COVID-19 infodemic or an “excess amount of information (misinformation) about a problem which makes it difficult to identify a solution” (Department of

Global Communications, 2020) According to the WHO, an infodemic allows for the "spread of misinformation, disinformation, and rumors during a health emergency," hampers an effective public health response, and has the potential to create confusion and distrust among populations (Department of Global Communications, 2020).

Because Twitter is so widely used a public source of communication and news, the accuracy, relevancy, and timeliness of information is important. For this reason, we chose to study health-related information regarding Twitter during this COVID-19 global pandemic. Our primary goal was to determine the accuracy of health-related tweets related to COVID-19. A secondary goal was to determine features associated with accurate tweets.

METHODS

Between March 24 and April 5, 2020, five new Twitter accounts were established with no followers, no accounts followed, default of English language, people (anyone), location (anywhere), and highly sensitive content turned off. Before performing the study, two physician study authors created five sets of search terms to be used. Search terms were chosen to elicit tweets that addressed common issues surrounding the management of COVID-19. These included "COVID-19" plus either "cure," "treat or treatment," "prevent or prevention," "emergency or emergency room," or "supplements or vitamins." Tweets were categorized as having an authoritative source if they were written by a government, physician/physician group, or hospital/hospital system. Tweets were defined as medical or health-related if they contained medical or health information presented as a fact, a recommendation, a statement, or an opinion. Tweets were categorized as news if they self-reported that the author was a news organization or worked for a news organization. Tweets that were primarily political, memes or jokes, or religious without health or medical claims were excluded.

Before initiating the study, a 2-h training session took place with all study authors (data abstractors) that emphasized definitions, uniform tweet reviews, and coding of information to be placed into an Excel spreadsheet. Two weeks before initiating this study, using "influenza" as a practice search term, all data abstractors simultaneously analyzed 10 non-COVID-19-related tweets to ensure uniform reviews and information collection. During the study, data abstraction, data entry, and coding rules were rereviewed with abstractors by the principal investigator after each 25 tweets. The principal investigator arbitrated all data collection and coding questions on an ongoing basis.

On three separate dates (Friday, April 17; Wednesday, April 22; Saturday, April 25, 2020) between 4:00 and 8:00 p.m. Eastern Standard Time the searches (queries) were performed on Twitter using previously selected terms. Each term was assigned to an individual study author/abstractor during this time period such that only one individual performed each search for only their assigned terms on each given day. To perform their search, five study authors logged into their new/native Twitter account and entered "COVID-19" into the search box within the Twitter search box plus either "cure," "treat or treatment," "prevent or prevention," "emergency or emergency room," or "supplements or vitamins" such that there was no overlap of searches. This time of day was selected to coincide with the peak time for retweets and click-throughs on Twitter across the United States (Sailer, 2019). On each date, the top 25 retained tweets for each search with any health or medical-related information were copied into a spreadsheet. Twenty-five tweets were chosen as the search limit since it was estimated that each tweet and accompanying links/figures/pictures could be read within one minute and the average half-life of a tweet is 18–24 min with engagement and retweets tapering rapidly after this period (Wilson, 2016). For each tweet, the following information was recorded: The tweet, any tweet hyperlinks, the author, author's country listed on their public profile, author's credentials, author's Twitter verification status, the number of followers, number of retweets, number of likes, and the tweet's rank order within that day's search. Duplicate tweets were excluded.

An online tool termed a Botometer developed by the Observatory on Social Media and the Network Science Institute at Indiana University was used to generate a score that estimated whether or not authors of Tweets exhibited bot-like activity (https://botometer.osome.iu.edu/; Botometer, 2021). Bots are automated programs that generate messages, follow accounts, reply to or share hashtags via automation or machine learning. The Botometer uses machine learning to characterize tweet authors based on user data, temporal features/patterns, content, friends/retweets, networking/links, and sentiment-related features. According to the Pew Research Center, a Botometer score > 0.43 on a 0–1 scale (>2.15 on a 5-point scale) is the optimum cutoff for classifying a Tweet as more likely to be written by a bot than a human (Wojcik et al., 2018).

Accuracy

Two physician authors independently reviewed and categorized information within each tweet as accurate/generally accepted or unproven/inaccurate. Before assessment, identifying information (author, affiliations, sponsors, advertisements, videos, nonessential pictures) was removed from each tweet to allow blind assessment. Accurate or generally accepted information was defined as that which agreed with the National Institutes of Health guidelines, Infectious Disease Society of America guidelines, WHO, Centers for Disease Control and Prevention, American College of Emergency Physicians, American Academy of Pediatrics and current major textbooks in emergency medicine, infectious disease, internal medicine, and pediatrics. In addition, reviewers were allowed to search the National Library of Medicine (PubMed) for original articles and the Cochrane Database to analyze the accuracy of tweets. For tweets with more than one health-related statement, it was predetermined that the presence of any single inaccurate statement would lead to the tweet being categorized as inaccurate. Disagreement between two reviewers were settled using a third physician author.

Statistics

Prior studies found that internet and social media-based medical information was frequently incorrect with 12%–40% of health-related tweets described as untrustworthy or inaccurate (Albalawi et al. 2019; Gage-Bouchard et al., 2018; Kedzior et al., 2019; Love et al., 2013; Shah et al., 2019). Assuming an inaccuracy rate within this range, it was estimated that a sample size of at least 369 tweets would be needed to derive an overall accuracy with 95% confidence that was within 5% of these values.

All data were treated as nonparametric. Categorical data were compared between accurate and inaccurate tweets using chi-squared analysis or Fisher's exact test. Pairwise comparisons of continuous and ordinal data were made using the Mann–Whitney *U* test. *p* Values were adjusted for multiple comparisons using Benjamini and Hochberg's method (McDonald, 2014). Tweets were ranked based on their order within a search. Spearman rank order was used to assess the correlation between tweet accuracy and their respective rank order.

Interrater correlation for initial tweet accuracy was calculated using Cohen's kappa. A kappa coefficient was considered almost perfect at 0.81–1, showed substantial or good agreement at 0.61–0.80, moderate agreement at 0.41–0.60, fair agreement at 0.21–0.40, slight agreement at 0.01–0.20, and less than chance at <0.

Data were analyzed using MedCalc (MedCalc Statistical software, v18.2.1; MedCalc Software Bvba).

RESULTS

There were 375 tweets collected during the study period with 17 duplicates deleted leaving 358 evaluable tweets. Two hundred and sixty-seven tweets (74.6%, 95% CI: 69.8–78.8) were graded as accurate. Tweets with the search terms "COVID-19" plus "cure" were more likely to be inaccurate compared to other tweets (Table 1).

Authoritative authors wrote 69 tweets (31 government, 25 physicians, and 13 hospital tweets) and nonauthoritative authors wrote 289 tweets. A total of 67 of 69 authoritative tweets were accurate compared to 200 of 289 nonauthoritative tweets (97.1% vs. 69.2%, 27.9% difference, 95% CI: 19.2–33.8). The inaccurate tweets were written by authoritative authors comprised two physician tweets claiming COVID-19 was cured with vitamin C (Table 2). Of the subset of authoritative authors listed as government or hospitals/hospital systems, 41 (100%, 95% CI: 91–100) tweets were accurate. A total of 64 accurate and 25 inaccurate tweets were authored by self-reported news organizations (24% vs. 27.5%, −3.5% difference, 95% CI: −14.5 to 6.3).

Overall, accurate tweets were significantly more likely to be written by authoritative sources (25.1% vs. 2.2%, 22.9% difference, 95% CI: 15.6–28.6) and authors verified by Twitter (49.8% vs. 20.9%, 28.9% difference, 95% CI: 17.7–38.2). Authors of accurate tweets had significantly more followers than authors of inaccurate tweets (19,491 vs. 7346; 3446 difference, 95% CI: 234–14,054). The number of likes, tweets authored by news organizations, Botometer scores, retweets, tweet length, and Flesch–Kincaid grade level did not differ between accurate and inaccurate tweets (Table 3). North America was the most common author location, $N = 171$ (47.8%), with the United States comprising the source for 153 (42.7%) of all tweets (Table 3).

The median overall rank order of retained tweets was 37 (95% CI: 32–46) with a range of 1–219. The rank order of tweets was not associated with tweet accuracy (Spearman's rho = −0.0164, 95% CI: −0.12 to 0.087).

The interrater reliability for the physicians assessing tweet accuracy was substantial (kappa = 0.77, 95% CI: 0.69–0.84).

TABLE 1 Accuracy of COVID-19 tweets for each query-search

Search term(s)	Number accurate/ total (%)	95% Confidence interval
Cure	34/69 (49.3%)	37.1%–61.5%
Emergency room or ER	58/70 (82.9%)	72.4%–89.9%
Prevent or prevention	66/75 (88%)	78.7%–93.6%
Treat or treatment	56/73 (76.7%)	65.8%–84.9%
Vitamins or supplements	53/71 (74.7%)	63.5%–83.3%
Total	267/358 (74.6%)	65.9%–84.1%

Abbreviation: COVID-19, coronavirus disease 2019.

TABLE 2 Inaccurate tweets by category

Inaccuracy[a]	Number of tweets[b]
Hydroxychloroquine or chloroquine can cure or have cured COVID-19[c]	23
Herbs or supplements can cure or have cured COVID-19 (most common supplement Artemis followed by coconut oil, garlic, ginger, honey, lemon, lime, melatonin, Peruvian bark, probiotics, turmeric)	18
Vitamin C can cure or has cured COVID-19	13
Zinc can cure or has cured COVID-19, zinc deficiency causes COVID-19	10
Bleach or chlorine dioxide ingestion—includes 3 mentions of injecting bleach and 2 mentions of vaping bleach	10
Big pharmaceutical companies are against a cure (3 mentions of big pharmaceutical companies blocking the use of hydroxychloroquine/chloroquine)	5
Azithromycin	4
Unknown product cures COVID-19 (uncertain if drug or supplement)	4
Ultraviolet light or sunlight will cure people with COVID-19 (these tweets do not refer to the use of UV light or sunlight to kill viruses on surfaces)	3
Vaccines weaken the immune system and will worsen COVID-19	2
States are purposefully undercounting cases to hide real mortality	2
One each of the following items were inaccurate: • Cures for COVID-19 = one each for breast milk, camel urine, cannabis, diet, hand sanitizer, homeopathy, immune globulin (nonspecific, pooled), placental cells, montelukast, vitamin A, vitamin D, whiskey • Death panels are the cause of COVID-19 mortality in the United States	1 Each (total subset 13 tweets)

Abbreviations: COVID-19, coronavirus disease 2019; UV, ultraviolet.

[a] Tweets that stated that supplements and vitamins (or a particular diet) cured COVID-19 were labeled as inaccurate. However, if tweets stated they supported or potentially strengthened the immune system, they were not labeled as inaccurate.

[b] Total adds up to more than 91 since multiple tweets listed more than one inaccurate product or statement.

[c] These were only labeled as inaccurate if the tweet stated these products cured COVID-19. Tweets that stated they hydroxychloroquine/zinc/azithromycin might have antiviral properties without stating they cured COVID-19 were not labeled as inaccurate. At the time of the study, definitive studies proving the ineffectiveness of hydroxychloroquine had not yet been published.

TABLE 3 Comparison of accurate versus inaccurate tweets

Features[a]	Accurate *N* = 267	Inaccurate *N* = 91	Differences in 95% confidence intervals	*p* Value[b]
Authoritative source (government, hospital or physician)	67 (25.1%)	2 (2.2%)	22.9% (15.6–28.6)	<0.01
News tweet—author self-report as news organization	64 (24%)	25 (27.5%)	−3.5% (−15.1 to 6.8)	0.67
News tweet/link—author self-report or link to news organization	98 (36.7%)	40 (44%)	−7.5% (−19 to 4.1)	0.33

TABLE 3 (Continued)

Features[a]	Accurate $N = 267$	Inaccurate $N = 91$	Differences in 95% confidence intervals	p Value[b]
Author's location[c]				0.23
North America	135 (50.6%)	36 (39.6%)		
Africa	21 (7.9%)	7 (7.7%)		
Asia	23 (8.6%)	5 (5.5%)		
Europe	21 (7.9%)	5 (5.5%)		
Australia/New Zealand	4 (1.5%)	2 (2.2%)		
South America	1 (0.4%)	0		
No location listed	62 (23.3%)	36 (39.6%)		
Author verified by Twitter	133 (49.8%)	19 (20.9%)	28.9% (17.7–38.2)	<.01
Number of followers	19,491 (1697–237,214)	7346 (877–71,025)	3446 (234–14054)	0.05
Botometer score > 0.43 (>2.15 on 5-point scale)[d]	114/248 (46%)	25/72 (34.7%)	11.3% (−2.5 to 23.6)	0.22
Botometer score > 0.43 (>2.15) in subset labeled news tweet/link[d]	52/94 (55.3%)	13/31 (41.9%)	13.3% (−8.2 to 33.1)	0.34
Number of retweets (shares)	36 (6–183)	45 (7–146)	0 (−12 to 9)	0.85
Number of likes	85 (10–334)	69 (17–313)	−1 (−23 to 17)	0.87
Tweet length (number of characters)	235 (155–264)	222 (149–265)	−6 (−27 to 12)	0.61
Flesch–Kincaid grade level	10.3 (7.6–14.2)	9.7 (7.1–11.8)	−1.2 (−2.3 to 0)	0.14

[a] Median (interquartile range) for continuous and ordinal data.

[b] p Values were corrected for multiple comparisons using the Benjamini and Hochberg adjustment with a corrected value ≤0.05 considered significant (McDonald, 2014).

[c] No location was listed for 98 authors, with North America comprising 171 tweets (US 153, Canada 18), Africa 28 tweets (Nigeria 14, South Africa 6, Kenya 4, Democratic Republic of Congo 2, 1 each Somalia, Uganda), Asia 28 tweets (India 8, Philippines 7, Pakistan 6, China 2, 1 each Hong Kong, Malaysia, Oman, Saudi Arabia, Thailand), Europe 26 tweets (United Kingdom 19, France 2, Netherlands 2, 1 each Belgium, Romania, Spain), Australia/New Zealand 6 tweets, and South America (Argentina) 1 tweet.

[d] Scores could not be calculated by the Botometer for 19 accurate and 19 inaccurate Tweets, Botometer scores could not be calculated for 13 Tweets in subset of news related/news link tweets.

DISCUSSION

Our study found 74.6% of COVID-19 health-related tweets to be accurate. Accurate tweets were more likely to be written by authoritative authors (physicians, hospitals, or government agencies), authors verified by Twitter, and authors with more followers compared to inaccurate tweets. We found no association between tweet accuracy and number of retweets (shares), number of likes, tweet length (number of characters), or Flesch–Kincaid Grade Level. These findings indicate that medical advice related to COVID-19 on Twitter should not be trusted when written by nonauthoritative sources. The high number of inaccurate tweets indicate that efforts to improve health-related information on Twitter regarding global outbreaks are needed.

The most common inaccurate tweets in our study comprised recommendations for using unproven prescription medicines, hydroxychloroquine or chloroquine, to treat or prevent COVID-19 (e.g., "#Hydroxychloroquine with Zn supplement cures #COVID-19"). The United States Food and Drug Administration (FDA) approves medicines after their effects have been reviewed by the Center for Drug Evaluation and Research and their benefits are found to outweigh known and potential risks for an intended population (Food and Drug Administration, 2019a). Since neither is approved for use in COVID-19, tweeted recommendations to use hydroxychloroquine or chloroquine for this disease would be classified as unapproved or off-label by the FDA. Off-label drug use is allowed by the FDA when there is no FDA-approved drug to treat a condition or there is insufficient supply of FDA-approved drugs for a particular condition (Food and Drug Administration, 2019b). Importantly, recent FDA attempts to limit off-label drug use have been constrained by court rulings that support a pharmaceutical company's right to "free speech" when promoting such use "as long as their statements are not false or misleading" (Kim & Kapcynski, 2017). In a similar manner, the FDA does not have the authority to regulate the free speech (i.e., tweets) of individuals especially if they have no commercial interest in a product (Kim & Kapcynski, 2017).

Unproven herbs, vitamins, and supplements were another common recommendation within inaccurate tweets (e.g. "there are medicinal plants in Madagascar such as Artemisia, which can cure COVID-19") These products, collectively termed dietary supplements, are characterized by containing at least one identified dietary ingredients such as a vitamin, mineral, herb, botanical, amino acid, enzyme, or metabolite. Dietary supplements are not approved for use by the FDA and can be brought to market without having been proven safe or effective (Harris, 2000). Product labeling, although regulated in the United States by the FDA (under the 1994 Dietary Supplement and Health Act), is much less stringently regulated. While specific disease claims are prohibited, the FDA allows for claims regarding the structure and function of these supplements with a required label that these products are "not intended to diagnose, treat, prevent, or cure any disease" (Harris, 2000; Owens et al., 2014). A 2014 study of 1300 dietary supplement retail and nonretail websites found that 20%–38% of websites made disease-related claims and only 8% of retail websites studied included the required FDA disclaimer regarding disease claims (Owens et al., 2014). This study cited a lack of FDA manpower and resources to adequately enforce labeling requirements for dietary supplements. Based on its limited ability to monitor and regulate both drugs and dietary supplements, it is likely the FDA would need more funding and more regulatory authority before it could meaningfully impact misinformation on social media platforms like Twitter.

The Federal Communications Commission (FCC) regulates interstate and international communications with authority over communications law, regulation, and technological innovation (Federal Communications Commission, 2021). While not directly tasked with verifying the accuracy of the information on social media sites, the FCC has the legal authority to interpret important aspects of communication laws regarding websites and social media companies. Section 230 of the Communications Act of 1934 and an amendment (the Telecommunications Act of 1996) state that "no provider or user of an interactive computer service shall be held liable on account of… any action voluntarily taken in good faith to restrict access to or availability of material that the provider or user considers to be obscene, lewd, lascivious, filthy, excessively violent, harassing, or otherwise objectionable, whether or not such material is constitutionally protected" (Johnson, 2020). In addition to protection from criminal lawsuits, experts have interpreted Section 230 as conferring protection to social media companies from civil lawsuits due to harm caused by third-party content (i.e., harmful or inaccurate information; Barriott & Wilkens, 2020). As such, social media companies have protection from liability when either illegal or inaccurate information is posted as long as those companies make good faith efforts to remove this material. While there may be bipartisan Congressional support to amend or replace Section 230 such that companies would be required to remove or moderate inaccurate or harmful content, it is undetermined if proposed changes would meaningfully improve the accuracy or validity of health-related content on social media (Reardon, 2020).

As in our study, others found that unverified Twitter accounts contain more misinformation compared to verified accounts (authors authenticated by Twitter (Kouzy et al., 2020). The 25% rate of inaccurate information in our study is consistent with these prior studies of epidemic-related tweets (Brennan et al., 2020; Kouzy et al., 2020). These findings indicate that misinformation during disease outbreaks continues to be a common and important problem.

While most tweets listed individual authors and contained no hyperlinks, 44% of inaccurate and 36.7% of accurate tweets were authored by or had links to self-reported news sites. Knowledge regarding the accuracy of news sites is especially important since up to 67% of Americans get their news from social media (Shao et al., 2018). Inaccurate tweets found in our study included those reported by an affiliate of major news organizations (e.g., NEWS4SanAntonia/NBC promoting melatonin for COVID-19), international news organizations (e.g., abs-cbn, “virgin coconut oil could be COVID-19 cure”), entertainment news, and news sites that appeared to mix advocacy with news (e.g., vaxxter.com, “China cures coronavirus with vitamin C”). Identifying whether or not a reported news story is real and verifying the legitimacy of a news source can be difficult. While there is no single technique for verifying whether or not a story is real (vs. fake), experts recommend reading reputable news sources, reading original studies or sources, looking for verification of stories on multiple sites, ensuring there are author attributions for stories, and using fact check tools (i.e., www.snopes.com, www.factcheck.org, www.politifact.com. www.punditfact.com; Spector, 2020). An international not-for-profit organization, Health on the Net/HON, exists for verifying the accuracy and legitimacy of health and medical websites (Boyer et al., 2016) However, HON requires that individual websites request a review. The review provided by HON only analyzes eight principles of information authority (e.g., confidentiality, authorship, source attribution, supporting information, transparency, advertising, objectiveness, and financial disclosure) and not the accuracy of the information within websites (Boyer et al., 2016). It is unlikely that a similar review process could be performed on Twitter which relies on a rapid dissemination of information during news cycles with immediate commentary and feedback by users of this platform. Due to the speed of information dissemination and high volumes of information on social media, automated algorithms (i.e., artificial intelligence) are one method for identifying real versus fake news currently being studied (Lara-Navarra et al., 2020).

Social media bots or automated programs used to engage social media have been accused of spreading misleading information on Twitter (Shi et al., 2020). Botometer scores were high for both accurate and inaccurate authors of Tweets in our study indicating that a substantial amount of COVID-19-related information on Twitter might be spread by these automated programs. Tweet accuracy did not appear to be associated with bot scores. Not all bots are malicious, and many bots can perform legitimate functions. Bots that appropriately follow Twitter rules can include those that update real-time news and weather. Human Twitter authors also can automate a portion of their account by forwarding Facebook posts, sending Real Simple Syndication feeds, or tweeting/retweeting in the absence of the human user. These bot functions would tend not to disseminate misinformation. Importantly, Botometer scores fluctuate over time leading some experts to question their reliability, validity, and reproducibility (Rauchfleisch & Kaiser, 2020). A recent study using the Botometer also incorrectly misclassified humans as bots in 41%–76% of political tweets (Rauchfleisch & Kaiser, 2020). Subsequently, Botometer scores should be interpreted with caution.

In addition to relaying inaccurate medical information, Twitter has been identified as a source for unfounded conspiracy theories during disease outbreaks. Government conspiracies to hide information, control populations, or hide treatments were rumored during Ebola, Zika, influenza-H1N1, and MERS outbreaks (Sell et al., 2020; Smallman, 2015; Vijaykumar et al., 2018; Yang & Lee, 2020). With COVID-19, an unfounded rumor linking the SARS-CoV-2 virus to 5G (fifth-generation mobile phone) networks began in late January 2020 and spread rapidly leading to widespread misinformation and the burning of 5G towers in the United Kindgom (Ahmed et al., 2020). Other COVID-19 conspiracies include the deliberate release of the virus as a bioweapon and pharmaceutical companies blocking known treatments to boost their own drugs and vaccines (Neil & Campbell, 2020). Experts have noted misinformation and conspiracy theories were amplified and retweeted more than accurate tweets during the Zika outbreak (Brennan et al., 2020; Cinelli et al., 2020; Vosoughi et al., 2018). Tweets describing conspiracies in our study included five linking pharmaceutical companies with attempts to suppress available cures, two stating governments were purposefully hiding cases, and one linking death panels to COVID-19 mortality in the United States.

Multiple organizations (i.e., WHO, United Nations, Centers for Disease Control, and IFCN) and experts have provided recommendations for combating misinformation on social media (Centers for Disease Control and Prevention, 2020; International Fact-Checking Network, 2020; United Nations, 2020; World Health Organization, 2020b). Proposals include a sustained coordinated effort by independent fact-checkers like the IFCN, an independent (nonbiased) news media, tracking of misinformation plus dissemination of accurate, easy to read, information by public health and government authorities/agencies, and censorship by social media companies (Brennan et al., 2020; Garrett, 2020; Limaye et al., 2020; LLewyllen, 2020; Sell et al. 2020; Yang & Lee, 2020). Our study was conducted after Twitter implemented a policy stating they would delete tweets that run the risk of causing harm by spreading misinformation about COVID-19. Thus, self-censorship alone may be an ineffective screen for information accuracy within Twitter (Gadde & Derella, 2020; Hern, 2020).

Limitations

Our study evaluated the content of tweets, not whether individuals acted on this information or were harmed by misinformation. Certain inaccurate tweets (e.g., ingesting bleach can cure disease) are potentially more harmful than other inaccurate tweets (e.g., taking vitamin C can cure disease). Despite this difference, we treated all inaccurate statements equally within our study. Future studies might concentrate on the potential of inaccurate tweets to cause harm when evaluating the accuracy of health-related information on social media.

We only evaluated the first 25 health-related tweets for each query/search. Since tweet searches partially use timelines to identify relevant tweets, older tweets may not have been identified during searches. In addition to the timeliness of tweets, other factors used by Twitter to rank results are proprietary and unknown. Tweets are also dependent upon the news cycle and evaluation of tweets on different dates or during different news cycles might yield different results.

Since our goal was to analyze the accuracy of the information on Twitter, we did not evaluate the accuracy or legitimacy of website hyperlinks within tweets. Within accurate and inaccurate tweets, there were links to self-reported news websites, online magazines, blogs, YouTube videos, published/unpublished studies, and health-related websites (integrated medicine, homeopathy). For websites describing themselves as news-related, some appeared to report legitimate news (e.g., a television news website wherein a nurse reporting he was cured of COVID-19 by taking hydroxychloroquine, vitamin C, and ritonavir, an antiretroviral HIV medicine) while others appeared to have a more commercial news slant (e.g., homeopathyplus.com which described homeopathic COVID-19 remedies).

While the authoritative tweet categories of hospitals and government agencies are easily identifiable, listing of author qualifications or training is often not apparent when analyzing biographies on Twitter. Thus, physician authors who did not detail their qualifications might have been erroneously labeled as nonauthoritative. It is unknown what effect miscategorization in this manner would have on the accuracy of tweets with authoritative authors.

Each author's country was determined by the country listed within their public Twitter profile. This setting is based upon the country selected by a user, can be changed by users, and cannot be independently verified (Twitter Help Center, 2021). Separately, Twitter uses Internet Protocol/IP addresses plus global positioning satellite/GPS information about wireless networks and cell towers to identify countries associated with users for internal purposes. This internal "country setting is non-public information," is used by Twitter to customize content and advertisements, and is not available for study (Twitter Help Center, 2021).

Countries with the highest use of Twitter include the United States and many Western European nations (Chen et al., 2020; Singh et al., 2020). Our study only analyzed English language tweets. Thus, our findings might not be applicable to countries outside these regions and to non-English speaking countries. Moreover, we only analyzed tweets related to five terms chosen by study authors. It is possible that alternate terms or combinations of terms would yield different results.

In the month before initiating our study, Twitter instituted new measures to limit potentially abusive, manipulative, and inaccurate content (Gadde & Derella, 2020). Part of this strategy involves machine learning and automation. Machine learning requires a large data set evaluated over time to create useful algorithms. Because of this, it is possible that Twitter will be better able to identify and remove this problematic content in the future.

CONCLUSION

We found over one-quarter of health-related COVID-19 tweets to be inaccurate. Authoritative authors of tweets, especially government entities and hospitals/hospitals systems, were more likely to post accurate tweets. These findings suggest the public be wary of COVID-19 health information posted on Twitter.

Ideally, Section 230 of the amended Communications Act should be updated by Congress to hold social media companies responsible for harm from inaccurate health-related information on their sites if comprehensive attempts are not made to identify and remove this information. This action would incentivize those companies to ensure information is fact-checked and removed if potentially harmful or misleading. Increased funding for the FDA would allow enhanced review of supplement companies for removal of improper disease and medical claims within advertisements and on their websites. Legislation that requires supplements to be proven safe with oversight and approval by the FDA would potentially decrease adverse events related to supplements. While not directly addressing misinformation, such legislation would increase surveillance of these companies and potentially improve their adherence to regulations disallowing health and medical claims for their products. Other measures to improve the accuracy of health-related information on social media include enhanced public/private industry oversight, independent fact-checking, and effective automated, artificial intelligence algorithms. It is doubtful that any single approach will resolve the "infodemic" of COVID-19 misinformation on Twitter and a multi-faceted approach encompassing each of these potential solutions is needed to improve the accuracy of health-related information on social media.

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests as per the ICJME guidelines.

AUTHOR CONTRIBUTIONS

All authors (Sarah B. Swetland, Ava N. Rothrock, Halle Andris, Bennett Davis, Linh Nguyen, Phil Davis, Steven G. Rothrock) were involved in the conception of study, design of the study, data collection and abstraction, drafting and revision of the manuscript. All authors analyzed the data and Sarah B. Swetland/Ava N. Rothrock/Steven G. Rothrock performed statistical analyses. All authors take responsibility for the paper as a whole.

ETHICS STATEMENT

The data, models, and methodology used in this research are not proprietary.

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ORIGINAL ARTICLE

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Access to genetic testing for rare diseases: Existing gaps in public-facing information

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Abstract

Genetic testing plays an increasingly important role in the diagnosis and potential treatment of inherited and rare conditions, such as aniridia—a disease that leads to abnormal eye development, as well as in health research on these conditions. As genetic testing is increasingly sought for accurate and early diagnosis of rare genetic disorders and in the context of direct-to-consumer genomics, it is critical to examine the public-facing information about access to these services and reimbursement policies. We conducted a targeted policy and public-facing resource search. Our analysis of resources available for the patient community revealed that there is very little practical guidance available about access and reimbursement for genetic testing for rare diseases. Greater clarity in public-facing resources about genetic testing would be beneficial to the patient community as it would promote informed choices about the procedure, mitigate potential harms associated with lack of information and enable patient engagement in their own health care.

KEYWORDS

aniridia, genetic testing, patient information,

Key points

- Genetic testing is crucial for diagnosis and treatment of inherited and rare conditions.
- Information about access to genetic testing and reimbursement for it is not easily available in public-facing resources.

- The patient community would benefit from greater clarity in available information about genetic testing, because it would facilitate informed decision-making and promote patient engagement in their care.

KEYWORDS

aniridia, genetic testing, patient information

INTRODUCTION

Although the term "rare disease" implies low prevalence, there are currently over 10,000 monogenetic inherited disorders that combined affect millions of individuals worldwide (Priori et al., 2009). Aniridia is one such rare condition: a genetic eye disorder that involves abnormal development of the iris and other parts of the eye, with long-term complications including vision loss and associated gene syndromes. Aniridia occurs one in 40,000–100,000 births, therefore it is not a part of routine neonatal or prenatal screening programs. It is diagnosed by an ophthalmological examination, however, *PAX6* mutation must be detected to confirm diagnosis, as the clinical phenotypes vary between patients (Richardson et al., 2016). Additionally, while some symptoms of aniridia are present at birth, other symptoms develop later in life and genetic testing can help determine the patient's prognosis (Richardson et al., 2016). In this paper, we will use the term *genetic testing* when referring to the *PAX6* gene sequencing, which is crucial for aniridia diagnosis. We use the terms *whole-genome* or *whole-exome sequencing* when referring to the comprehensive analysis of the entire genome or exome which are significantly more costly and less accessible than the previously mentioned methods.

Aniridia is a progressive disease, involving multiple vision pathologies that vary in severity (Orphanet: Isolated aniridia, n.d.). Current treatment for patients with aniridia includes the management of symptoms associated with the condition, as well as progressive complications. Among interventions for aniridic eyes are monitoring and relieving high eye pressure and light sensitivity, treatment of cataracts, glaucoma and keratopathy (Lee et al., 2008). These treatments can only slow the progression of the disease—however research is underway to address the underlying causal mutations in the transcription factor *PAX6*. For aniridia as well as many other inherited conditions, genetic testing is playing an increasingly significant role in diagnosis and management of the disease. Two in three individuals diagnosed with aniridia have inherited the condition from their parent and specific mutations can be associated with various clinical outcomes (Richardson et al., 2016). Specific gene mutations may also be inclusion criteria for participation in health research and as such may determine eligibility for specific research opportunities (Hingorani & Moore, 1993) and potential future therapy.

In Canada, access to genetic testing varies greatly across health conditions and even between provinces and territories. The aim of this project was to characterize the landscape of public-facing information about access and reimbursement policies for genetic testing for aniridia in Canada.

MATERIALS AND METHODS

We conducted a targeted search of Canadian policies and public-facing information about access and reimbursement for genetic testing for aniridia. Our search strategy (Table 1) targeted freely accessible, English-language information available in the following resources:

TABLE 1 Search strategy

Provincial and territorial policies or guidelines	Provincial/territorial health authorities' websites
Federal policies or guidelines	Health Canada
Private insurance coverage	Sun Life
	Manulife
	The Great West Life Assurance Company
	Desjardins Insurance
	SSQ Insurance
	Green Shield Canada
	Pacific Blue Cross
	Medavie Blue Cross
	Industrial Alliance
	Alberta Blue Cross
Private companies' offers	Life Labs
	23andMe
	GenomeMe
	Molecular You
Non-profit foundation information	Canadian Aniridia Foundation
	Choosing Wisely Canada
	Genetics Education Canada
	Canadian Association of Genetic Counsellors
	The Foundation Fighting Blindness

1) Des Libris, an online database of Canadian policies;
2) Federal (e.g., Health Canada) and provincial (e.g., BC Ministry of Health) government websites;
3) Regional health authorities in Canada (e.g., Vancouver Coastal Health);
4) The top ten private health insurance companies (Benefits Canada.com, n.d.),
5) Private genetic testing companies (e.g., 23ande); and
6) Non-profit organizations related to aniridia (e.g., the Canadian Aniridia Foundation).

The search terms used were “aniridia,” “genetic,” and “rare diseases”. All pages of search results were examined. When a search returned over 1000 results, we narrowed the search to include the exact word or phrase, combined keywords or refined the results by theme (e.g., health). Where there was no search option available on the website, we manually evaluated the website for information related genetic testing for aniridia. Provincial/territorial health department websites were also manually mined to determine medical benefits covered under the provincial/territorial plan. For insurance websites, we assessed the most basic individual insurance plan if the policy was available. A full summary of the websites visited, search results and dates of access can be found in Table S1.

RESULTS

The search of DesLibris yielded two documents relating directly to our research question (Gauvin & Wilson, 2012; Waddell, n.d.). An evidence brief from 2012 ("Coordinating the Use of Genetic Tests and Related Services in British Columbia") provides a comprehensive overview of genetic testing in BC, Canada. At that time, the authors found no information on which specific genetic tests are covered by the Medical Services Plan (Gauvin & Wilson, 2012). The second publication, "Examining the Public Provision and Funding of Clinical Genetic Tests," is from 2017 and aimed at investigating the availability of genetic tests in different jurisdictions across Canada, Australia, New Zealand, UK, and United States as well as examining the factors taken into account when deciding which genetic tests will be covered (Waddell, n.d.). Regarding the access and reimbursement for genetic testing, the synthesis reports that there is little information available for each jurisdiction, with most places subsidizing or covering the service when the test can advance treatment or is considered a medical necessity, but there is a lack of a formal list of available/covered tests (Waddell, n.d.). The American Academy of Ophthalmology Task Force on Gene Sequencing (Stone et al., 2012) offered specific recommendations on when to offer genetic testing, that is, to "patients with clinical findings suggestive of a Mendelian disorder whose causative gene(s) have been identified."

The search of Canadian federal and provincial government websites yielded similar results. None of the health agencies' publicly available content in the 85 websites we consulted included mentions of genetic testing for rare diseases. Information regarding access and coverage of genetic testing is limited to a description that physicians need to provide a referral for laboratory tests and services. Health Canada resources referred to Orphanet (www.orpha.net/consor/cgi-bin/index.php), an online portal for rare diseases. This site lists laboratories from around the world that conduct genetic testing for rare diseases. According to our search on Orphanet (conducted in November 2018) only one laboratory in Canada (Alberta Children's Hospital) does sequencing only for the *WT1* mutation (WAGR syndrome), not for the *PAX6* mutation. Eight other laboratories in Canada offer cytogenetics/FISH services for WAGR syndrome, but not sequencing. Manual search of laboratory service providers such as LifeLabs showed, however, that complete genome sequencing as well as specific *PAX6* tests are available at any of their locations (with a referral from a physician). Samples are drawn at LifeLabs locations and then are shipped to Germany for testing.

Of the top 10 insurance companies in Canada (Benefits Canada.com, n.d.) Sun Life, the Great West Life Assurance Company, Desjardins Insurance, and Green Shield Canada cover laboratory/diagnostic services. Pacific Blue Cross covers services that are not included in the government plan. None of the private insurers' websites mentions genetic testing, rare diseases, or aniridia.

Direct-to-consumer genetic testing companies (23andMe, Molecular You, Genome Me) did not include tests for aniridia/*PAX6* at the time of search (November 2018).

The Canadian Aniridia Foundation website does not provide details on access or reimbursement for genetic testing. The Fighting Blindness Canada website has a section that addresses questions about genetic testing. It provides information about access to genetic testing services via a genetic counselor and acknowledges that there is a limited number of ocular genetics specialists available in Canada. Information about coverage of the tests is limited, as the conditions for coverage differ between the provinces and territories.

The full data set extracted from the consulted websites is available in Table S1.

DISCUSSION

Our policy and public-facing resource search revealed that the information available on access to and reimbursement of genetic testing for rare diseases like aniridia is scarce. This finding is consistent with the North American literature on genetic testing for rare diseases. Chiang et al. contrast the rapid development and increased availability of genetic testing with the lack of legislative efforts and the need for introduction of specific guidelines (Chiang et al., 2015). Somerville and Allingham-Hawkins (2010) point out that because of the division of responsibility for health services among provincial and federal institutions there are no unified guidelines about the delivery of genetic testing in Canada. The authors report that while the *Canada Health Act* protects the access to hospital and diagnostic services across Canada, the federal/territorial governments regulate whether and how genetic testing is funded, which results in varied access and pricing of these services in the country.

The lack of clear information and guidance on public health authorities' websites may result in patients relying on information available in the media. Benjaminy and colleagues (2015) point out that in popular broadcasting of research about gene therapy for ocular disease, research is often presented as therapy which may result in initial confusion when making decisions to take part in research trials (Benjaminy et al., 2015). The authors mention organizations that contribute to the communication and education about genetic ocular diseases, such as Fighting Blindness Canada (www.fightingblindness.ca), which among other services connects patients to clinical trials and specialists that focus on their condition (Benjaminy et al., 2015). Patient registries and natural history studies increasingly play a role in bringing together patients with rare diseases and building a sense of support and community (Boulanger et al., 2020). Once the patients obtain their diagnosis, they get the opportunity to connect with other individuals with the same condition and engage in peer support (Doyle, 2015). Participating in patient registries and research efforts can be empowering, as the patients get actively involved in their care and contribute to better understanding of their specific condition (Smith et al., 2021). One potential challenge for patients with rare diseases is distinguishing between legitimate clinical trials and trials that do not meet safety or ethics standards but are still searchable in databases like clinicaltrials.gov. Fighting Blindness warns against attempts to abuse patients' hope for a cure to gain financial profit (Fighting Blindness Canada, n.d.).

The lack of information about access to and reimbursement for genetic testing may prevent patients from seeking these potentially beneficial services. Some benefits from genetic testing for inherited eye diseases include diagnostic confirmation, medical surveillance for complications, reduction of anxiety and medical costs, more treatment options, such as gene therapy, participation in clinical trials and better family planning (Chiang et al., 2015; Drack et al., 2010; Gillespie et al., 2014; Stone, 2007; Wiggs & Pierce, 2013; Zanolli et al., 2014). For instance, the presence of *PAX6* mutations in an individual may affect person's reproductive decisions, as two in three aniridia patients have an affected parent, or it could inform a predictive prenatal test (Richardson et al., 2016). While there are many potential benefits of genetic testing, it is also critical that the risks and ethical issues of these diagnostic tests are communicated to the patients. Thus, easily accessible genetic counseling is crucial for patients considering and undergoing genetic testing. One potential solution to address some of the access barriers, especially in rural and remote areas, is to expand the availability of telehealth and online counseling solutions (Cohen et al., 2019). The transformation of healthcare systems due to the COVID-19 pandemic accelerated the introduction of telehealth services across different settings (Wosik et al., 2020). As a result, it is likely that accessibility of virtual counseling will also increase. Some other known issues explored in the literature regarding genetic testing decision-making include applicability of genetic testing to complex disorders, predictive testing for untreatable conditions, genetic discrimination, prenatal sequencing, and abortion (Combs et al., 2013; Mezer & Wygnanski-Jaffe, 2009; Zanolli et al., 2014).

While there have been efforts to develop guidelines for providing genetic test coverage in Canada in fields such as oncology and epilepsy (Butts et al., 2013; Jain et al., 2019; Petit et al., 2008), we found a clear gap in the lack of unified policy in public-facing sources and of detailed policies for relevant jurisdictions (e.g., provinces). This issue is further compounded by the challenge of providing patients with information that is up-to-date. It is also important to note that while there are gaps in information about access to and reimbursement for sequencing of specific genes or gene panels, some individuals with rare diseases require more comprehensive testing, such as whole-genome or whole exome-sequencing. This type of testing which is crucial for identifying a number of diseases, obtaining a diagnosis and planning treatment is currently not reimbursed in Canada under any health plan.

An additional barrier to whole-genome and whole-exome sequencing, as well as targeted sequencing tests is a limited number of laboratories in Canada with the appropriate expertise and equipment to perform these types of tests. As revealed by our search, many laboratories (such as LifeLabs) outsource the tests to other countries which increases the overall costs. Consequently, organizations such as Genome Canada are working on developing a national strategy to make whole-genome sequencing more accessible to Canadian patients (Genome Canada, Genome Canada launches national initiative to bring precision health to patients, n.d.). The rapid pace of development of genetic testing for rare diseases may result in frequent guideline changes that would have to be captured by public-facing resources. Ensuring current information is easily available to patients requires commitment to ongoing updates and oversight.

LIMITATIONS

This study is not without limitations. Due to the gap in publicly available policies regarding access and reimbursement of genetic testing for rare diseases, the focus of our research question shifted to consider public-facing information about genetic testing. Additionally, we limited our search to public-facing information extracted using keyword combinations and targeted types of resources (Table 1)—as such, our sample may exclude items returned when doing a query in a search engine. Finally, our sample is limited to English-language resources—future work in this area will benefit from expanded inclusion criteria.

CONCLUSION

Overall, our search yielded very little practical guidance at the policy level for members of the patient community who may have questions about genetic testing for aniridia. We found that there is a need for clearer and more easily accessible information about genetic testing, especially on public-facing health authorities' websites. It would not only benefit the aniridia patient community, but also other patients with rare diseases and those who have not yet been diagnosed. In 10 out of the 13 provinces and territories, we found that genetic testing was covered by provincial or territorial plans if it was considered medically necessary. However, no information was available about how these terms are defined and whether sequencing for *PAX6* is considered a medical necessity by physicians. We also found conflicting evidence about access to genetic testing for aniridia, which may cause confusion for aniridia patients when debating taking the test. Faced with lack of resources and confusing information, patients with aniridia may feel limited in their choices, which in turn may result in them enrolling in research studies specifically to obtain access to genetic sequencing. Clarity around access and reimbursement would help address some of the ethical issues associated with genetic testing, including access to genetic counseling, empowerment of patients by greater awareness of treatment options and prognosis, as well as better personal planning.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

ETHICS STATEMENT

No human participants were involved in this study.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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World Medical and Health Policy

The Geography of Life and Death: Evidence and Values in the Evolution of U.S. Liver Transplant Rules

Logan Patrick Moore and David L. Weimer

For a quarter-century, the Organ Procurement and Transplantation Network (OPTN) has confronted the role of geography in the allocation of deceased-donor livers for transplantation. An historical legacy of a geographical hierarchy giving priority to patients within the same local Donor Service Area (DSA) as the donor gradually evolved to give some regional and national patients priority. However, in 2020, an eight-year process resulted in the allocation system being revised to centralize the granting of exemptions to the quantitative severity index and eliminate the DSA and region as relevant geographic units in favor of direct distance measures called acuity circles. In this account, we focus on the roles of expertise, values, and interests during this development to assess the OPTN as a form of stakeholder rulemaking. We find extensive use of medical evidence that may make such stakeholder rulemaking worthy of consideration as a governance alternative in evidence-rich applications.

KEY WORDS: liver transplant, organ procurement and transplantation, organ donation, rulemaking

Introduction

Patients with a variety of liver diseases can usually obtain a higher quality of life from receiving liver transplants; patients with liver failure face imminent death without transplants. Unfortunately, the supply of livers for transplant falls far short of the demand. In the United States, at the beginning of 2020, approximately 12,700 patients were on the waiting list for liver transplants, but in 2019 there were only 8,896 liver transplants, and 1,161 patients died while on the waiting list (OPTN, 2020a). As the donation of a fraction of a liver from a living donor involves both donor risk and inconvenience, both substantially greater than for the relatively common living kidney donations, it is not surprising that in 2019 over 94 percent of liver transplants were from deceased rather than living donors. Thus, livers from deceased donors are a scarce and highly valuable resource. As federal law since the 1984 National Organ Transplant Act (Public Law 98-507) has prohibited private exchange of solid organs, the limited supply of deceased-donor livers has been allocated by rules developed by the Organ Procurement and Transplantation Network (OPTN). As these rules literally have life and death implications, their content has at times been hotly debated.

Two features of the rules for liver allocation have been the primary topics of controversy. First, the definition of medical necessity determines what types of

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patients receive the highest priority for liver transplants. Conflicts over whether acute and chronic patients should be treated differently and how classifications could be made more objective, and therefore less susceptible to manipulation, were especially important in the major changes made to allocation rules in the late 1990s. Second, and intertwined with definitions of medical necessity, the role of geography has been a continuing source of conflict. The initial priority for allocation of deceased-donor livers to local transplant centers was replaced initially by a shift in some priority from the local to the regional and, more recently and the subject of this analysis, to distance-based priority.

Geographic priority in organ allocation initially stemmed from the OPTN as a formalization of voluntary sharing arrangements among transplant centers to avoid wasting organs that could not be used locally (Weimer, 2006). Beyond this institutional legacy, there were initially several reasons potentially justifying the local allocation of deceased-donor livers (Weimer, 2007). First, the livers have relatively short cold ischemic times (the period of viability once livers are removed from donors) so that long delays between their recovery and transplantation reduce the likelihood of successful grafts. Local allocation reduced delays. Second, the recovery of deceased-donor livers often involves a substantial effort by surgeons, often including rushed travel by small planes to intensive care units in hospitals located far from transplant centers (Mezrich, 2019). The incentive to make this effort is greatest when the recovered transplant organs are available for patients in the surgeon's transplant center and declines as the probability of sharing the organs with other transplant centers increases. Third, transplant centers that invested heavily in the recovery of livers feared that other transplant centers would game the rules to take a disproportionate share of recovered livers. Centers could game a system emphasizing medical necessity by fraudulently listing patients as sicker than they are. For example, in 2003, three Chicago area transplant centers paid fines for listing liver transplant candidates as being in intensive care when in fact they were living in the community (Murphy, 2004).

Over the last 20 years, the definition of medical necessity and the priority given to geography in the OPTN liver allocation rules have evolved incrementally. In December 2018, however, the OPTN adopted a major change in allocation rules that shifted priority from historically defined regions to "acuity circles" based on the distance between where the organ is recovered and the transplant centers where qualified transplant recipients are registered. Although the rule is being challenged in federal court, in January 2020, the court ruled that it would not issue an injunction against implementation, allowing the implementation to begin in February.

In this essay, we explore the development of the new liver allocation rules. Although the substantive importance of the rules justifies our attention, our primary motivation is understanding the effectiveness of the OPTN, a forum for stakeholder rulemaking, in balancing values, interests, and expertise. In other words, we seek to understand the strengths and weaknesses of the OPTN as a form of medical governance that might be used in other applications, a timely topic in light of fears of overt political pressure on federal agencies during the current pandemic. Our investigation parallels the analysis of a substantial change in the kidney allocation rules implemented in 2014 (Weimer & Wilk, 2019). Specifically, we trace a process that draws on the tacit knowledge of OPTN committee members, statistical evidence and modeling, and comment from the broader transplant community.

Our analysis proceeds as follows. First, we sketch the OPTN as a form of medical governance. Specifically, we note its mechanisms for combining the tacit knowledge of transplant professionals with statistical and simulation information provided by the Scientific Registry of Transplant Recipients (SRTR). Second, we provide an overview of the evolution of the liver allocation rules leading up to the most recent changes. Third, we consider how the definition of medical necessity, the primary value underlying transplant priority, has changed over time, especially in terms of recognition of the increasing use of exceptions that varied across regions. Fourth, we trace the process leading to the replacement of the regions with acuity circles as the basis for geographic priority. Fifth, we conclude with an assessment of the advantages and disadvantages of the OPTN as a form of medical governance.

OPTN as a Form of Medical Governance

In the United States, rulemaking within broad legal frameworks determines much of the content of the public policy. Executive bureaus, such as the Environmental Protection Agency, implement laws through rules vetted by the administration through its Office of Management and Budget. Appointed directors with fixed terms give independent agencies, such as the Federal Communications Commission, somewhat greater independence from administrative oversight of their rulemaking. Even greater independence has been given to several congressionally chartered but private organizations that effectively make rules, such as agricultural marketing boards and fishery management plans (Weimer, 2006). In such cases, the organizations do not create legally binding rules. However, the rules become effectively binding when either they are routinely adopted and published by their sponsoring agency without substantive review, as is the case for the quotas adopted by regional fishery councils (Thomas, Soule, & Davis, 2010) or the Advisory Commission on Immunization Practices (Weimer, 2010a), or they must be followed by organizational members to remain in good standing, and good standing has substantive consequences, such as eligibility for participation in federal programs. The OPTN is an example of such private, or stakeholder, rulemaking that gains force through mandatory membership (Weimer, 2010b).

The OPTN was created in 1984 by the National Organ Transplant Act (Public Law 98-507) and its primary role in de facto rulemaking regarding the allocation of organs was established in 1986 when membership in the OPTN and compliance with its rules became a requirement for hospitals to participate in Medicare and Medicaid (Public Law 99-509). The National Organ Transplant Act also created the SRTR contract, which requires maintaining and analyzing nearly universal longitudinal data on transplant candidates and recipients, systematic data on medical access and outcomes unrivaled within the U.S. health-care system. Both organizations were originally administered under contract with the Department of Health and Human Services (DHHS) by the United Network for Organ Sharing

(UNOS), a formalization of the voluntary sharing organization that inspired the creation of the OPTN. Subsequently, UNOS has continuously held the contract for administering the OPTN, but the SRTR has been administered by several organizations, and it is currently being administered and staffed by the Hennepin Healthcare Research Institute.

An assessment of the OPTN over its first two decades identified several characteristics of its rulemaking (Weimer, 2010a). First, the rulemaking was continuous in the sense of ongoing attention to the implications of rules but generally incremental in revisions. Substantive committees within the OPTN monitored issues relevant to specific organs as well as the overall performance of the transplantation system. Frequent, but small, changes in rules were proposed, commented on by other committees and often the public, and were generally accepted by the Board of Directors.

Second, the continuing assessment of rules was explicitly informed by both medical and more general social values. Dominant medical values differed across organ systems, reflecting the role of transplantation as a treatment—medical urgency for liver transplants, which lack alternatives for the seriously ill, and medical utility for kidney transplants, which have dialysis as a viable, if relatively undesirable, alternative. Although there has been some debate over whether liver allocation should also be based on medical utility to increase the number of life years produced (Luo et al., 2018; Schaubel et al., 2009), medical urgency has remained the dominant medical value. In addition, there was concern about racial, and as already noted, geographic equity in terms of access to transplants.

Third, the assessment of rules and possible alternatives was extensively informed by both quantitative medical evidence and the tacit knowledge of transplant practitioners. The SRTR provided evidence and simulations relevant to diagnosing problems with the allocation rules and assessing alternatives to improve them. OPTN committees frequently requested studies, discussed them, and requested follow-ups. The institutional design of the OPTN was successful in keeping transplant professionals, including surgeons, engaged in committees—having a voice in setting the rules for allocation of scarce organs motivated participation. These professionals often drew on their experience to provide insights that informed the requests for studies and raised concerns about the implementation of proposed alternatives.

Fourth, even though the rulemaking process was informed explicitly by values and evidence-based, the interests of the members sometimes conflicted and occasionally led losing interests to try to circumvent OPTN decisions. The majority-rule voting by the Board of Directors that facilitated the frequent but incremental rule changes also meant that these changes did not always correspond to the interests of large and politically influential transplant centers that were outvoted by representatives of the more numerous smaller centers. Indeed, as we briefly discuss in the next section, the controversy over liver allocation during the late 1990s involved the DHHS, the Congress, and the courts.

Except for lungs, changes to organ allocation rules during the first two decades of OPTN governance were incremental, especially with respect to the kidneys and livers. However, the last 10 years have witnessed major changes to the allocation rules for these organs. An assessment of new kidney rules that went into effect in

2015 found that their development involved explicit tradeoffs among competing values as well as the extensive use of medical evidence (Weimer & Wilks, 2019). In this review, we assess the roles of values, evidence, and interests in shaping the recent major change in liver allocation rules.

Overview of the Evolution of Liver Allocation Policies

The evolution of organ allocation rules since the creation of the OPTN divides into four periods, each with its own dynamics, and is now entering a fifth period. During the first period, the OPTN formalized the existing UNOS allocation priorities and began a process of incremental change to accommodate new evidence about their consequences. For example, evidence suggesting the inappropriate use of the UNOS/STAT designation, which gave the highest priority to patients with less than 24 hours to live without a transplant, led to its elimination. In 1996, the highest priority (Status 1) was given to patients who were expected to have fewer than 7 days to live without a transplant—a change that effectively reduced the priority previously enjoyed by many patients with chronic liver disease. Also, despite pressure from several of the largest transplant centers for less reliance on geography in allocation, the 1996 rules maintained the hierarchy of local, then regional, and only then national priority (Table 1).

Table 1. Five Eras in the Evolution of Liver Allocation Rules

Eras	Major Events
Formalization of Voluntary Sharing 1986–1996	Local allocation first with initial regional sharing in cases of imminent death removed because of concern about abuse; rulemaking for stronger federal role revived in the context of protests over the reduction in priority for chronic patients.
Change Driven by Controversy 1996–2002	DHHS "Final Rule" calls for national sharing; controversy spills beyond OPTN members to Congressional moratorium, state-level legislative responses, and the Institute of Medicine study suggesting regional rather than national sharing; revised Final Rule: "Neither place of residence nor place of listing shall be a major determinant of access to a transplant."
Moves Toward Broader Geographic Sharing 2002–2012	Introduction of MELD/PELD scores to provide more objective assessment of medical urgency to support broader sharing; regional sharing for transplant candidates with scores of 15 or greater; regional sharing for all Status 1 patients; DHHS Advisory Committee on Transplantation recommends that allocation not be based on local OPO and DSA boundaries; OPTN Strategic Plan includes reducing geographic disparities.
Major Efforts to Reduce Importance of Geography 2012–2020	OPTN directs organ-specific committees to develop plans to minimize the effects of geography in allocation; subsequent steps by the Liver Committee and OPTN leading to a liver allocation system implemented in 2020 with the elimination of OPO and DSA boundaries as detailed in Table 2.
Continuous Distribution Measures Replacing Boundaries 2020–	OPTN initiative underway to develop for *all organs* continuous allocation priority scores that take account of geography only in terms of "placement efficiency," the resources required in matching, transporting, and transplanting.

An extreme controversy that drew attention to the issue beyond the OPTN membership characterized the second period. The University of Pittsburgh Medical Center, which had been the early leader in liver transplantation, found that the transplant surgeons it trained were using many livers in their new locales that it previously would have transplanted. It was able to gain the ear of the president, who, in turn, put pressure on the Secretary of DHHS to reopen a rulemaking it had started in 1994 in an unsuccessful effort to provide greater federal oversight of the OPTN and modify it to call specifically for national allocation of organs. The larger transplant centers favoring national allocation were able to take advantage of the opposition of chronic liver disease patients to the 1996 rules. Of the 85 transplant centers that submitted letters to the regulatory docket, only 7 favored moving toward national allocation (Weimer, 2007). Both sides of the geographic-based controversy employed simulation models based on SRTR data to support their positions. Opponents mobilized several state governments to support their position. They also had substantially more support in Congress, which ordered a one-year moratorium on the implementation of what DHHS considered the Final Rule and required that the Institute of Medicine (IOM), now the National Academy of Medicine, be commissioned to conduct a study of the appropriateness of broader geographic sharing, especially of the livers.

The IOM report undercut the rationale for, and feasibility of, national allocation (IOM, 1999). First, it found that geographic disparities in access were primarily for lower priority patients. Second, it concluded that the medically acceptable cold ischemic time for the livers was 12 hours, rather than the 12 to 18 hours cited by DHHS in its rulemaking. Third, rather than recommending national sharing, it suggested priority be given within units of at least 9 million people, a population larger than that served by most organ procurement organizations but smaller than any of the eleven OPTN regions. The IOM study led DHHS to revise the final rule so that it no longer called for national sharing but rather directed the OPTN to reduce “arbitrary geographic barriers” to allocation to the greatest extent possible (DHHS, 1999, p. 56651; DHHS, 2000).

During this controversy, the OPTN committees continued to assess changes to the liver allocation rules that resulted in several modifications that moved incrementally closer to broader geographic allocation. The adopted modifications included: establishment of regional boards to review the assignment of patient status; adoption of a purely quantitative severity scoring method (MELD/PELD, which we subsequently discuss in detail); and, most importantly, gave priority to regional Status 1 patients (those with the shortest life expectancy without a transplant) over all non-Status 1 patients. These changes were fully implemented in a new liver allocation system in 2002.

The third period involved continued efforts within the OPTN to improve allocation and incrementally reduce the importance of geography in liver allocation. In 2005, patients within the region with the worst prognoses (Status 1) were given priority in allocation over local non-Status 1 patients but not over local Status 1 patients; in 2010, all Status 1 patients within the region were placed on the same waiting list so that local Status 1 patients no longer had priority over regional Status

1 patients. In 2012, the stage was set for substantial reconsideration of the geographic basis for liver allocation with recommendations from the DHHS Advisory Committee on Transplantation and the adoption of a strategic plan by the OPTN Board of Directors calling for reductions in the importance of geography for allocation of all organs.

The fourth period, the focus of our analysis, involves the response of the Liver and Intestinal Organ Transplantation Committee to the OPTN strategic plan (see Table 2). The result of this effort was the substantially new liver allocation system that took effect in February 2020. A fifth period now underway involves efforts to replace local and regional boundaries with continuous measures of distance reflecting “placement efficiency”, not just in liver allocation but in organ allocation generally.

Defining Medical Urgency: MELD/PELD and Its Discontents

In 2000, the DHHS Final Rule declared that liver allocation should be determined by medical urgency and that weight given to the geographic location of patients and their time spent on the waiting list should be minimized. The rule came in response to objections to the previous system, whereby patients with a less urgent need but favorable geographic location and more time on the waiting list were given liver transplants before those with greater medical urgency (i.e., high waiting list mortality). In response, the OPTN sought a metric that would more objectively measure the severity of the chronic liver disease to facilitate more equitable allocation within geographic units. The resulting metric, which built on a scale originally developed to assess mortality risk from shunts used to treat complications of portal hypertension (Malinchoc et al., 2000), is called the Model for End-Stage Liver Disease (MELD).

MELD is a scoring system that determines medical urgency for those on the liver transplant waiting list based on three quantitative scores from lab-based tests: the levels of serum bilirubin, the international normalized ratio of prothrombin time (INR), and serum creatinine (Elwir & Lake, 2016; OPTN, 2020b). Calculated MELD scores range from 6 to 40, with higher scores indicating greater medical urgency. A parallel version of MELD, called the Pediatric End-stage Liver Disease (PELD) model, was created for assessing disease severity for pediatric patients 11 years or younger (Chang et al., 2018). Like MELD, it includes bilirubin and prothrombin time, but also albumin (as a measure of the capacity of the liver to store nutrients), growth failure, and the status of the child as being younger than 1-year old (McDiarmid Sue, Anand, Lindblad, & Principal Investigators and Institutions of the Studies of Pediatric Liver Transplantation SPLIT Research Group, 2002). The latter two metrics have obvious relevance to children. The scoring systems were created by researchers at the Mayo Clinic as metrics of the likelihood of mortality within three months for patients in need of a liver transplant (Forman & Lucy, 2001; Kamath et al., 2001). The MELD/PELD score replaced the alternative scoring system called the Pugh-Child-Turcotte medical urgency classification (Weimer, 2010a), which assigned points for both quantitative and

Table 2. Major Effort to Reduce Importance of Geography in Allocation

2012: *Board directs organ-specific committees to define the measure of fairness*	Board agreed that observed geographic disparities in access to organ offers were unacceptably high and charges organ-specific committees to develop policies to minimize the effects of geography.
2013: *Share 35 policy broadens regional and national access for highly urgent liver transplant candidates*	Decreased wait time, increased access, and decreased waitlist mortality for candidates with a MELD of 35 or higher.
2014: *Liver Redistricting Concept Paper*	The Liver Committee released a concept paper and questionnaire seeking public input on distributing livers over larger districts than existing regions.
2014: *Public forum on liver redistricting in Chicago*	The Liver Committee held a public forum to seek additional input regarding liver redistricting concepts. Workgroups were formed to study issues relating to potential redistricting.
2015: *2nd public forum on liver redistricting in Chicago*	Workgroup findings and modeling results were presented; additional modeling was requested to study the potential impact of distribution within concentric circles surrounding donor hospital.
2015: *Revised policy for exception scores for hepatocellular carcinoma (HCC)*	Capped HCC exception pointed at 34 and added a 6-month delay before HCC points are initially awarded.
2016: *Additional element added to medical urgency calculation*	Helps patients whose MELD will increase by adding serum sodium as an additional factor.
2016: *Initial public comment on the proposal*	The Liver Committee sought public feedback on a proposal to establish new districts for liver distribution. Based on public feedback, the committee chose to investigate other options.
2017: *Enhanced liver distribution policy approved*	The revised policy offers greater transplant access to candidates at a higher medical priority level who are local to the donor hospital, whether they are inside or outside current regional boundaries.
2017: *National Liver Review Board (NLRB) approved*	A national board will replace the individual review boards in each of the 11 OPTN regions, creating greater consistency in assigning exception scores for medical conditions not assessed reliably by MELD or PELD scores.
2018: *New geographic rules approved*	New geographic allocation rules are determined by the Ad Hoc Geography Committee. These new rules consider no fixed boundaries and consider organ allocation through a combination of factors, particularly medical urgency and proximity.
2019: *MELD exception scores during NLRB transition*	Using the median MELD at transplant in the Donation Service Areas (MMaT/DSA) instead of MMaT/250 during the period between the implementation of the National Liver Review Board (NLRB) and implementation of liver allocation changes.
2019: *Suit filed to block implementation of a new policy*	Challenge from several patients and transplant centers on procedural grounds.
2020: *Court lifts injunction and new policy with acuity circles takes effect on February 4.*	Acuity circles replace DSA and region as geographic determinants: priority based on distance in nautical miles from donor hospital: 150, 250, and 500 nm define circles within 150 nm unless other more distant candidates have considerably greater medical urgency.

qualitative patient characteristics. The MELD/PELD score has been central to liver allocation since its introduction in 2002.

The structure of liver allocation in 1996 provides the reference point for conveying the nature of the shift ushered in by the MELD scoring system. In 1996, patients had four status levels, from most urgent to least (Edwards & Harper, 1996). Status 1 was for patients admitted to intensive care units for illnesses attributed to chronic liver failure and who had life expectancies of less than a week. Status 2 was for patients who were in intensive care units or who have been in an acute care bed for 5 or more days. Status 3 was for patients who required continuous medical treatment on an ongoing basis but without hospitalization. Status 4 was for patients functioning without significant morbidity so that a liver transplant would be considered elective. Geographic priority was given first for local patients (those at transplant centers served by the Organ Procurement Organization that recovered the liver), then to regional patients (those at transplant centers in the OPTN region within which the Organ Procurement Organization was located), and finally national patients (those at any U.S. transplant center). Within each of these geographic designations, patients were prioritized by status into three categories: Status 1 (highest priority), Status 2, and those in either Status 3 or Status 4 (lowest priority). Within each category, priority was determined by the most accumulated points. Up to 10 points were given for waiting time and up to 10 points for blood type compatibility within each category; within the third category Status 3 patients received 12 points and Status 4 patients received 6 points.

In 2002, the MELD scoring system became the primary indicator of patient status and therefore rank-ordering of patients within a geographic area (UNOS, 2002). Patients with fulminant liver failure and a life expectancy shorter than 7 days were assigned Status 1. The geographic-status hierarchy gave priority for allocation according to MELD score within six categories: (i) local Status 1 patients, (ii) regional Status 1 patients, (iii) local non-Status 1 patients, (iv) regional non-Status 1 patients, (v) national Status 1 patients, (vi) national non-Status 1 patients. When patients had equal MELD scores (which were rounded to the nearest integer), ties were broken in favor of the patient with the longer time on the transplant waiting list.

The implementation of the MELD/PELD scoring system resulted in measurable improvement by reducing the racial disparities that had existed in liver allocation (Moylan et al., 2008). Before MELD/PELD, black patients were more likely to die or become sick before organ transplantation, were generally younger, and were less likely to obtain an organ within 3 years of being placed on the waiting list compared to white patients. However, after the implementation of MELD/PELD, significant disparities in liver access between black and white patients were effectively eliminated. Using medical severity as the primary factor in liver allocation, MELD/PELD ensured that livers went to the sickest of patients rather than to those who spent the most time on the waiting list. While the use of MELD/PELD has contributed to a more equitable system in terms of medical urgency, the disparity between men and women in liver allocation remained. Even after the introduction of MELD/PELD, women were more likely to die or get sick while on the liver transplant waiting list and less likely than men to receive a liver (Moylan et al., 2008).

Despite MELD/PELD's positive impact on the liver allocation system, the OPTN has continuously sought to make exceptions to accommodate cases for which the MELD/PELD scores seemed not to reflect medical urgency appropriately. As noted, MELD scores are based on laboratory tests to determine the likelihood of survival over three months without a transplant. After the lab tests are conducted, the MELD formula produces a score that indicates the urgency with which the candidate needs a transplant. While this approach has made the system more equitable overall, the OPTN's Liver and Intestinal Organ Transplantation Committee (the Committee) has provided several exceptions to the scoring system. For some diseases, lab-test results used in MELD do not accurately capture the urgency with which candidates need liver transplants. For these cases, medical teams caring for liver transplant candidates can request exceptions to the MELD score that give patients higher priority. The clearest example of such exceptions is the one for Hepatocellular carcinoma (HCC), the most frequently requested exception (OPTN, 2016a).

The HCC exception illustrates how rules are adopted by the OPTN. Committee members typically draw on two sources of information to assess proposed rule changes: SRTR modeling and public comment to supplement the tacit knowledge of committee members. The Committee uses SRTR statistical analyses and modeling to predict the consequences of possible rule changes. Public comment occurs when the OPTN releases its proposed rule changes to allow the public (in theory, any interested party but typically those involved in transplantation as providers, patients, or interest groups) to offer comments and analysis. For example, in January of 2016, the Committee submitted for public comment a proposal to cap HCC MELD scores (OPTN, 2016b). To improve equity, the Committee set the HCC exception score at 34. However, this unintentionally conflicted with an existing policy that mandates candidates younger than 12 years with HCC be given a PELD score of 41. As there was no evidence that the HCC dropout rate for children was the same as for adults, for whom tumor growth can preclude transplantation, the Committee decided that it would remove the cap for pediatric candidates until additional modeling could provide guidelines. At the end of this process, the Committee proposed that all candidates with HCC under 12 years would receive PELD scores of 41 following their second exception extension (points added every three months to their scores) granted while on the waitlist. The above process is the typical format for changes to OPTN policies: a problem becomes apparent, the Committee seeks more information and modeling to help identify and support a proposed response, and the proposal is submitted for public comment.

When the Committee is seeking evidence to assess possible policy changes, it often turns to the SRTR to model the potential impacts of the changes. The SRTR receives data primarily from the OPTN, organizes these data, and compiles statistics, summary reports, and other statistical analyses. These analyses are then provided to the various OPTN committees as requested and are publicly available for other members of the transplant community to view (SRTR, 2020a). The key metrics studied in SRTR analyses are "deaths within the DSA [the Donation Service Area that defines 'local'], deaths meeting standardized definitions of 'eligible' or 'imminent' deaths, how often deceased individuals become donors, and how many organs are successfully placed for transplant" (SRTR, 2020b). For example, in October 2017 (OPTN, 2017c), the Committee requested modeling from the SRTR to evaluate its proposal to award proximity MELD points to transplant candidates who were within 150 miles of a transplant center and had a minimum MELD score of 29. SRTR staff attended Committee meetings to discuss their findings. In this case, using the Liver Simulated Allocation Model (LSAM), the SRTR staff reported that, among other findings, this policy change would result in waitlist mortality rate decreases across all regions (OPTN, 2017b). As in this case, Committee members commonly discuss the results with the SRTR staff during meetings and consider their implications for moving forward with proposed changes.

In 2016, several changes were proposed to make the MELD/PELD scoring system more accurately reflect medical urgency. Several members of the Committee began to acknowledge that the MELD/PELD lab scoring system was flawed and that patients on the list often received exceptions to the lab-test-based scores (OPTN, 2016b). However, there was a considerable irregularity in the granting of exceptions accompanied by their increased use—between 2002 and 2008, the proportion of patients receiving exceptions steadily rose, reaching 15.5 percent for HCC and 13.5 percent for other exceptions (Massie et al., 2011). Further, the average change in MELD points varied from 1.5 to 12 points across DSAs (Ladner & Mehrotra, 2016). To correct for these irregularities, the Committee proposed the National Liver Review Board, a body meant to replace the eleven Regional Review Boards (RRBs) and thereby make the exception-granting system more uniform nationally. While the NLRB was awaiting OPTN approval, the Committee sought to address disparities, such as by providing formal guidance for MELD/PELD exceptions (OPTN, 2016a).

In 2017, the proposals for the NLRB and the MELD/PELD exception guidelines were accepted by the OPTN Board of Directors (OPTN, 2017e). Transplant center-specific calculations of Median MELD at Transplant (MMaT) are routinely updated and serve as the basis for awarding exceptions (Kalra & Briggins, 2018). For example, the exception for adult hepatopulmonary syndrome is the MMaT minus three points and thus varies across transplant centers to reflect the medical urgency of those receiving transplants. Following the adoption of the exception proposals, the Committee began to make the MELD/PELD scores sensitive to geography, adding three MELD/PELD points to patients at transplant centers within 150 nautical miles from a donated liver and a score of at least 32. For many exception cases, the MELD/PELD score is adjusted to the usually capped score of 40. However, the Committee proposed lifting the cap for those within the geographical range as necessary to obtain additional points (OPTN, 2017c). The OPTN's frequent willingness to change the liver allocation rules demonstrates the complexity of the interests at play and the analysis and information needed to properly accommodate them in rule changes.

It is worth noting the value of simulation models made possible by the SRTR database in supporting changes in liver allocation rules. In 2001, the Liver Simulated Allocation Model (LSAM) replaced an older simulation model, the UNOS Liver Allocation Model (ULAM), as a tool for predicting the consequences of changes in liver rules (Kim, Gupta, Israni, & Kasiske, 2015). The LSAM provides quantitative predictions of the impacts of potential rule changes. LSAM and its adaptations have also been the basis for published research addressing a variety of policy alternatives, such as with respect to exception scores (Heimbach et al., 2015), alternatives to MELD scoring (Bertsimas et al., 2019), redrawing geographic boundaries (Kilambi et al., 2017; Mehrotra et al., 2018), and as the focus for debates over how dynamic geographic boundaries should be in the face of behavioral responses to rule changes (Gentry, Dorry, Kasiske, Mulligan, & Hirose, 2015; Mehrotra et al., 2015).

Defining Geography: Historical Versus Distance-Based Boundaries

With the stated aim of improving equity in allocating liver transplants, the Committee has often considered the role of geography. Until recently, most of the discussion has been in the context of shifting allocation priority from the local area toward the existing OPTN regions. However, the most recent change in allocation rules involved a fundamental tension between maintaining the historical reliance on regions and switching to a purely distance-based measure for defining geographic priority.

As previously noted, the Final Rule in 2000 required that decisions be made based on medical urgency and that location should not be a major factor in liver allocation. However, with cold ischemic times for livers placing limitations on the distance they can be transported, some geographic considerations were medically relevant. As a result, liver allocation is based on both medical urgency (determined by MELD/PELD and exceptions) and the local-regional-national priority for Status 1 patients (Elwir & Lake, 2016). In 2005 the Regional Share 15 Rule, which stated that "Organs must first be offered to patients with MELD scores of 15 or greater locally and then regionally before making the organs available to local patients with MELD scores under 15," was adopted to reduce geographic disparity (Bittermann et al., 2012, p. 1302). Following the implementation of the Regional Share 15 Rule, waitlist mortality declined nationally (Washburn, Pomfret, & Roberts, 2011).

In 2012, the DHHS Advisory Committee on Transplantation recommended that organs be allocated based on medical criteria and not on the arbitrary confines of OPOs, or DSAs for which they recover organs. As a result, the Health Resources and Services Administration (HRSA) indicated its support for the development of organ allocation systems that minimize the inconsistency among DSAs (OPTN, 2019a). In response to the DHHS recommendations, the OPTN issued a strategic plan aimed at reducing geographic disparities in transplantation access across all organs.

The next step in this process with respect to livers was the 2013 Regional Share 35/National Share 15 policy, which required that patients within the region with

MELD scores greater than or equal to 35 be given priority over local patients and that if no patient within the region had a MELD score of 15 or greater, then the liver would be offered nationally before being made available locally (Elwir & Lake, 2016). One year after the implementation of the Regional Share 35/National Share 15 policy, a study found that there was a 30 percent lower waitlist mortality for patients with MELD scores higher than 30, an increased number of transplants, and fewer discarded livers (Massie et al., 2015).

In 2014, the Committee circulated a concept paper on approaches to reducing geographic disparity (OPTN, 2014). It presented results from analyses using the LSAM to find optimal regions in terms of reducing variance in MMaT across regions and minimizing volume-weighted average transport times (Gentry et al., 2013; Gentry, Hirose, & Mulligan, 2016). The concept paper focused on comparisons of transplant outcomes of the then existing system with fully regional sharing, national sharing, and sharing within either four or eight novel regions created through optimization algorithms. Compared to the existing system, the novel regions were predicted to reduce the percentage of transplants for patients with MELD scores of less than 15 and increase the percentage of transplants for patients with MELD scores of greater than 25; increase the percentage of pediatric transplants; and reduce both the overall mortality and waiting list mortality rates (p. 10). The modeling approach and results were not without critics. For example, some researchers noted that the modeling did not adequately take account of various uncertainties and others feared substantial reductions in the volume of their transplants (Lamas & Rosenbaum, 2014).

In December 2017, the OPTN Board of Directors created the Ad Hoc Committee on Geography. Among its charges was "Reviewing and recommending models for incorporating geographic principles into allocation policies" for all transplant organs (OPTN, 2018a). It recommended three different models: first, boundaries based on the sort of mathematical optimization discussed in the Committee's concept paper; second, circular boundaries based on distance (what would subsequently be referred to as acuity circles); and third, the replacement of boundaries with weights applied directly to proximity, which later gained the current label of "continuous distribution." The weight would be based on medically relevant factors, such as cold ischemic time, and likely be discontinuous across "nearest donor," "neither near nor too far," and "likely too far" (Snyder et al., 2018). The Board of Directors approved the principles set out in the report by a vote of 32 to 5 on June 12, 2018.

The Committee had already begun to consider making use of concentric circles to increase national sharing, which would award three MELD/PELD proximity points to candidates within a 150 nautical mile (nm) radius circle around the donor hospital (OPTN, 2017a, 2017d). In July 2018, the DHHS Secretary, prompted by a lawsuit filed against the Secretary and OPTN to eliminate the use of "arbitrarily drown boundaries" in liver allocation, called on the OPTN to adopt a liver allocation policy that did not use DSAs (Dunn & Shepard, 2019). The OPTN Board instructed the Committee to respond. In addition to acuity circles, the Committee considered the Broader 2 Circle (B2C) plan, which would sort candidates into larger bands of MELD/PELD scores than would acuity circles proposal. The Board posted the proposals for public comment between October 8 and November 1, 2018.

Based on SRTR modeling of the two plans and consideration of over 1,200 public comments, the Committee voted 11 to 9 in favor of recommending the B2C plan (OPTN, 2018f). The subsequent Board meeting considered the proposals (OPTN, 2018g). After a presentation by the Committee chair, presentations by members of the Board, and over four hours of debate, the Board voted in favor of adopting acuity circles with 24 votes in favor and 14 opposed (Dunn & Shepard, 2019).

During the debate over the rule change, many regional representatives voiced their concerns that this push toward broader sharing would hurt patients in rural areas, as they typically live farther away from donor hospitals than patients in urban areas. Additionally, there was concern that such broader sharing would reduce the quality and success of liver transplantation because of the longer time livers would spend in transit. However, modeling by the SRTR suggested that the policy would increase pediatric transplantation, reduce geographic variation in medical urgency scores at the time of transplant, and reduce pre-transplant deaths (UNOS, 2020). Additionally, the U.S. Department of Justice had labeled the use DSAs in allocation in its review of lung transplantation as irrational and without basis, further bolstering the move toward acuity circles (OPTN, 2018b).

Basing geographic allocation on acuity circles was not without precedent. For heart and lung transplants, DSAs and concentric circles around them have been used since the first allocation system adopted in the 1980s. The allocation begins in DSAs, followed by zones A through E. Zone A is defined as within 500 nautical miles from the donor hospital, zone B is within 1,000 miles, zone C is within 1,500 miles, zone D is within 2,500 miles, and zone E is within 2,500 miles (Colvin-Adams et al., 2012). A major rationale for transitioning to acuity circles over sharing within existing regions is that the large and historically determined regions do not result in consistent distances between transplant candidates and donor hospitals. Most dramatically, a patient just across the regional border from a donor would receive lower priority than someone potentially hundreds of miles away but within the donor's regions. Acuity circles provide a direct measure of how close a candidate is to the donor.

Under the new rule, a reference to DSAs and regions are removed from allocation in favor of distance from donor hospital. The distance categories in this new framework are 150 nautical miles (nm), 250 nm, and 500 nm (OPTN, 2020d). As procurement methods need to be adjusted from driving to flying at about 150 nm, the 150 nm radius was suggested as the smallest circle (OPTN, 2018e). The outcome of this policy was meant to align with the Final Rule's aim to improve efficiency in allocation. As with lung transplant allocation policy, simulations of the transition to using 250 nm circles did not show an increase in discards, an example of a use of the liver allocation model that influenced discussion within the committee (OPTN, 2018c). The 500 nm circle is approximately the size of OPTN regions. Additionally, about 95 percent of liver transplants already occurred within 600 nm of the donor hospital. Overall, the modeling provided enough evidence for the Committee to be comfortable moving forward (OPTN, 2018d).

After proposing this policy, the Committee sought public comment. The public comment was open from October 8, 2018 to November 1, 2018 (OPTN, 2018h). Some of the commenters thought that the proposal did not go far enough toward achieving equity or other stated goals, some approved of the changes, and others saw the proposal as overreach. The public comment entries totaled 821. In terms of the status of commenters, 42 of the entries were from transplant centers, 20 were from different regions and OPTN Committees, 427 were from individuals and other organizations, and 332 were anonymous.

In response to these concerns, the Committee made four changes to its proposal. The first was to change "the MELD threshold to 29 for liver allocation and SLK [simultaneous liver-kidney transplants]," the second was to add "an exception to blood type O allocation for Puerto Rico," the third was to add "a provision for treating livers from Alaska as if they were recovered in Seattle," and the fourth was to establish a "recommendation that the changes to allocation will not take effect until at least three months after the implementation of the NLRB" (OPTN, 2018h).

Concerns were raised, especially by transplant centers, about how high the sharing threshold for MELD was set in the proposal. About 10 percent of comments supported the proposed threshold was 32. As was pointed out in various comments, a threshold of 29 for the 250 nm circle is where the difference in mortality rates increased the most dramatically, so placing it there would most effectively promote access to transplantation for those who most urgently need it. This view was expressed by 24 percent of the commenters, which made it the most popular position. To "balance efficiency and access by urgency," OPTN made the decision to lower the MELD sharing threshold to 29 for the 250 nm circle, which was also the desired threshold in the public comment (OPTN, 2018h).

In the public comment proposal, Hawaii was granted a blood type O donor allocation variance, which would keep more of these livers in Hawaii. However, a similar variance was not included for Puerto Rico (OPTN, 2018h). According to the Committee, "the variance changes the order of allocation to include any blood type recipients in the same classifications. This removes the priority for O and B candidates that would otherwise exist when allocating O donors and allows for the allocation of O donors to A and AB candidates in Hawaii before national offers to O and B candidates" (OPTN, 2018h). In addition to the public comments seeking a variance for Puerto Rico, the Minority Affairs Committee recommended that, due to Puerto Rico and Hawaii's similar situations of geographic isolation and largely ethnic populations, the variance be extended to Puerto Rico. As a result of these recommendations, the Committee decided to extend the variance to Puerto Rico.

Concerns were raised about access to livers recovered in Alaska, which does not have any transplant hospitals. As all U.S. transplant centers would be outside the 500 nm acuity circle, livers recovered in Alaska would be equally available to all U.S. patients, even those from whom transportation was not feasible. In response, the proposal was modified so that Alaskan organs are to be treated as if they were recovered in Seattle (OPTN, 2018h).

The fourth policy change responded to comments that the desired implementation to proceed more slowly so that the transplant community would have more time to adjust to the new allocation system. In response, the geographic changes to the allocation system would be implemented only three months after the implementation of the NLRB (OPTN, 2018h). The delay ensured that the NLRB would be able to produce consistent exception scores before the new allocation rules are implemented.

In addition to these concerns raised in public comments that elicited proposal modifications, there were some that were not addressed. One of the most frequently raised concerns was that the proposed acuity circles were not large enough. Of specific concern, especially expressed by commenters from South Texas, was that areas near large bodies of water and those isolated from large population centers were disadvantaged in a system with smaller circles. Another related complaint was that the proposed circles did not account for population density. Advocates of implementing a population-based framework found it more equitable to have wider circles for rural areas and smaller ones for urban areas.

After the adoption of the acuity circle policy, a lawsuit was brought against the OPTN, suggesting that the policy violates the Final Rule. The plaintiffs, 13 liver transplant centers, and several transplant candidates argued that the use of acuity circles is a move away from the Final Rule's mandate that organ allocation be primarily based on medical urgency rather than geography. Although the suit primarily alleged procedural defects, the plaintiffs made substantive claims of harm: "This policy will result in fewer liver transplants performed nationally and considerably fewer liver transplants performed in the communities that the Transplant Center Plaintiffs serve. Dramatically longer travel times for available organs and logistical inefficiencies will cause an increased percentage of viable livers to go to waste (*Callahan et al. v. DHHS and UNOS*, 2019, p. 9). The defendants in the case (OPTN and DHHS) have relied on the reasoning that the policy of using OPTN regions and DSAs are not representative of a donor's geographic distance from transplant candidates. Unlike acuity circles, DSAs and regions vary in shape, size, and population, which generates inconsistency in how organs are allocated. According to the defendants, this inconsistency itself violates the Final Rule (OPTN, 2018g, 2019b). Implementation of the acuity circle policy for livers and intestines began February 4, 2020.

The acuity circle policy replaced the legacy of local and regional boundaries with distances between donors and transplant candidates. In parallel with the finalization of this policy, the OPTN committed to developing priority scores that take account of distance as a continuous measure rather than through boundaries (Dunn & Shepard, 2018). The goal of the continuous distribution approach is eventually to base allocation for all organs on priority scores computed as weighted sums of measures of medical urgency, post-transplant survival, candidate biology, patient access, and placement efficiency. Within this framework, the distance will enter only through placement efficiency, the resources required to identify candidates willing to accept organs and to deliver the organs for transplant. The challenge in this new era will be reaching sufficient consensus on the weights to be placed on measures to support the adoption of continuous measures. Students of multidimensional decision-making may want to take advantage of rare opportunities to study this consequential multistakeholder balancing process made possible by OPTN transparency.

Discussion

In the United States, geography predicts social conditions, such as crime and poverty, and influences the provision of public services such as schooling. Both public health and the accessibility of medical care depend in important ways on geography. Air pollution, poor water quality, food deserts, and gun violence disproportionately affect neighborhoods with low-income populations. Even with health insurance, many rural residents face high travel costs that greatly reduce their effective access to medical care. Despite the nationalization of the supply of deceased-donor organs for transplantation in 1984, geography continues to play a role in who gets a transplant. Especially with respect to liver transplants, which are the only life-preserving response to liver failure, this role has life and death consequences.

The role of geography in organ allocation has both a normative rationale and positive explanations. The normative rationale is that a donated organ has a cold ischemic time during which it is viable that is less than a day. Consequently, other things equal, gaining the greatest medical value from this scarce resource requires as short a time as possible between donation and transplant to maximize graft success. As cold ischemic time necessarily increases with the time it takes to transport an organ from the donor to the recipient; there is a medical rationale for considering geography.

Geography has persisted as an important factor in organ allocation for two positive reasons. First, the historical legacy of the voluntary organ sharing system established a status quo of existing geographic boundaries when the OPTN was created. Consequently, allocation of solid organs began in the context of local priority that was inherent in the pre-OPTN voluntary sharing system. Explicit changes that often create very aware losers as well as winners have been required to reduce the importance of geography. Second, as organs are a scarce resource in transplantation and therefore relevant to both the rents enjoyed by transplant centers and the welfare of their patients, transplant centers have strong incentives to preserve or obtain favorable rules for receiving organs. These interests make changing the role of geography inherently controversial.

The liver allocation rules that went into effect in 2020 include a major change in the role of geography that resulted from an incremental decision process operating over 8 years. Motivating the process was the Final Rule, which called for minimization of the role of geography in allocation. Its more vigorous embrace by the Board of Directors in the 2012 OPTN strategic plan created an expectation for change by the Committee. As with the major changes to kidney allocation rules implemented in 2014, the process was characterized by the necessity to deal with multiple dimensions of complex allocation rules, use of SRTR data and simulations, reliance on both Committee and external expertise, evaluations of the impacts of incremental changes in policy, solicitation of comment from the wider transplantation community, and transparency. On the one hand, the replacement of local and regional boundaries with acuity circles seems like a natural borrowing of an approach that was being used in heart and lung allocation. On the other hand, their use in conjunction with the total elimination of DSAs in the allocation process is more radical and likely paved the way for a similar change to kidney allocation adopted in December 2019 and initially scheduled for implementation in December 2020.

Conclusion and Policy Implications

An increasing role of the federal government in overseeing the provision of medical care will almost certainly raise issues with conflicting values and interests. The traditional form of governance, agency rulemaking, poses challenges in engaging appropriate expertise and maintaining legitimacy. The OPTN changes in liver allocation rules, albeit slow and not without controversy, demonstrate how expertise and evidence can be continually engaged, medical values weighed, and legitimacy achieved through transparency. In this form of governance, the federal agency sets general goals but relies on the stakeholder organization to do the substantive work necessary to make informed policy changes to promote those goals. In situations in which scarce medical resources must be allocated, similar institutional arrangements should be considered as alternatives to traditional agency rulemaking for transparently implementing evidence-based medicine.

What conditions would make stakeholder rulemaking like that of the OPTN feasible and possibly more attractive than agency rulemaking? To be feasible, the stakes must be sufficient to engage the full range of stakeholders on a continuing basis to provide an ongoing representation of interests and credible expertise so that the arrangement is widely accepted as a legitimate forum for rulemaking. Access to scarce transplant organs provides such stakes for the OPTN. Budget constraints imposed on some categories of medical care could provide sufficient stakes if they are binding. Cost-control measures in the context of universal healthcare access in the United States might set the stage for such hard budget constraints. For example, stakeholder rulemaking might be employed to set reimbursement rates in the context of a surgery budget for Medicare (Weimer, 2010a).

Stakeholder rulemaking is likely to be relatively desirable when accumulating knowledge supports incremental adjustments to rules. Through the continuing engagement of stakeholders with expertise and explicit decision rules, it has the potential for incrementally integrating new evidence into rules rather than episodically through the major rule changes that tend to characterize agency rulemaking. It might also provide an incentive to develop better evidence—for example, having to justify reimbursement rates for surgeries would create an incentive to develop more information on effectiveness. Current concerns about inappropriate political influence over the Centers for Disease Control and Prevention, the Food and Drug Administration, and other federal agencies with health-related responsibilities during the COVID-19 pandemic also make the consideration of governance forms like the OPTN timely. Unlike these federal agencies, which develop the content of rules largely in the camera before seeking public comment, OPTN processes are fully transparent and therefore more credibly based on appropriate medical evidence and explicit consideration of values.

Finally, it is important to recognize the value of having near-universal longitudinal data on transplant candidates and recipients—evidence-based medicine requires evidence, which, in turn, requires data. The analyses produced by the OPTN and SRTR have played a fundamental role in supporting changes in allocation rules. Investment in comparable databases in other areas of medicine would potentially contribute to both knowledge and better practice.

Notes

Conflicts of interest: None declared.

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World Medical and Health Policy

Policy Analysis of Gastrointestinal Cancer Prevention in Iran: A Framework Based on a Qualitative Study

Neda Kabiri, Rahim Khodayari-zarnaq, Manouchehr Khoshbaten, and Ali Janati

This study aimed to analyze the current policies of common gastrointestinal cancer prevention. This qualitative instrumental case study was conducted in 2019 to analyze policies using the "policy triangle framework." Two data collection methods were used: document review and semistructured interviews. The country's related documents were searched through databases. Semistructured interviews were conducted at the interviewee's workplace. In total, 22 participants were interviewed, 12 of whom were from the Ministry of Health. Interviews and documents were analyzed using directed content analysis in MAXQDA v10 software. Interobserver reliability, peer check, and member check were done to confirm the trustworthiness of data. The main contextual factors affecting gastrointestinal cancers in Iran were socioeconomic, structural, political, and legal factors. Content of gastrointestinal cancer prevention in the national policies were mostly about lifestyle changes, food security, and environmental conditions. Efforts for cancer prevention policymaking in Iran starts in 1984 with a top-down approach to the implementation and three types of evaluation. Stakeholders of gastrointestinal cancer prevention policies in Iran were categorized into three groups of governmental, nongovernmental, and semigovernmental organizations. Coordination among different organizations should be strengthened through setting common goals and creating a shared vision, and finally, political leadership should be realized by the Ministry of Health.

KEY WORDS: gastrointestinal cancers, health policy triangle, Iran, policy analysis

Introduction

Cancer is a result of abnormal and uncontrolled growth of cells in the body, attacking normal tissues, and may spread to other organs throughout the body (Prasad et al., 2020). Cancers are the second cause of global death, which led to 9.6 million deaths in 2018 (WHO, 2019). Results from a study in 2018 showed that five types of gastrointestinal cancers, including gastric, colorectal, esophageal, liver, and pancreas, continue to be the major challenges of health systems worldwide. Among these, esophageal, gastric, and liver cancers were more common in Asian countries (Arnold et al., 2020).

Trends for gastrointestinal cancers are increasing, especially for stomach, colorectal, esophageal, and liver cancers in Iran (Moradpour et al., 2016; Nikbakht et al., 2020; Salehi, Ahmadi, Ahmadi Soodejani, & Shahini Shams Abadi, 2018; Salimzadeh et al., 2018). Iran has a higher burden of stomach and esophagus

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cancers in comparison with countries from the Middle East and North Africa (Sepanlou et al., 2015). In 2017, the incidence of stomach cancer worldwide was more than 1.22 million cases (Etemadi et al., 2020). Results from the global burden of diseases in 2015 showed that stomach cancer was ranked second in Iran for the age-standardized incidence rate (GBD, 2018). The age-standardized mortality rate for liver cancer in Iran has increased significantly during recent years (Naghavi et al., 2014). Results of one study from Central Iran showed that the age-standardized incidence rate of gastric cancer has increased in females (Moradzadeh & Anoushirvani, 2020). Also, in another study, the northern half and south border of Iran were recognized as high-risk regions of gastric cancer (Pourhoseingholi, Najafimehr, Hajizadeh, & Zali, 2020). Research from Golestan province showed that the overall incidence of colorectal cancer increased in men and women in recent decades, mostly in urban areas (Hasanpour-Heidari et al., 2019). Liver diseases have also shown to increase in Iran, accounting for 1.42 percent of all deaths in Iran in 2017 (Anushiravani & Sepanlou, 2019; Farhood et al., 2019). Based on the results of research, age-standardized incidence rates of esophageal cancer increased in North and West of Iran (Moradzadeh, Golmohammadi, Ghaitasi, Nadrian, & Najafi, 2019; Pournaghi et al., 2019). These examples of increasing trends in the studied cancers in Iran might be considered as a warning to Iranian health stakeholders, including health policymakers and health-care providers, to design interventions and policies to prevent these fatal conditions and their risk factors.

Although there are no recommended cost-effective and sensitive screening interventions for gastrointestinal cancers except for colorectal, primordial prevention strategies are available for these cancers (Griffin-Sobel, 2017; Hamashima, 2014; Kim & Shah, 2017; Lindquist, Miller, Hammond, & Nikolaidis, 2018). Interventions adopted by different countries for primary prevention of gastrointestinal cancers include hepatitis B vaccination, anti-*Helicobacter pylori* (*H. pylori*) treatment, lifestyle change, and physical activity promotion (Brenner & Chen, 2018; Cheng, Yao, Xu, & Niu, 2016; Shams & Haug, 2017). These interventions have shown to be effective in different countries. For instance, the eradication of H.pylori in China significantly decreased the development of gastric cancer (Wong et al., 2004). Also, hepatitis vaccination and controlling alcohol consumption in Africa had led to a decrease in liver cancer (Ndom, 2019).

Concerns regarding gastrointestinal cancers and their high prevalence in Iran forced us to analyze the current policies related to the prevention of cancers of the colon, stomach, liver, esophageal, and pancreas.

Methods

Study Framework

This study was conducted in 2019 to analyze gastrointestinal cancer prevention policies in Iran. We adopted Walt and Gilson's (Walt et al., 2008) “Policy triangle framework” approach that focuses on content, context, process, and actors (see Figure 1). This model is widely utilized in analyzing health sector policies in different

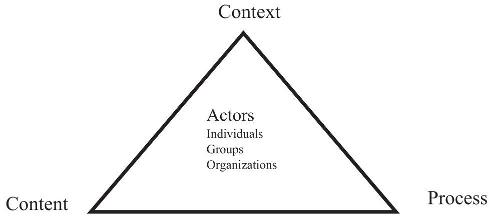

Figure 1 Policy Analysis Triangle.

countries (Chen, Wong Wu, & Zhu, 2020; Doshmangir, Moshiri, Mostafavi, Sakha, & Assan, 2019; Munabi-Babigumira, Nabudere, Asiimwe, Fretheim, & Sandberg, 2019). Also, the model was useful in obtaining the objectives of the current study.

- Context: refers to political, economic, and social factors that may influence health policy.
- Content: refers to the detail of the policy and its constituent parts.
- Process: involves how policies are initiated, developed, negotiated, implemented, and evaluated.
- Actors: refers to individuals, organizations, and governments who influence policy (Buse, Mays, & Walt, 2012).

Type of Study

We used a qualitative instrumental case study methodology to analyze policies implemented for the prevention of gastrointestinal cancers in Iran. An instrumental case study is used to accomplish something other than understanding a particular situation. The case is looked at in-depth in this type of study (Baxter & Jack 2008).

Data Collection Techniques

We used two data collection methods: document review and in-depth interviews.

Document Review

A document review was used initially to identify policies. The main focus of the document review was the selection of main policies of the Ministry of Health in Iran and the policies of other organizations related to the prevention of cancers. A comprehensive search, with no time limit, was conducted on the policies related to the prevention of gastrointestinal cancers. The search engine used was Google. In addition, the available documents on the web pages of MOHME, all medical sciences universities, and their concerning research centers, which were related to gastrointestinal cancers in Iran, were searched. Also, the web page of Salamat News newspaper was searched for any related news about the prevention of gastrointestinal cancers. Minutes and meeting agendas for "supreme council for health and food security" and "noncommunicable diseases committee of ministry of health" were also manually searched and retrieved. The keywords used in the search for the pertinent documents were: gastrointestinal cancer, colon cancer, stomach cancer, liver cancer, esophageal cancer, and pancreas cancer, along with the terms prevention and screening. Each of these keywords was used separately in the Persian language. We searched PubMed and SCOPUS with the above-mentioned keywords in combination with "Iran" AND "policy OR program," in order to find any related articles. As the first integrated program of WHO to prevent and control noncommunicable diseases was published in 1988, the search in these databases was limited to the studies published between January 1988 and October 30, 2018.

The documents reviewed for this research included comprehensive policies of health, environment, population, and resistant economy developed by the supreme leader of Iran; Iran's first to sixth 5-year developmental plans; Iran's 20-year vision plan; comprehensive scientific map of Iran; a comprehensive scientific roadmap of the health system; national program for prevention and control of noncommunicable diseases; Iran's Package of Essential NCD interventions for primary health care (IraPEN); minutes and meeting agendas of "supreme council for health and food security" and "noncommunicable diseases committee of Ministry of Health." Besides, the available document in the web pages of the Ministry of Health, all medical sciences universities, and relevant research centers were searched. Also, the web page of the "Salamat news" newspaper was searched for any related news about the prevention of gastrointestinal cancers.

Key Informant Interviews

Semistructured interviews were conducted at the interviewee's workplace by an experienced female researcher who was a PhD student in health policy at the time of the study. As an exception, one of the participants refused to have a face-to-face interview because he was too busy and answered our questions in writing. The list of respondents was prepared by reviewing relevant documents and was updated by interviewees using the snowball sampling method. Most of the interviews were conducted without the presence of any other participant or researcher unless interviewees had another roommate. The objectives of the research, as well as the reasons and interests in the research topic, were first described to the participants. The topic guide was developed using the policy triangle framework. The topic guide was pretested in three interviews and based on the results from the analysis some small changes were made to the topic guide. The main questions were: what are the influencing factors on gastrointestinal cancers in Iran? What is the content of gastrointestinal cancer prevention policies and programs in Iran? What is the process of gastrointestinal cancer prevention policy development? Who are the stakeholders of the field? What are their roles, places, and powers? At the end of each interview, interviewees were asked if they wanted to add any other issue that was not covered during the interview. Also, they were asked to introduce any relevant documents or experts in the field for future interviews. Interviews were conducted and lasted between 30 and 45 minutes. All interviews were tape-recorded after obtaining signed informed consent from interviewees. Also, notes were taken during interviews. In total, 22 participants (14 men and 8 women) were interviewed, 12 of whom were from the different levels of Ministry of Health, health, research, and social deputy, head of the health network, nurses caring for cancer patients, general physician, subspecialists in the gastrointestinal tract, academicians, and epidemiologists. The other 10 participants were from Ministries of Education, Agriculture Jihad, Industry, Sport and youth, Iran Broadcasting, Department of environment, Standard organization, and NGOs (Non-Governmental Organizations). The process of interviewing was continued until theoretical saturation of data.

Data Analysis

All interviews were transcribed verbatim. The directed content analysis approach was used to analyze the interview data. According to the method of Assarroudi, Heshmati Nabavi, Armat, Ebadi, and Vaismoradi (2018), directed content analysis is a method of qualitative data analysis in health-care research, which tries to validate, refine and/or extend a theoretical framework in a new context consisting of 16 steps and three phases of preparation, organization, and reporting. Preparation phase related to sample selection, developing interview guide, conducting interviews, and immersion in data. Transcribed interviews were read and re-read to fulfill data saturation. In the organization phase, a formative matrix for the main categories of the policy triangle framework was derived, which consisted of four categories of content, context, policy, and actors. Then texts were open-coded and categorized independently by two authors (NK and RK). The difficulties in coding and categorizing were discussed by the two authors. Samples of direct quotes for the main categories and subcategories were selected from the texts. The preliminary codes were grouped and categorized according to their meanings, similarities, and differences. Finally, in the reporting phase, codes were reported based on the four parts of the policy triangle framework. Data analysis was done using qualitative data analysis software (MAXQDA v10). Interview data were triangulated with the findings from document analysis to enhance the credibility of our findings.

Documents were analyzed using directed content analysis. This method was used to extract data from policy documents and searched web pages in four elements of the policy triangle (context, content, process, and actors). Also, a timeline of policy development from minutes, agendas, and media was drawn. Documents were organized according to their publication date. Then, after the duplicates were discarded, they were analyzed by means of using directed content analysis. The steps of directed content analysis were the same as analyzing the interviews. MAXQDA 10 software was used to organize and analyze the data.

Rigor of the Study

We include participants from different levels of the policymaking hierarchy to increase the conformability of the study. To ensure the reliability of extracted codes and themes, interobserver reliability was used, and disagreements were resolved through discussion. Also, peer check was done by sharing extracted themes with other coauthors and asking their comments. A member check was done after each interview, showing the notes and asking what was understood from interviewees. Collecting and analyzing the data were conducted simultaneously.

Ethical Issues

The study was approved by the ethics committee of Tabriz University of Medical Sciences (IR.TBZMED.REC.1397.618). Signed informed consent was obtained from the key informants in the study. Research objectives were explained to participants. Also, interviewees were free to leave from the research at any time. Participant's quotes were fully anonymized by removing the information about their position and profession.

Results

The mean age of participants in the current research was 45 years. Also, the level of education for most of the interviewees was PhD. The mean number of years of experience in gastrointestinal cancer prevention policymaking for the interviewees from the Ministry of Health was 18. In this section, findings from interviews supplemented by document review are presented in four headings, namely context, content, policy process, and actors.

Context

This research explored the contextual factors of gastrointestinal cancer prevention policymaking in Iran. We adopted Lichter's interpretation of contextual factors as structural-managerial, situational, political-legal-international, and socioeconomic factors (Leichter, 1979). The themes and subthemes are presented in Table 1.

Lifestyle and nutrition have an important impact on gastrointestinal cancers. This issue was mentioned by most of the informants and documents. One of the interviewees noted:

> *Several environmental factors and lifestyle factors are critical, especially in the case of colorectal cancer. The role of healthy nutrition, fruit use, physical mobility, and all of these have an impact (Participant 17).*

Besides, one of the key informants declared:

Table 1. Contextual Factors Affecting Gastrointestinal Cancer Prevention Policies in Iran

Contextual main factor	Themes	Subthemes
Structural-managerial	Organizational structure	– Weakness of structures and facilities for education and information on the importance of screening – Unhealthy distribution system of food products – Inadequate road transport infrastructure in the country
	Managerial	– Financing • Lack of financial resources • Mismatch of programs formulated with available financial resources – Planning • Arbitrary planning without coordination of other organizations – Administrative • Lack of coordination among different organizations • Weakness of the patient referral system • Weakness in the organization and management of programs – Facilities and essentials • Unfair distribution of second-level facilities in the country in the field of prevention of these cancers • Disproportion between the number of patients referred to the second level and the facilities at this level
Socio-cultural	Lifestyle	– Unhealthy diet and low consumption of fresh fruits and vegetables – Hot tea and drinks – Using untapped water in some parts of the country – High opium consumption – Poor oral hygiene – Physical inactivity
	Socioeconomic	– The impact of economic problems of individuals on increasing the level of anxiety and stress – The impact of the economic problems of the individuals on the lack of access to healthy foods – Late referral to the doctor and necessary tests because of shame and embarrassment – Lack of sufficient knowledge of the risk factors in society – Lack of sports facilities in the community – Wrong urban transportation system – Class differences in society – Gender and ethnic discrimination – Poverty – Illiteracy – Migration to the margins of metropolises – Reduction of social capital – Psychosocial factors – Stressful Lives

(*Continued*)

Table 1. Continued

Contextual main factor	Themes	Subthemes
Political	Political	– The dependence of policymaking on policymakers and their interests (political instability) – Weakness in the serious pursuit of programs after several years of starting them – Import of unhealthy products. Distribution of economic subsidies irrespective of noncommunicable disease control policies
	Legal	– Weaknesses in the use of the tools and arrangements necessary for the implementation of Article 37 of the fifth development program on the prohibition of the advertising and taxation of unhealthy food – Serious weaknesses in proper oversight of the process of production and supply of ready and semiprepared food
	International	– International sanctions – WHO's inaction on opium as one of the most important risk factors for these cancers
Situational factors	Change in the lifestyle	– Cheap and harmful food availability – Universalization of unhealthy lifestyles
	Environmental factors	– Air pollution – Dust – Increasing the use of pesticides and fertilizers – Industrialization of the country – Rapid and dramatic social changes resulting from the development process, and in particular the aging of the population – Unplanned and rapid expansion of urbanization – Long-distance cities with clean city standards – Increased consumption of fossil fuels

> *Opium has a crucial role to play. Not just in esophageal cancer, but also gastric, lung, pancreatic, bladder cancer (Participant 14).*

On the other hand, food and crop production should meet the required standards to be healthy for use, which needs market control and monitoring. Nevertheless, there are some barriers, such as "lack of human resources" to control the whole market. One of the participants from the standard organization mentioned:

> *One of the programs of the standard organization is market inspection to see that they do not supply non-standard material. In this debate, there is the issue of limited human resources and a broad market (Participant 18).*

Most of the interviewees commented on the impact of the socioeconomic situation on cancers. For instance:

> *Socioeconomic factors certainly have an impact on all cancers. For example, in terms of economic factors, the family situation may be such that they cannot provide the fruits and vegetables they need, and they can't have access to health care or diagnostic services (Participant 17).*

One of the key informants with direct contact with cancer patients mentioned:

> *The main cause of cancer is stress and negative intuition. Nutrition and other things that all doctors say are important, but I have been dealing with cancer patients for almost 20 years now, and I found that stress, fear, and negative intuition are the main causes of these cancers. Raising the level of culture and changing your intuition in a positive direction is very important (Participant 6).*

One important political and international factor of gastrointestinal cancers is sanctions. One of the key informants commented:

> *Sanctions are now in place. Drug sanctions can even be effective (Participant 12).*

One of the situational factors that have an impact on gastrointestinal cancer is the low price and high access to fast foods, especially for young people:

> *Many of our young people have to use fast food because it is cheaper and easier to access (Participant 16).*

Content

From the document review, it was obvious that the interventions for gastrointestinal cancer prevention in Iran were divided into two main categories: policies for primary prevention and policies for secondary prevention (screening).

Primary Prevention

Primary prevention recommended interventions for the control of major risk factors. The main risk factors of gastrointestinal cancers are divided into three categories: they are biological and unchangeable, such as genetic factors, age, ethnicity, blood type, and family history (Brenner, Kloor, & Pox, 2014; Karimi, Islami, Anandasabapathy, Freedman, & Kamangar, 2014; Matsushita & Takaki, 2019; McGuigan et al., 2018; Rawla, Sunkara, & Gaduputi, 2019; Xie & Lagergren, 2018). Two other risk factors are lifestyle and socioeconomic risk factors. Elements of these risk factors include unhealthy diet, low consumption of fresh fruit and vegetable; obesity; physical inactivity; high intake of alcohol, opium, and tobacco; consumption of hot drink; occupational exposure to chrome, cadmium, arsenic, and nickel; exposure to dust and radiation; un-piped and un-chlorinated drinking water; poor socioeconomic situation; and poor oral health (Brenner et al., 2014; Ghaffari et al., 2019; Karimi et al., 2014; Maisonneuve, 2019; Matsushita & Takaki, 2019; Rawla et al., 2019; Xie & Lagergren, 2018; Zhang, 2013).

Table 2. Content of Primary Prevention Policies of Gastrointestinal Cancers in Iran

Type of policies	Content of policies
Improving lifestyle standards	– Developing a curriculum for health promotion and healthy lifestyles – Food security – Controlling and preventing overweight and obesity in different groups – Development of sports infrastructure – Prohibition of advertising and taxation on harmful health products
Improving environmental standards	– Compiling and implementing a comprehensive document to promote access to safe drinking water – Confronting antimicrobes and air pollution – Limiting the use of pesticides and fertilizers for agricultural production – Expansion and improvement of the quality of public transport
Improving health service packages	– Development of health insurance coverage to early prevention and screening services – Development and implementation of cancer prevention and screening guidelines in family physicians' service package

It was observed from the document review that the risk factors mentioned above are similar among most cancers and noncommunicable diseases. Hence, in this part of the study, we summarized the policies related to the avoidance and control of all these risk factors. These policies are listed in Table 2.

Secondary Prevention

Among the five cancers of gastric, colorectal, pancreas, esophageal, and liver, there are guidelines and policies only for colorectal cancer screening. Screening methods for others are shown to be less cost-effective and safe. So Iran, like other countries, does not adopt these policies for screening. An informant remarked:

> *Of course, for the rest (esophagus, gastric, liver), we have no plans in our health system. For liver, we might say hepatitis, for example. Because both hepatitis vaccination and screening are being conducted in Iran. People with hepatitis will be followed up. Well, people who have hepatitis do not necessarily mean liver cancer. In addition, the pancreas, which we have virtually no plans for, such as liver, esophagus, and stomach. What we officially have planned is colorectal cancer (Participant 8).*

There are three methods for screening of colorectal cancers mentioned in the document. The first method, which is conducted in the first level of service provision, is the Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT). The second method suitable for the second level of service provision is a colonoscopy. Colonoscopy is the best and most valid method for screening of colorectal cancer that is preferred in people with suspicious symptoms or with the positive FIT result. Finally, doing surgery is proposed in policies that can be done in the third level of service provision.

Informants thought that different policies and documents for the prevention of gastrointestinal cancers developed in Iran were not organized, and there were various policies with the same content. A respondent explained:

> *They were trying to do different things. But it was not a coherent plan (Participant 13).*

Policy Process

The policymaking process consists of four components of agenda-setting, policy development, policy implementation, and policy evaluation.

Agenda Setting

We used Kingdon's multiple streams theory to indicate the problem stream, policy stream, and political stream (Kingdon, 2002). The findings from agenda setting are displayed in Figure 2. A window of opportunity has been open now at this time due to the current situation.

Policy Development

The timeline in Figure 3 displays the cancer prevention policymaking process in Iran from 1984 to 2016. By recognizing the need and necessity of registering cancers nationwide, the rule of "mandatory registering and reporting cancers" was approved by Iran's parliament in 1984. In 2011, following an increase in cancer epidemic in the world and especially in low- and middle-income countries, the first plan, namely "the comprehensive national cancer control program," was developed by the Ministry of Health with the aim of improving overall health, especially reducing death from cancer. In 2013, the national committee for prevention and control of NCDs in Iran was formed, which had then developed the "national document for prevention and control of NCDs in Iran." The Health Supreme Council approved this document in 2015. Later in that year, IraPEN was developed by the Ministry of Health that was piloted in four counties of Maragheh, Naghadeh, Baft, and Shahreza.

There are shortcomings and difficulties in formulating these policies based on the viewpoints of interviewees. The first issue is "inadequate participation of all those involved in policy formulation or inactive participation." One of the key informants declared:

> *Everybody has to be involved, unfortunately, are not, or if they attend in meetings, they are inactive. Moreover, if there are active, they are persons who are non-decision makers in their organizations. Some neutral experts are not just active in the meetings (Participant 2).*

The other issue relates to "having a one-dimensional vision and not considering facilities and available equipment for implementing these policies. The same informant explained:

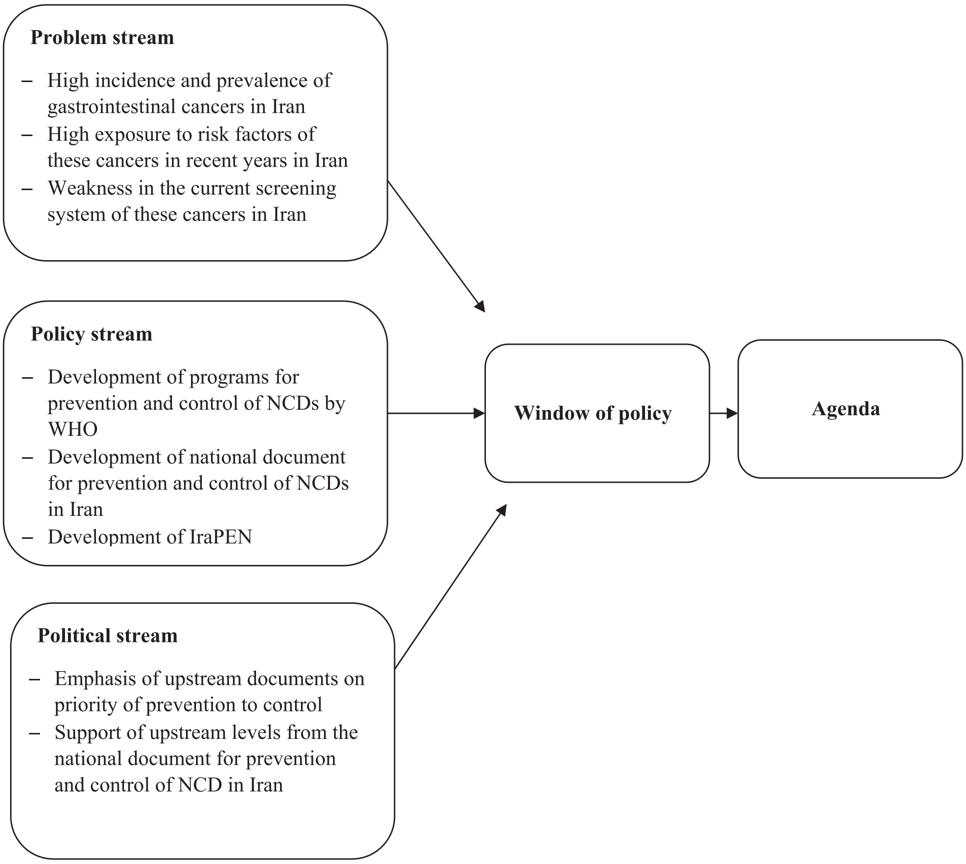

Figure 2 Kingdon's Multiple Streams Theory in the Gastrointestinal Cancer Prevention Policies agenda setting in Iran.

> *We are planning to screen, for example, 100 patients per day for the colonoscopy, but we only have the capacity of 10 patients per day for colonoscopy. So what about 90 other patients? (Participant 2).*

Policy Implementation

There is a top-down approach to the implementation of cancer prevention policies. An academic quote about this is:

> *These programs are national. I mean, the program was signed by the Ministry of Health, and the provinces were involved (Participant 8).*

Interviewees thought that there are challenges attributed to policy implementation of such programs. The first serious challenge was "lack of financial resources":

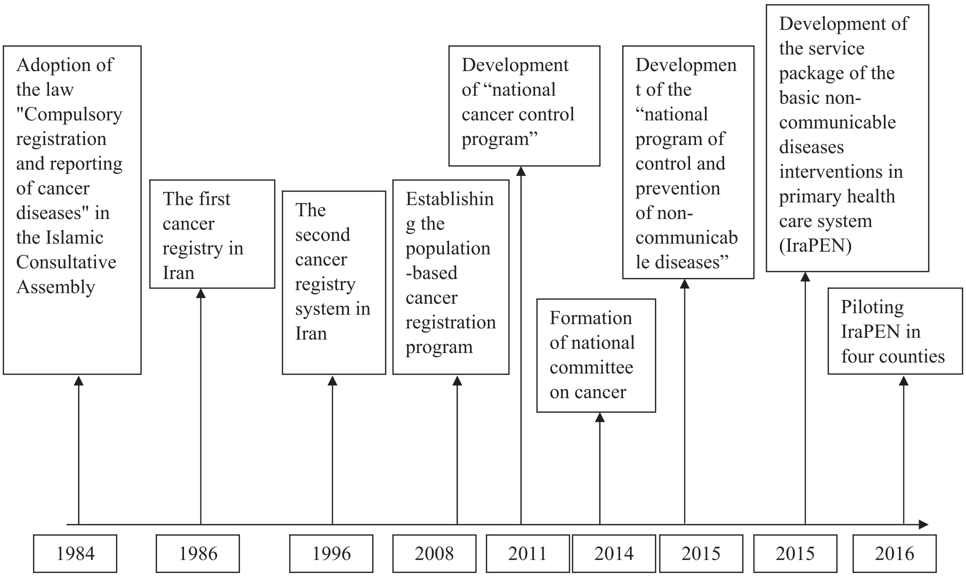

Figure 3 Timeline of Cancer Prevention Policymaking Process in Iran, 1984–2016.

> *By the end of the year 2019, we were going to screen all those who needed to be tested and send them to further examinations based on the results. Practically they could not provide FIT (Fecal Immunochemical Test) test kits."… "From the day that the IraPEN started in the country, we have started doing the program in our province seriously. We have included three common cancers of the breast, cervical, and colorectal in our screening. Unfortunately, due to the lack of funding since the first year, we limited the screening to 50,000 people in the province by the suggestion of the Ministry of Health (Participant 2).*

Findings revealed another gap in the implementation of these policies: "lack of political support and lack of enough executive assurance." Although the Ministry of Health has the stewardship of the overall health of people, it does not have enough political power to attract the support and participation of other parallel institutions. On this challenge, one informant added:

> *We have the tool, but we are not using it properly. That is the Health Supreme Council and Supreme Leader. The Health Supreme Council, which is chaired by the President, should meet regularly. When I can't force my parallel organs such as the Ministry of Agriculture Jihad to give people healthy food, let's tell the President to give it a go. This may have an executive assurance. We had defined this mechanism and this element but, we don't use it properly. So these potentials should be used, which is not (Participant 13).*

> *As for education and information, we can do the education that the University of Medical Sciences wants us to do. Nevertheless, in executive cases, he cannot command us to do these things… In executive cases; the executive hierarchy must be followed. We have our own Ministry.*

> *The Ministry of Health should ask our Ministry, to make it a guideline and give it to the provincial units so that we can implement it (Participant 19).*

Policy Evaluation

Evaluation methods, as well as indicators and checklists, should be defined in the formulation phase of policies. The findings of the current study showed that there are three types of evaluation for cancer prevention policies in Iran. One of the types of policy evaluation in this research is the self-evaluation of policies within each organization. For example, the "national document for prevention and control of noncommunicable diseases in Iran" has designed a level-by-level monitoring and evaluation system. Managers in each level monitor their submanagers using specific checklists and provide feedback to them. Following is a related quote:

> *Evaluation should also be included in the policy package if necessary; senior experts of the level should evaluate each level (Participant 2).*

On the other hand, the Ministry of Health can do the final evaluation and review the fulfillment of policy objectives. As one interviewee commented:

> *The best stewardship for such programs should be at the Social Deputy of Ministry of Health. You see, the social factors are called social, which is the result of our interaction with humans. When the Ministry of Health has a social deputy, whose job it is to observe and monitor such things, it is better to build an office and demand performance reports from all (Participant 8).*

The public is the third type of evaluation method:

> *Public opinion pressure is much, much stronger now. With a social network, we can implement public surveillances more seriously (Participant 8).*

Actors

Not all stakeholders of an issue can be identified in research; however, we identified the main stakeholders of gastrointestinal cancer prevention in Iran, which are listed in Table 3. The majority of respondents described the Ministry of Health as the stewardship of cancer prevention:

> *The main stewardship is with the Ministry of Health with all its deputies (Participant 2).*

The supreme leader of Iran in overall health policies declared that all sectors and organizations are responsible for people's health. In addition, most of the

Table 3. Main Actors and Stakeholders of Gastrointestinal Cancer Prevention Policies in Iran

Governmental Organizations	Semigovernmental Organizations	Nongovernmental Organizations
Ministry of Health	Islamic Republic of Iran Broadcasting	NGOs in cancer
Ministry of Education	Municipalities	Academics
Ministry of Science and Research		Researchers
Ministry of Sport and Youth		
Ministry of Industry, Mine and Trade		
Ministry of Agriculture Jihad		
Ministry of Co-Operation, Labor and Social welfare		
Islamic Consultative Assembly		
Department of Environment		
National Institute of Standards		
Iranian Health Insurance Organization		

ministries of the country had signed the "national document for prevention and control of noncommunicable diseases." Nearly all of the participants in the current research noted that all sectors and people themselves are a stakeholder in gastrointestinal cancer prevention. Commenting on policy actors, one informant declared:

> *This program needs the support of all sectors (Participant 17).*

The positions of stakeholders are different in supporting and affecting these policies. The Ministry of Health is considered as an effective stakeholder that has great support for policies. The level of interest and power of stakeholders are different. Following are some related quotes:

> *In general, the problem we have with chronic diseases, including cancer, is to be involved with other organizations. See, you can't find an organization that doesn't work. Everyone has a stake. There may be more to one or less to another organization (Participant 8).*

> *…organizations, including the municipality, through these educating billboards across the city, the sports and youth organization play an important role in providing the public with the necessary access to sports aids, and Islamic Republic of Iran Broadcasting. NGOs (Non-Governmental Organizations) and charities can play a significant role (Participant 17).*

> *All societies and organizations, government and non-governmental, must involve. Education must start at every level, from school to university (Participant 16).*

Some organizations that have low activity in cancer prevention policies should be strengthened. In addition, organizations such as the Islamic Republic of Iran Broadcasting should be enhanced, and interaction between the Ministry of Health and Broadcasting should be strengthened because of the important role of television and radio in informing the public about a better lifestyle and improving other contextual factors. An informant from the Islamic Republic of Iran Broadcasting explained:

> *The main practitioners of the cancer field should remind us of our duty. If that happens, the media will be more focused on the issue then (Participant 7).*

Focusing on the impact of broadcasting on behaviors of children, an informant remarked:

> *Some of our patients are children, and lifestyle changes can be advertised through animation (Participant 3).*

For health policies to be successful, there should be good coordination among different stakeholders. However, cancer prevention policies are not an exception. One interviewee noted:

> *…In these cases, Agriculture Jihad must have a close relationship with the standard organization. Because I think the main problem with colorectal cancer is nutrition (Participant 18).*

Discussion

Document analysis and key informant viewpoints indicated that there is not a comprehensive policy or document for gastrointestinal cancer prevention and screening except for colorectal cancer.

Findings showed that the main contextual factors affecting gastrointestinal cancers were lifestyle and nutrition, socioeconomic factors, and political and legal factors. Low socioeconomic status has been shown to correlate with cancers of the digestive system (Galvao de Azevedo, Leal Muniz Carneiro, Oliveira Tomiya, & Pessoa de Araujo Burgos, 2015; Vohra, Marmot, Bauld, & Hiatt, 2016), although for colorectal cancer, this factor has a reverse effect meaning that colorectal cancer incidence rises with socioeconomic development. However, this can relate to the leading risk factor of colorectal cancer, which is physical inactivity, and this risk factor has a positive correlation with high socioeconomic status and urbanization (Wen et al., 2018). Similar studies of conducting policy analysis in Iran recognized socioeconomic factors as a contextual factor relating to policies. Mohseni and colleagues found social factors and socioeconomic status in the context of prevention of malnutrition policymaking in Iran (Mohseni, Aryankhesal, & Kalantari, 2019). Also, Faraji and coauthors indicated in their research that political and social factors consisted of the context of policymaking for the prevention and control of diabetes in Iran (Faraji, Etemad, Sari, & Ravaghi, 2015). These similarities show the importance of these contextual factors in policymaking for the prevention of NCDs in Iran.

Dietary and lifestyle habits were also associated with gastrointestinal cancers that were a point for policymakers to plan prevention policies (Gonzalez et al., 2006; Yassibas, Arslan, & Yalcin, 2012). In 2013, a policy package for healthy diets and the prevention of obesity and diet-related NCDs was developed in the United Kingdom (Hawkes, Jewell, & Allen, 2013).

Results of the current study showed that embarrassment was one of the factors that affect colorectal cancer screening in Iran; however, it had the same impact in other countries (Oh, Park, & Jacobsen, 2019; Wang et al., 2019). Laws of taxation on unhealthy food and marketing of these foods on television lack support of upstream levels of policymaking in Iran. In addition, there is a weakness in the proper monitoring of the process of production and supply of ready and semiprepared foods. These legal factors can be resolved by the integration and coordination of all members of society. Similarly, Mohseni and coauthors found legal factors, including rules and regulations, as a contextual factor in their policy analysis (Mohseni et al., 2019).

For the content of prevention policies, infrastructures and facilities of government should be considered. Sometimes making simple changes in the inputs have positive impacts on the results. For instance, in order to improve exercise among people, it is better and cost-effective to promote walking or biking ways in the city.

Attention to changes in different regions of the country should be taken into account in the content of these policies. For example, air pollution and dust in different parts of Iran have various measures that should be considered in the content of policies.

Expansion of health insurance services to prevention and screening services, that is mentioned in the content of upstream policies, need more considerations in infrastructure, cost, induced demand of patients and physicians. Results of research showed that cancer preventive screening behaviors were significantly greater in participants with health insurance (King et al., 2019). In addition, induced demand has shown to increase with health insurance coverage (Mohammadshahi et al., 2019; Yu, Qiu, & He, 2018). However, Faraji and coauthors reported in the study that for the patients who did not attempt to control their blood sugar, their insurance contract is recommended to be revised and insurance premium is suggested to be increased (Faraji et al., 2015).

In the content of screening policies, there were three methods for colorectal cancer screening. These three methods are similar in most of the other colorectal cancer guidelines and programs in Iran and worldwide (Buchman, Rozmovits, & Glazier, 2016; Clavarino et al., 2004; Goel et al., 2004). Screening methods for gastric cancer, such as eradication of *H. pylori*, have been shown to reduce the incidence of gastric cancer, but still, it is less cost-effective, and its adverse effects and resistance remain a concern for researchers worldwide (Lee et al., 2016; Pasechnikov, Chukov, Fedorov, Kikuste, & Leja, 2014). However, recently published research showed that *H. pylori* eradication was a cost-effective method to reduce the morbidity of gastric cancer in asymptomatic infected individuals (Han et al., 2019).

In the process of gastrointestinal cancer prevention policymaking, lack of political support, and lack of coordination among different ministries of the country is an important point. Loloei et al. (2019) indicated a lack of intersectoral collaboration in their policy analysis as a major problem. In Norway, they use political leadership and bureaucratic change to translate "Health in All Policies" goals to practice. These two strategies have enhanced intersectoral integration in Norway (Hofstad, 2016). National and local leadership, as well as a shared vision among organizations and accountability, are strategies for the implementation of health in all policies (Guglielmin, Muntaner, Campo, & Shankardass, 2018). The implementation approach in the current research was shown to be top-down, which is in line with other similar policy analysis in Iran (Heidari, Arab, & Damari, 2020; Loloei et al., 2019; Mohseni et al., 2019).

Conclusions and Policy Implications

Findings from the current policy analysis case study indicated the complex policymaking process and multiple contextual factors and influencing actors over the process. A policy window is now open, which presents opportunities for health researchers and the public to engage in policymaking of gastrointestinal cancer prevention. The results highlighted shortcomings in the current policymaking process. Financial problems and shortages can be resolved by engaging NGOs, private sector, and civil society in different parts of the process. Coordination among different organizations should be strengthened through setting common goals and creating a shared vision. Also, political assurance and support of upstream can be resolved by the political leadership of the Ministry of Health.

Limitations and Biases

Selecting the key informants who participated in this study from involving members of the gastrointestinal cancer prevention policymaking process in the country can lead to response bias due to their experiences and involvement in the policy process. However, data from informants were comparable to data extracted from the document review. Therefore, this bias cannot have much impact on the results of the study.

Notes

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World Medical and Health Policy

The Impact of United Kingdom and Malaysia's Inherent Health Systems on Their COVID-19 Responses: A Comparison of Containment Strategies

Shereen Allaham, Isabel-Cathérine Demel, Intesar Nur, Faizul Nizam Abu Salim, and Logan Manikam

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In March 2020, the outbreak of COVID-19 was officially declared a global pandemic by the World Health Organization. Given the novelty of the virus, and hence, lack of official guidance on effective containment strategies, individual countries opted for different containment approaches ranging from herd immunity to strict lockdown. The opposing strategies followed by the United Kingdom and its former colony, Malaysia, stand exemplary for this. Real-time polymerase chain reaction was implemented for testing in both counties. Malaysia acted with strict quarantining rules and infection surveillance. The United Kingdom followed an initially lenient, herd-immunity approach with strict lockdown only enforced weeks later. Although based on the same health-care structure historically, Malaysia developed a more unified health system compared with the United Kingdom. We suggest that this more centralized structure could be one possible explanation for why Malaysia was able to react in a more timely and efficient manner, despite its closer geographic proximity to China. We further explore how the differences in testing and quarantining strategy, as well as political situation and societal compliance could account for the discrepancy in the United Kingdom's versus Malaysia's relative success of COVID-19 containment.

Key Points

1. Different countries employed a range of strategies toward the COVID-19 pandemic, with varying levels of success.
2. Malaysia's strict rule enforcement were reflected both in quantitative and qualitative terms.
3. Despite the closer geographical proximity to the source of the outbreak, Malaysia fared better than the United Kingdom in its response to the pandemic, suggesting that there are valuable lessons to be learned for the developed from developing, limited-resource countries.

KEY WORDS: COVID-19, community spread, inherent health system, pandemic response, public health

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Introduction

The first case of COVID-19 was officially reported by the Chinese authorities on December 31, 2019. Three months later, on March 11, 2020, the outbreak was declared a global pandemic by the World Health Organization, 2020c). Given the novelty of the SARS-COV2 virus and the unprecedented nature of the situation, little to no official guidelines were available to advise governments on the most effective containment strategy. Countries were thus forced to react on a national and local, rather than global level, some opting for herd immunity with voluntary social distancing, while others enforced prompt lockdown with intense infection surveillance.

The varying approaches employed by the United Kingdom and its former colony, Malaysia, stand exemplary for this: despite similarities in their historic health-care structure and recent political situation at the time of the outbreak, the two countries fared differently during the pandemic. The ultimate success, and long-term consequences of their approach, that is, from a social and economic perspective, remains to be determined (Gibney, 2020).

The aim of this paper is to compare and contrast their containment approaches by shedding light on factors that facilitated—or hindered—the combatting of the COVID-19 pandemic. Using the case study of the United Kingdom versus Malaysia, we explore the role their health systems and organizational structure, pandemic preparedness, and response, as well as governance and societal compliance, have played in shaping the overall impact of the pandemic on their respective population.

Health Systems—The United Kingdom Versus Malaysia

The United Kingdom funded the National Health Service (NHS) in 1948 with the primary objective of offering treatment to everyone irrespective of their ability to pay (Triggle, 2018). The NHS is subdivided into four different countries (England, Scotland, Wales, and Northern Ireland) each of which controls the specific individual and public health-care policies for that respective area (Boyle, 2011). In the United Kingdom, different independent organizations are responsible for the delivery of numerous facets of health care. For example, Public Health England (PHE) oversees the public health component, while the NHS manages clinical and health-related services, and the Department of Health and Social Care (DHSC) coordinates government policy on health and adult social care matters in England (National Healthcare Service, 2013).

As a former British colony, Malaysia "inherited" the British health-care system. Malaysia, however, has since followed—or maintained—a more unified health-care system approach. The country's main provider of health-care services, the Ministry of Health (MOH), can effectuate changes from a National to a District level (Thomas, Beh, & Nordin, 2011 Ministry of Health Malaysia, 2019). The local system hence remained very centralized at the Federal Government level, with the MOH asserting control over State Health Department at 13 states and 3 federal territories. At the federal level, the Director-General of Health (DG) is assisted by three deputies namely the Medical Deputy DG (similar to NHS National Medical Director), Public Health Deputy DG (similar to PHE), and Research and Technical Support Deputy DG (who oversee six MOH research institutes and the planning division, mimicking DHSC to a certain extent). Furthermore, Malaysia has both a public and a private health sector. Rather than paying health-care-related services for everyone, the Malaysian approach prioritizes spending on essential care and promotes equity by subsidizing treatments those who cannot afford it. This is associated with a reduction in the government's burden, leading to Malaysia only allocating around 4.24 percent of GDP on health care—less than half compared with the United Kingdom (Cooper, 2020; Ministry of Health Malaysia, 2019).

Pandemic Preparedness, COVID-19 Arrival and Response: The United Kingdom Versus Malaysia

The first case of COVID-19 was discovered in the United Kingdom on January 29 (Gallagher, 2020) compared with January 24, 2020, in Malaysia (World Health Organization, 2020a), where the first surge of COVID-19 infections likely originated from a group of Chinese travelers entering the country via Singapore. As an early preventive measure, a stringent screening process was imposed at all Malaysian airports given the geographic proximity to the source of the outbreak (Shah et al., 2020). With this strict approach, the initial wave was contained successfully, counting only 22 cases over a span of 3 weeks ending February 16, 2020 (World Health Organization, 2020b). A second case surge was noted on February 27, overlapping with a religious gathering in Seri Petaling Mosque attended by 16,000 individuals (DG of Health,2020a). This likely had significant consequences on Malaysia's infection numbers and its overall performance in containing the pandemic. Malaysia's first fatal case, reported on March 17, 2020, was also found to be related to this religious gathering (Shah et al., 2020).

Subsequently, the Malaysian government, in collaboration with the MOH, focused considerable efforts into containing the outbreak. Participants who had attended the gathering at Seri Petaling Mosque were urged to undergo screening. The resources available to private and public hospitals were enhanced and local bed availability for COVID-19 cases was increased. On March 1, an alliance involving 38 professional medical societies was established with the aim of keeping the population well-informed with accurate and up-to-date guidance (Shah et al., 2020).

Furthermore, Malaysia instated a Movement Control Order (MCO) on March 18, 2020 after the official classification of COVID-19 as a global pandemic (*New Straits Times*, 2020). This encompassed regulations on international and interstate traveling, shop operating, schools and universities opening, as well as the cancellation of worship services (Shah et al., 2020; World Health Organization, 2020c). With regards to funding, the MHO set up an action coalition to obtain financial aid from companies, NGOs, and other organizations to fight the outbreak (Shah et al., 2020).

Malaysia's rapid response and strict enforcement of rules had imperative value, especially when accounting for COVID-19's mode of transmission (respiratory droplet and direct contact, and consequently, the importance of reducing human-to-human contact in its containment) (Public Health England, 2020).

By contrast, the United Kingdom followed a different, more lenient approach. Although the PHE mentioned their 5-year plan to tackle future pandemics in 2019, specifically referring to the United Kingdom's ability of “Test and Trace” for MERS-COV and its successes, the procedure for an outbreak of an unknown disease was not mentioned (Public Health England, 2019). Similarly, the issue around access to and availability of personal protective equipment remains untouched upon.

Consequently, the United Kingdom found itself poorly prepared with the third-lowest number of hospital beds per 1,000 population among the Group of 20 countries (Organisation for Economic Co-operation and Development, 2020). Irrespective of that, the country initially opted for a “herd immunity” approach due to a concern about the economic and social consequences, for example, loneliness, isolation, lack of health-care access, of a strict lockdown situation (Hunter, 2020). A change in government advice followed on March 16, as cases requiring ICU admission started exceeding the NHS’ capacities: Symptomatic individuals and their close household contacts were advised to self-isolate for 7 days, with anyone over 70 to avoid any “non-essential social contact” (Hunter, 2020). Mass gatherings were discouraged, but not banned. The hard lockdown was enforced on March 23, 2020. By this time, 6,650 people had been confirmed positive for the disease with 335 fatalities (Rawlinson, 2020) compared to only 2 deaths and 673 cases in Malaysia on March 17 (DG of Health, 2020b). Thorough preparation, a timely and stricter response, as well as consistent government advice would likely have lessened United Kingdom infections and deaths.

Approach to “Test and Trace”: The United Kingdom Versus Malaysia

What both countries share is that real-time reverse-transcription polymerase chain reaction (RT-PCR) (Watson, Whiting, & Brush, 2020) was employed in the detection and diagnosis of COVID-19 infected individuals. Although this is the WHO-recommended gold standard, RT-PCR requires big laboratories, hence being subject to limitations in scalability and time. Consequently, testing capacities were limited at the initial stages in both countries. In the United Kingdom, testing commenced at a capacity of only 5,000 a day, rendering it almost impossible to make accurate estimations on national infection numbers in the early stages of the outbreak (Department of Health and Social Care, 2020). Malaysia had a testing capacity of 11,500 at the same point in time—a number more than double that of the United Kingdom (Murugesan & Harun, 2020). Interestingly, the Institute for Medical Research, MOH had already started studying and designing primers and probes specific for COVID-19 detection on March 11 based on the genetic information of the virus China had shared with the world. This was even before WHO published a similar protocol on March 17 (DG of Health, 2020c).

The approach toward "Testing and Tracing," however, varied greatly between both countries. Although real-time RT-PCR is a very specific test (test specificity 95 percent), it is reported to have a relatively high false-negative rate, that is, a significant probability of having COVID-19 despite being tested negative (Watson et al., 2020). Furthermore, due to the test's high sensitivity, patients who are no longer infectious, yet have not fully cleared the virus, are frequently misdiagnosed as positive, given the presence of remnants of viral RNA in their system. This, overall, creates a logistic problem where a negative test result may indeed be positive and vice versa.

Again, both countries responded differently to this challenge: in Malaysia, all individuals who tested positive were admitted to hospital for observation and/or early treatment irrespective of symptom strength. Even the asymptomatic were hospitalized for monitoring purposes (NADMA Malaysia, 2020). Those who tested negative, but showed symptoms were classified as "Persons under Surveillance" based on clinical suspicion with compulsory quarantine for 14 days, either at home or approved quarantine station. RT-PCR was repeated on Day 13.

Unlike Malaysia, the United Kingdom implemented "at home isolation"—a strategy that may be cost-effective but came with the trade-off that numerous infected individuals got significantly worse before intervention was offered (National Health Service, 2020). This is particularly problematic in cases where coronavirus is known to have a worse outcome (Office for National Statistics, 2019), namely in the elderly and those with pre-existing medical conditions. This is a pertinent point, especially when considering the two countries' respective population demographics: England has a more elderly population with 18 percent over the age of 65 (Office for National Statistics, 2019) compared with 6.9 percent in Malaysia (Razak, 2020). Had the United Kingdom adopted the aggressive Malaysian style of test, trace, isolate and treat, it would have likely reduced mortality rates, especially among the elderly who could have received earlier intervention. Since then, the United Kingdom has focused its efforts on scaling up its testing capacity: the country is currently performing 450.48 COVID-19 tests/1,000 people per day compared with 69.16 COVID-19 tests/1,000 people in Malaysia (data accurate as of November 9, 2020) (Our World in Data, 2020). Furthermore, early preventive measures have recently been announced by the U.K. government to prevent, or at least limit the severity, of a second wave. These encompass tight regulations on social gatherings, for example, a maximum of 15 guests attending weddings and funerals, and restrictions on the opening hours for cafes, restaurants, and bars. Measures will be effective from September 24, likely lasting for a period of 6 months (*BBC News*, 2020). The United Kingdom has further recently introduced a three-tier system, classifying regions within the country with an ample system according to the number of infected individual in the region in question, that is, green/Tier 1 = low risk, yellow/Tier 2 = intermediate risk, red/Tier 3 = high risk. This allows restrictions and lockdown measures to be implemented at a local and regional, rather than national level. In terms of who to test, the NHS continues offering free testing merely to symptomatic individuals and their close household contacts. Asymptomatic individuals can request COVID-19 testing only against a fee in the private sector (gov.uk, 2020). In contrast, Malaysia has opted for "open public testing" including the asymptomatic, through "drive-through testing" and other facilities. Comprehensive contact tracing of all confirmed cases is conducted in both counties (Our World in Data, 2020).

Governance and Societal Compliance: The United Kingdom Versus Malaysia

Governance and coordination are crucial to any country, even more so in critical situations like the COVID-19 pandemic. Both the United Kingdom and Malaysia were experiencing political issues at or close to the time of the outbreak. The United Kingdom, in light of discussions around Brexit, had recently had three Prime Minister changes from 2015 to 2020 (Edginton, 2020). This political instability may have resulted in insecurity amongst the population, leaving many apprehensive and distrustful toward the government. These factors may be inherently linked to societal compliance. Furthermore, the U.K. government has less power over health care since the Health and Social Care Act 2012, meaning it cannot enact quick changes to public health (The Kings Fund, 2017). Given the lack of a hierarchical system, the minister is unable to effectuate changes without prior authorization from other sectors. Although this is a sensible approach in general, it can result in a significant slow-down of the decision making in situations where timely reactions are of the essence, like in the recent pandemic.

The Malaysian government was also facing issues as Prime Minister, Mahathir bin Mohamad, stepped down on February 24 (Ratcliffe, 2020). Following his resignation, the country found itself in a precarious situation: without a Prime Minister and functioning Cabinet, Malaysia was unable to activate the "Disease Control Act" (Act 342) for its lockdown endeavors. There was, however, a quick succession through political party realignment in the House of Representatives on March 1, 2020, leading to a new coalition governing Malaysia. Despite some opposing voices in the public, implementation was swift, involving a democratic process in alignment with the Malaysian constitution. Once the Prime Minister and Cabinet were in power, the "Disease Control Act" was successfully instated and decisions were made promptly. The National Security Council took charge of non-health matters, while MOH was given full authority over health matters. This clear division of roles allowed for quicker implementation of public health reforms and inspired confidence in the government by the Malaysian people, and also among those initially opposing the new government. Furthermore, the central control of MOH/DG of Health over the three big functions held by the Deputy DGs and the 13 states/3 federal territories facilitated the decision making and crisis response. Unlike in the United Kingdom, many technical decisions could be made by the technocrat chief, for example, the Director-General of Health in central committee meetings, allowing for a prompt translation into public health actions on the ground (at the district level), labs, clinics, and hospitals. A combination of these factors likely contributed to reducing the spread of COVID-19.

A study of public views carried out by King's College London found that 9 percent of the U.K. population were resisting the quarantine (Duffy & Allington, 2020). Given the recent political uncertainty, this dark figure, however, may be much higher. In Malaysia, on the other hand, people's behavior changed even before the implementation of the MCO. People started social distancing (83.4 percent) and trusted the government (89.9 percent) (Azlan, Hamzah, Sern, Ayub, & Mohamad, 2020).

Conclusion

The United Kingdom's response to Coronavirus led to 62.64 COVID-19 deaths per million people compared to 1.79 deaths per million in Malaysia (data accurate as of November 9) (gov.uk, 2020; Our World in Data, 2020). Although multiple reasons contributed to this large disparity, it also suggests issues related to a lack of public health intervention or timeliness of its intervention. The United Kingdom, despite being more developed and economically advanced than Malaysia, fared worse in the COVID-19 pandemic. The late response, the greater population density in the United Kingdom, the lack of testing capacity, and societal compliance at the beginning of the pandemic contributed to a substantial number of infections and fatalities. Despite having a well-differentiated, mature health system, the U.K. failed to respond sooner to the WHO's warning, the country's deaths, and confirmed cases. Political uncertainty and inherent features of the country's health system may have contributed to this. Malaysia, by contrast, acted sooner, employing strict, effective measures. Consequently, the Malaysian population largely trusted their government and the MOH, changing their behavior to align with the new rules. Lockdown implemented at the right time, strong public health prowess of MOH at the federal level, all the way to state and local districts, seemed to have made the difference, setting Malaysia apart from the United Kingdom, despite its geographic proximity to the origin of the outbreak—China.

In recent weeks and months, however, it seems the United Kingdom has attempted to learn from its past mistakes, employing early preventive measures for the impending second wave. Nevertheless, national-level reviews will be required during the years to come to understand how the United Kingdom's capabilities were squandered.

Undoubtedly, there are areas for improvement for both countries. It does, however, appear that the British could learn from its former colony on how to deliver better preventive public health for its people. The three main lessons learned from the COVID-19 pandemic include the importance of

(i) acting early and allocating enough time to prepare the health-care system,
(ii) minimizing infection numbers, and
(iii) empowerment of and trust from the public.

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Information Sharing and Community Resilience: Toward a Whole Community Approach to Surveillance and Combatting the "Infodemic"

Nathan Myers

Developing and strengthening systems for information sharing as well as detecting and addressing dis/misinformation can not only protect capacity for public health emergency preparedness and response, but potentially increase overall community resilience and social capital. More actively involving citizens in the government's collection and sharing of information can generate more public buy-in so people will be more invested in making certain that such information is not arbitrarily dismissed or drowned out by conspiracy theories. Such an approach may have the added the benefit of creating stronger collaborative connections between government, individual citizens, and civic organizations to promote overall resilience. More community involvement in terms of the collection and dissemination of information can provide value in terms of preparation for a public health emergency by bolstering surveillance efforts to detect a threat early on. Getting the public more integrated into the public health information system can also be valuable in terms of diminishing the threat of mis/disinformation. Building up relationships between the public and the public health sector can advance the mission of improving community resilience through education, engagement, and collaboration. In this review, we will examine existing evidence for this approach and will then conclude with possible new approaches.

KEY WORDS: information sharing, public health emergency preparedness and response, public health surveillance

Introduction

Developing and strengthening systems for information sharing as well as detecting and addressing dis/misinformation can not only protect capacity for public health emergency preparedness and response, but potentially increase overall community resilience and social capital. LeBlanc, Ekperi, Kosmos, and Avchen (2019) raise the important question of how do we ensure that virtual communities are prepared for disasters given that the Internet allows almost universal sharing of both information and mis/disinformation, while at the same time providing the opportunity to interact with only news sources that agree with their perspective? One approach, discussed in the following paper, would be to more actively involve citizens in the government's collection and sharing of information so that they will be more invested in making certain that such information is not arbitrarily dismissed or drowned out by conspiracy theories. Such an approach may have the

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added the benefit of creating stronger collaborative connections between government, individual citizens, and civic organizations to promote overall resilience.

More community involvement in terms of the collection and dissemination of information can provide value in terms of preparation for a public health emergency by bolstering surveillance efforts to detect a threat early on. Getting the public more integrated into the public health information system can also be valuable in terms of diminishing the threat of mis/disinformation. If people are more aware of how data regarding public health threats are collected and more connected with the public health system, they may be less inclined to be swayed by misinformation or disinformation on-line, and such citizens could be employed as a resource to dissuade others from embracing inaccurate or deliberately false information. Building up relationships between the public and the public health sector can advance the mission of improving community resilience, as articulated by Chandra et al. (2011), by promoting levers for action such as education, engagement, and partnership (see also Plough et al., 2013). In this review, we will examine literature published both prior to and during the COVID-19 pandemic to determine what evidence already exists for this approach. We will then conclude with approaches that could be taken moving forward in the wake of COVID-19.

Information Sharing and Surveillance

Surveillance systems can provide mechanisms for early detection of pandemics, identify time and space trends, identify risk factors and contributing behaviors, target interventions, and inform decisions (Baseman et al., 2013). French and Monahan (2020) cite the definition of surveillance according to the International Health Regulations as "the systematic ongoing collection, collation and analysis of data for public health purposes and the timely dissemination of public health information for assessment and public health response as necessary" (World Health Organization [WHO], 2005, p. 10). In an example from the international perspective, Goniewicz et al. (2020) discuss how member states in the European Union contribute information to the Integrated Situational Awareness and Analysis intelligence and then can access reports prepared by the European Commission and the European External Action Service based on the integration of this information.

As an example from the United States prior to COVID-19, state and local responses to outbreaks of Hepatitis A provided instructive examples of using information for coordinating responses. Baseman et al. (2013) noted the value of effective surveillance systems to address more localized threats like Hepatitis A, as well as managing a global pandemic. During a recent Hepatitis A outbreak, the California State Department of Health issued recommendations involving surveillance and information sharing regarding infected patients, which included the need for stronger communication between hospitals, public health departments, and other community organizations (State of California Health and Human Services Agencies & California Department of Health, 2017). Sharing of key surveillance indicators was noted to be especially important for communities trying to address the needs of homeless populations and drug users and indicators were disseminated through mechanisms like preparedness conferences (County of San Diego (California), 2018).

This aligns with the findings of Radianti, Gjøsæter, and Chen (2017) who note evidence in the literature that it is important for crisis response and management information systems to support those community members with disabilities and other vulnerable groups, something that is too often neglected. Data on people with disabilities and other vulnerable groups need to be entered into emergency response information systems and coordination must be improved between those agencies charged with addressing the needs of vulnerable populations. DeBruin, Liaschenko, and Marshall (2012) note the influence of sociodemographic factors on minority hospitalizations during H1N1. They discuss the CDC's explanation for the difference in hospitalizations, which focused on structural inequalities like access to care, underlying health conditions, and care-seeking or self-care behaviors. Ethnic and minority populations tend to be more vulnerable to illness, be less able to employ strategies to avoid illness, and experience a greater burden from government interventions than more privileged groups. Information systems used to prepare for or respond to public health emergencies should take these differences into account.

Chandra et al. (2010) identified one value of partnering with community members for the purposes of collecting and sharing information as the improvement of risk communication. As noted by Shiu-Thornton, Balabis, Senturia, Tamayo, and Oberle (2007), such an approach can aid local public health agencies in both disease surveillance and acting in a culturally competent manner. Bourdeaux et al. (2020) discuss the need to include medical providers and public health officials in an active research agenda to incorporate all the points of community vulnerability into the surveillance systems and other information management networks. Surveillance ahead of an emerging threat is vital for stopping an outbreak from becoming a pandemic.

Another example of information systems being used for surveillance purposes is the reporting of respiratory diseases through the FluWatch program (Baseman et al., 2013). Infectious disease response plans at the state local level include special surveillance and information technology groups to manage the collection, analysis, and sharing of information during an emergency (see San Francisco Department of Public Health, 2011). Along with data collected through more conventional means, information from social media (Hadi, 2014) as well as information from pharmacies related to trends in prescriptions have also come to be incorporated into the surveillance network. Investment in both maintaining and developing data collection and analysis systems is critical, as is the cybersecurity infrastructure to maintain it. Pulido, Ruiz-Eugenio, Redondo-Sama, and Villarejo-Carballido (2020) note the use of artificial intelligence and big data to identify threats in real time. Information sharing is used to improve response coordination, thereby improving both surveillance and diagnostics. Social media is cited as a potential tool for soliciting feedback on public health policy proposals.

Programs like Public Health Emergency Preparedness (PHEP) and Hospital Preparedness Program (HPP) need their funding restored to promote strong coordination at the state and local levels. The United States must also work on developing improved coordination between federal, state, and local officials to facilitate better operations of the Strategic National Stockpile and improve capabilities for rapidly disseminating vaccines. Although much about the response to COVID-19, especially in the United States, has been lacking, the quality and effects of information sharing have provided bright spots. Chinese scientists quickly unlocked the virus's genetic code and shared that information with researchers around the world. Research on a novel pathogen has been conducted and disseminated in a groundbreaking fashion. Some hope that a positive outcome of the pandemic is that it will leave behind a new era of open science (Michael et al., 2020).

Information Sharing and Combatting Mis/Disinformation

Mazarr et al. (2019) define several different types of potentially dangerous information behavior. For our purposes, the two most important types of behavior will be “misinformation” and “disinformation.” The authors define misinformation as “inadvertent sharing of false or misleading information” (Mazarr et al., 2019, p. 12). Disinformation is defined as the “purposeful spreading of a combination of false and true information to create inaccurate impressions” (Mazarr et al., 2019, p. 14). Both concepts of information behavior are relevant to the following discussion as they can affect surveillance and coordination in regard to public health emergencies. Misinformation can inadvertently make it difficult to identify the emergence and track the spread of a pathogen. Disinformation can intentionally obscure the emergence of such a threat and stymie efforts to collect reliable data. Lack of good data stemming from misinformation and disinformation can make it difficult to coordinate response efforts such as directing limited supplies and personnel where they are most needed and determine the level of non-pharmaceutical restrictions required. In regard to pharmaceutical interventions like vaccines and/or anti-virals, misinformation and disinformation can hinder the development of these resources, their distribution and dispensing, and the level of trust the public has in them. The spreading of untrue or unconfirmed information, even if done without negative intent, can complicate efforts to generate buy-in from a public in which many are already inclined due to ideology, media consumption, and lack of trust in government to disregard many of the recommendations coming from official channels (Baum, 2011; Gollust, Attanasio, Dempsey, Benson, & Franklin Fowler, 2013; Mesch & Schwirian, 2014; Ronnerstrand, 2016).

Broniatowski et al. (2018) report findings that Russian actors had employed online bots to post inflammatory information regarding both the pro-and anti-vaccine positions in the run-up to the 2016 U.S. election to promote further political divisions. Misinformation can be particularly potent if it plays into people's pre-existing beliefs. The effects of the anti-vaccination movement on the uptake of the measles vaccine suggest that social media and other channels could propagate distrust of a new vaccine once it is developed. Politicians may add to the confusion by amplifying conspiracies or unproven rumors (Center for Health Security, 2019). Abuses committed against African Americans, Native Americans, and Latinos have already created distrust toward the government in areas like medical research. Russia has a history of exploiting these cleavages, such as its efforts to promote the conspiracy theory that the U.S. government had deployed the HIV virus as a biological weapon against African Americans in order to foment global distrust of the United States (Garsd, 2018, August 22).

French and Monahan (2020) cite Mark Andrejevic (2005) who argues that the current information ecology is characterized by erosion in trust of institutions, leaving it difficult to make definitive claims that something is the truth as opposed to mis/disinformation. Lack of clear institutional authority can give rise to fear and racism, as seen with the reaction to the Chinese during the COVID-19 pandemic. Erosion of institutional trust can make it difficult for institutions like the World Health Organization to combat the deluge of mis/disinformation, dubbed an "infodemic," brought on by COVID-19. Such a situation makes it difficult for people to find reliable and trustworthy information even when they are trying to seek it out. Nevertheless, the WHO has made extensive attempts to disseminate accurate information through social media and its website. At the local level, there is a need to employ strategies to educate people on media literacy, as well as provide guidance on assessing information sources and not engaging in self-confirmation (Pulido et al., 2020). Swire-Thompson and Lazer (2020) lay out a series of action steps for combatting mis/disinformation, including promoting more judicious evaluation of on-line health information, providing clearer indicators of high-quality, evidence-based content, and making corrections clearly and frequently where necessary. Also noted are using on-line resources collaboratively with physicians and effectively utilizing cutting-edge technology.

Research into acceptance of the H1N1 vaccination during the 2009–10 pandemic by Baum (2011) finds that ideology influenced the type of media that people consumed and that the messaging taken from that media affected people's level of concern about H1N1 and their intention to take the vaccine. Meirick (2012) concludes based on his research that Fox News contributed to the mainstreaming of mistaken beliefs. The spreading of messages that the severity of the coronavirus is being played up for political reasons or that the government is behaving in an incompetent manner could dull enthusiasm about accepting a new vaccine once it is rolled out. Political leadership should have a message strategy to respond to opposition from the anti-vaccination movement, particularly in the event that some Americans experience a negative reaction to a new vaccine, which is likely in the case of a new countermeasure (Neustadt, 1978).

In October of 2019, the Johns Hopkins University Center for Health Security held a tabletop exercise called Event 201 which looked at a hypothetical response to a coronavirus pandemic. One segment of the exercise dealt specifically with misinformation, noting that conspiracy theories were likely to circulate on-line that pharmaceutical companies or governments had released the novel virus for their benefit (a prediction that came to pass with the emergence of the 2019 coronavirus). Such theories are especially counter-productive during a pandemic like COVID-19, however, it was noted during the exercise that unscrupulous companies could also use online platforms to manipulate the market and profit through short-selling (Center for Health Security, 2019).

Brunson et al. (2017) address the threat of social media manipulation during an on-going pandemic through the development of a tabletop risk communication exercise. The scenario for the exercise assumes the United States has "isolated and highly fragmented communities with widespread access to information technology" (p. 2), a state that one could argue applies today. The previously cited literature notes that authorities need to provide information to the public during an emergency or mis/disinformation could fill the vacuum. The developers of the exercise agree with this, noting that risk communication specialists advocate being very clear and transparent with the public about what is known and what is uncertain. The exercise also warns that the government needs to do the work to create trust among the public prior to an emergency, as it is challenging to create trust under stressful conditions. Particularly relevant to the type of manipulation addressed by Broniatowski et al. (2018), the government will need to be able to take on concerns about the safety of a vaccine to combat a novel virus, while taking care not to make claims about long-term safety without evidence.

Abramowitz et al. (2017) did find in their study of combatting misinformation in Monrovia during the Ebola crisis that health information was accepted and incorrect information rejected in the face of mounting mortalities, but note that behavioral change can lag due to physical, structural, sociocultural, and institutional constraints. Brainard and Hunters (2020) investigated the idea of immunizing people against misinformation and noted that creating a ratio of 60:40 in regard to good information and misleading information respectively diminished the threat of misinformation contributing to outbreaks in three cities. They did note that more "real-world" testing was required.

Information Sharing and Resilience

Hyvärinen and Vos (2015) advance the view that community resilience is a product of collaboration between government, communities, individuals, and response/recovery organizations to address the phases of disaster response. This includes being able to recognize unusual conditions, engage in resource mobilization, and demonstrate the capacity for self-organization during a crisis. Eisenman et al. (2014) discuss the Los Angeles County Community Disaster Resilience (LACCDR) Project, an organization in line with the capabilities above. The LACCDR was structured based on the levers of community resilience identified by Chandra et al. (2011): education, engagement, self-sufficiency, and partnership. The lever of organizational partnership is a particularly strong connection, as Eisenman et al. (2014) discuss the importance of expanding and strengthening connections between non-government and government organizations, as well as between various non-government organizations in the community. Hyvarinen and Vos also cite McGee's (2011) work, which advocates strengthening relationships between government agencies and local residents.

Resilient information networks can generate trust and cooperation, and it is important to create trust before a disaster (Hyvärinen & Vos, 2015). The LACCDR, for example, uses novel mapping software that allows for mapping of risk and resilience aspects of communities. This allows for the visualization of connections between hazards, demographics, and resources in a community. This assists with planning and prioritization in advance of an emergency, particularly in regard to incorporating faith-based and community organizations into the planning as well as government entities. This effort supports the resilience lever of increasing partnerships between organizations through deeper linkages between community NGOs (Eisenman et al., 2014).

Public administration needs to shift to further incorporate citizens into response activities, abandoning the refuted myth that most U.S. citizens will respond irrationally in such a situation. In order to facilitate community resilience to disasters, social networks must promote collective community behavior. A variety of networks are involved in producing resilience, inclusive of authorities, community groups, and civil organizations from the local level to the international level. Individuals and the networks to which they belong must be empowered before a crisis becomes a reality through approaches such as embracing all-hazards preparedness, identifying community resilience barriers, and determining the types of crisis communication that are needed (Hyvärinen & Vos, 2015). Reilly, Serafinelli, Stevenson, Petersen, and Fallou (2018) advise that operators of critical infrastructure in communities should familiarize themselves with the ways in which local populations seek information to inform their communication strategies, as well as partnering with community stakeholders to facilitate consistent messages across communication platforms.

Plodinec, John, Edwards, and White (2014) note the importance of a strong leadership team to implementing whole community resilience initiatives. Such teams should include representation from government, business, faith communities, and neighborhood associations to align actions with community goals. Once constituted, this leadership will conduct an assessment of their community's areas of risk and resilience, which will address issues like the most prominent risks facing the community, service capacity, what assets are put at risk by community threats, and what resources are available during the recovery phase. Subject matter experts in the community can work through a series of questions and their responses would shape community action plans.

Information and the Nexus Between Surveillance, Mis/Disinformation, and Community Resilience

Raina (2018) note that while top-down organization is common in public health, it may not be effective when it comes to a public health emergency. In such situations, a multi-stakeholder approach may be needed wherein the general public is called upon to actively participate in the management and dissemination of information. Community stakeholders can serve as independent sources of information that public health officials and policymakers can collate and draw from in the future, as well as employ to dispel mis/disinformation during an emergency response. Ratzan, Sommarivac, and Rauh (2020) lay out a series of steps to improve global health communication, which emphasizes the value of community information sharing, surveillance, resilience, and combatting misinformation. In keeping with the recommendations above, trusted leadership must be established to promote the tracking of available scientific evidence and advancement of health and media literacy. Communities will not be able to appropriately identify an emerging threat unless they are aware of what could be out there and can distinguish between reliable and misleading information. Community stakeholders, with the appropriate leadership, must actively combat mis/disinformation while consulting on a coordinated communication strategy and response to promote good information over unreliable or intentionally misleading information.

Although there have been many efforts at the international, national, and state level to combat mis/disinformation, activities must be implemented at the local level to not only improve information sharing but also improve community resilience. The prevalence of anti-vaccine information on-line, as well as misinformation and disinformation spread on-line regarding Ebola and Zika, have provided public health officials at the federal, state, and local levels some opportunities to practice communication and information sharing response in the event of a pandemic virus. Local public health departments like that of New York City employ Virtual Operations Support Teams (VOST's) to monitor on-line information for rumors or intentionally misleading information and to correct the information in real time, in addition to providing accurate information to help people avoid danger and access necessary resources (Hadi, 2014). Such efforts can be staffed by volunteers from organizations like the Medical Reserve Corps.

Other recommendations that link surveillance, combatting mis/disinformation, and community resilience include having certain public health announcements likely to be needed during a public health emergency prepared in advance in multiple languages (Medford-Davis & Kapur, 2014; Sutton et al., 2015). Lists of locally trusted media sources and other sources of information should be maintained through which to disseminate accurate advice or correct mis/disinformation, while also maintaining listservs to allow rapid dissemination of data across public, private, and non-profit organizations (Medford-Davis & Kapur, 2014). Runblad, Knapton, and Hunter (2010) advised that community and personal networks be established, maintained, and updated with standards and protocols to insure that official notifications are fully disseminated. Sutton et al. (2015) found in their study of social media activity after the Boston Marathon bombing that messaging promoting community resiliency seems to have a high degree of retransmissibility in the midst of a terrorist threat. This may also hold true in the midst of a severe public health emergency. In summation, promoting community resilience in a public health emergency involves assisting with gathering of useful data, assisting with the dissemination of this data, refuting unintentionally or intentionally misleading data, and maintaining on-going and varied networks of information sharing.

Conclusion

Hyvärinen and Vos (2015) discussed evidence that a well-developed economic system, social capital, and competencies within the population contribute to community resilience, along with information and communication. In the aftermath of the COVID-19 pandemic, there will need to be extensive focus on how to make U.S. communities more resilient to future public health emergencies. The evidence above supports the notion that a variety of community stakeholders and organizations should be coordinated at the grassroots level to aid in the quick identification and understanding of emerging threats and combatting mis/disinformation. Although putting together such coalitions will require some degree of pre-existing community resilience, involving stakeholders in this work in a more substantive way is likely to build further community resilience by creating a better understanding of how health data is produced and what separates trustworthy and untrustworthy information sources. Such efforts will hopefully create more trust between community stakeholders and the public health sector, allowing for faster community buy-in and more rapid responses in the midst of future outbreaks.

The COVID-19 pandemic has sharply illustrated the difficulties involved with trying to control a threat as data is being questioned, inaccurate information is being disseminated, and communities are not united in common goals. Goniewicz et al. (2020) conclude that moving forward a "fail-safe information system" that is "independent of sociopolitical relations to avoid misinformation and confusion" will be necessary (p. 9). As we continue to fight our way through the current emergency while looking ahead to the next, we must continue to pursue ways to make all community members invested in the response. If more citizens are engaged from the very beginning by helping to detect the threat, they will be more invested in sounding the alarm and overcoming voices of mis/disinformation. Furthermore, both preparing for such events and then working together in the aftermath builds on Chandra et al.'s (2011) levers of community resilience, particularly education, engagement, and partnership. It is important moving forward to transition community members from being passive consumers of information in regard to health threats to producers and defenders of this vital resource.

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Note

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World Medical and Health Policy

BOOK REVIEW

Katharine M. Broton, Clare L. Cady. *Food Insecurity on Campus: Action and Intervention. Baltimore, MD: Johns Hopkins University Press, 2020. $39.95. pp. 312. ISBN 9781421437729.*

Many students cannot finish their college work because they are too tired from working multiple jobs or too hungry to concentrate, and often need to leave their university to focus on meeting their basic needs. If universities want their students to succeed (and finish their degrees), what are they to do? *Food Insecurity on Campus*, edited by Katherine Broton and Clare Cady, provides an overview of how colleges can take action to support their students who face food insecurity. The purpose of the book is to "provide a venue for college, community, and policy leaders to share the lessons they have learned in the fight to end student hunger and compile a comprehensive source of information, guidance, and support for those seeking to develop an intervention or strategy" (p. 1) and the book accomplishes this well. As the editorial team is made up of a researcher (Broton) and a practitioner (Cady), the book maintains a balance between studying food insecurity and making concrete changes to help alleviate that specific issue.

The introductory chapters by the editors frame the issue and then the book transitions into examples from authors across the country. The first chapter, written by Broton, provides the national context on income inequality, inflation, and financial aid to set the stage for needing food insecurity work. She defines food insecurity in accordance with the USDA guidelines and explains that students face food insecurity along a spectrum, from high food security where students rarely face issues with accessing food to very low food security where students have "multiple indicators of disrupted eating patterns and reduced food intake" (p. 18). In consideration of this spectrum of needs, the next chapters outline how efforts to alleviate food insecurity also exist on a continuum.

Cady starts the discussion of how to alleviate food insecurity and hunger in the second chapter. She describes her (and her group's) efforts to serve universities on a national scale regarding the most popular method of serving students: the campus food pantry. Through this chapter, Cady explicitly details what they did, how they did it, and what they learned which provides credibility to her as a leading

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practitioner in the field. For instance, Cady discusses the need for partnering with local organizations, finding a dedicated space, and establishing a sustainability plan to serve students for the long term. She also emphasizes the need for research in understanding the problem and larger policy changes to solve the root of the problem (i.e., poverty) rather than the symptoms. Chapters 3 through 9 detail other initiatives by groups, each describing their solutions and providing recommendations based on their experiences. As such, university administrators would be an ideal audience to take what has been learned and directly translate that into action on their own campuses. Readers who do not have a role to play on campuses may feel they also have no role to play in fighting food insecurity until the end of the book.

The penultimate chapter of the book takes a larger view of the issue of food insecurity and outlines specific policies that should be changed in order to systematically and strategically alleviate student food insecurity. This includes an overview of common federal initiatives, such as the Supplemental Nutrition Assistance Program (SNAP; formerly known as "food stamps"), to provide awareness and eliminate misconceptions. This detailed information makes change accessible for readers who are outside of higher education administration. Finally, the editors conclude the book with hope: upcoming initiatives that will provide more insight into what works along with recommendations for research, practice, and policy.

Although the issue of food insecurity is not new, this research area is new; *Food Insecurity on Campus* helps summarize what we do know and how universities can help their students immediately and profoundly. Overall, this book is a must-read for all university staff, especially those who work in student support areas. Faculty members would also benefit from reading this book to understand how they can play an instrumental role in identifying and serving students who encounter this problem. However, this book only pertains to a U.S. audience because of the university examples presented and the issues relating to financial insecurity and college affordability. Still, one theme from this book applies to all readers: more research must be done to fill the gap on this important problem. As such, future research should include best practices found during large-scale emergencies (i.e., COVID-19) and those from other nations.

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World Medical and Health Policy

Book Review

Pamela Herd and Donald P. Moynihan. *Administrative Burden: Policymaking by Other Means. New York, NY: Russell Sage Foundation, 2018. pp. 360 ISBN: 9780871544445.*

Administrative Burden: Policymaking by Other Means by Drs. Pamela Herd and Donald P. Moynihan discusses an insufficiently researched area in public policy: administrative burdens, or the costs associated with accessing public services, as it affects both public administrators and the people receiving (or eligible to receive) the services. From their extensive research in this area, the authors define administrative burdens as encompassing three types of costs; learning, psychological, and compliance, which when used to varying degrees can help or hinder participation in a program or service.

Drs. Herd and Moynihan are professors in Public Policy at the Georgetown University and experts in this niche area of public administration research; particularly as administrative burdens lead to social inequality. Rather than being academic in nature, the authors clearly choose to write *Administrative Burden* for policy professionals, given the tone, writing style, and readability of the book for non-academic audiences. Each chapter provides a brief history of different health and social policy programs, their associated decisions, and its impact on administrative burdens for the citizenry. Finally, the authors conclude with a practical set of tools and guidance for public health, health policy, and public administration officials alike to build considerations of these burdens into future policymaking.

Most notable are the attempts by political actors to reinforce stereotypes or support negative ideologies of service recipients through applied administrative burdens. This book serves as a clear call to action for policy advocates in these communities to continue addressing the consequences of these decisions. Although the entire book outlines this concept, the chapters on voting (Chapter 2), SNAP (Chapter 6), and Medicaid (Chapter 7) resonate most closely with this concept.

In Chapter 2, the authors review the history of the Voting Rights Act. Throughout the chapter, they note the comparative use of restrictions both pre-Voting Rights Act (poll taxes, literacy tests, etc.) and today (voter ID, limiting auto-enrollment, etc.), limiting rights for citizens deemed to be "less than" others or

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believed to potentially vote for opposing candidates or parties. Today's political actors continue this vein under the guise of voter fraud to implement these restrictions and burdens; which for many lower-income, urban, and primarily minority, U.S. citizens may be prohibitive hurdles to exercising their constitutional rights.

Chapter 6 exhibits similar concerns related to SNAP, as recipients are scrutinized and stereotyped for attempting to defraud or take advantage of the U.S. government; implying laziness or avoidance of honest employment. At some points, the authors highlight explicitly classist (within the context) and potentially racist behavior, such as a quote from Bill O'Reilly referring to SNAP recipients as "parasites" taking what they can without "remorse" (p. 144).

Successes in applying administrative burdens in Medicaid within the State of Wisconsin are highlighted in Chapter 7, providing a summary of political decisions that significantly impact citizens within a very short span of time. Compared with the chapter on Medicare (Chapter 5), it is clear that perceptions of people on Medicaid (low-income, disabled) differ from those on Medicare (generally all eligible senior citizens)—and as a result, lead to very different administrations of each program. Governors Thompson and Doyle's attempts to streamline the Medicaid program reduced those differences in treatment and stereotypes, while Governor Walker's attempts exacerbated them. This was a refreshing overview to read and marked a noticeable shift in tone and treatment of different public programs and administrative burdens, which the authors highlight throughout the book.

The authors close the book by introducing the concept of creating a set of professional norms in public sector and policy administration for assessing burdens in service delivery (Chapter 10). This chapter also includes tools for administrators to use when assessing burdens and developing necessary changes to programs—all focused on reducing burdens for the service recipient.

These tools draw on a human-centered design approach used in a number of disciplines, from technology to business, to create effective systems. Exploring the connection and utilization of this approach by public administrators in future literature could lead to a more practical application of the authors' recommendations. In addition, these tools could be further incorporated into a "Code of Ethics" for the public sector and policy professionals, similar to the American Public Health Association's new Public Health Code of Ethics (2019) which includes practical tools and questions to consider as professionals develop ethical and effective community-level programming.

Although limited use of administrative burdens by the Democratic party is discussed by authors in the final chapter through their recognition that Democrats have not been as effective as Republicans at using this policy tool, it would have been instructive to see an additional chapter or two that gave an in-depth treatment into these failures of utilizing administrative burdens in policy.

Overall, this book should be read by any professional in government, health, or social policy and program implementation. This book serves as a reminder that every political decision regarding health and human services impacts an individual or family's ability to access services—for better or worse. By keeping this in mind, and leveraging power and opportunities to create change, policy professionals may "….more rationally assess how policy design and implementation will affect [our] citizens" (p. 250).

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World Medical and Health Policy

BOOK REVIEW

Adam Kucharski. *The Rules of Contagion: Why Things Spread and Why They Stop. New York City, New York: Basic Books, 2020. $30.00. pp. 352. Hardcover. ISBN: 9781541674318.*

There may be no better time in history to understand why things spread and why they stop. The rules of contagion have been brought into focus with current events. Although COVID-19 might be the easiest connection, contagion also has social implications in the spread of violence, how riots start and proliferate, information sharing (misinformation and disinformation included), propagation of social justice reform and protests, and social media influence. Each of these types of contagion may be unique at first glance but in fact, have many overlapping concepts. *The Rules of Contagion* provides a thorough background on everything contagion from a social behavioral lens.

Adam Kucharski is just the right person to write such a book. An Associate Professor and Sir Henry Dale Fellow in the Department of Infectious Disease Epidemiology, Kucharski uses statistical models to better understand disease outbreaks with a specific focus on social behavior. His research follows how social behavior impacts disease transmission (Kucharski et al., 2020), what factors influence the containment and transmission of disease (Kucharski et al., 2020; Robert et al., 2019), and how to measure and model these impacts and factors (Kucharski & Nilles, 2020). He has worked on endemic infections like seasonal influenza and dengue fever and outbreaks such as Ebola (Robert et al., 2019), Zika (O'Reilly et al., 2018), and COVID-19 (Kucharski et al., 2020; Kucharski et al., 2020; Kucharski & Nilles, 2020).

Firmly entrenched in theory and history, Kucharski brings out the rules of contagion through learning from past outbreaks as well as adding in key insights on the statistical and behind the scenes aspects of tracking outbreaks. The book starts from how past scientists, doctors, and researchers conceptualized, tracked, and studied outbreaks of infectious disease. This history lesson is well done and provides a thorough background in past research while engaging the reader through storytelling. Kucharski aptly moves through epidemiological and social network theory to explain the spread of these diseases as well as explain how and

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why theories and modeling approaches are used to better understand contagion. He also provides enough of the statistical background for readers to understand the basics of these models without detracting from the readability of the book. These concepts of contagion applied to infectious disease would be critical for readers looking to better understand how the projections and models for assessing COVID-19 outbreaks and spread were formed and continue to be reassessed. Although Kucharski does not bring up COVID-19 specifically the connection is obvious, and groundwork applies.

Next, Kucharski appropriately blends in other forms of contagion to reinforce the elements of the book as well as expand the reach and implications of the work. Touching on misinformation and disinformation on social media platforms, violence in urban settings, and riot behavior, Kucharski provides stories from a public health and epidemiological lens to help inform the reader of this very real application of social contagion. He weaves these concepts and applications together rather seamlessly to further imply the associations and crossovers between these forms of contagion. These concepts can easily be applied to how information is spread online including but not limited to vaccination misinformation and political disinformation. Kucharski uses examples of both from the 2016 election as well as measles vaccination concerns. Likewise, examples of rioting behavior being similarly contagious are appropriate now more than ever given the events in the Capitol. Again, while Kucharski does not comment on these events the commentary of how these ideologies and movements spread is important to note.

As already noted, despite being published in June of 2020, the book does not investigate or frame any concepts in the current events. COVID-19 is mentioned twice throughout. This is understandable as I am sure the book was written well in advance of the 2020 publish date. Perhaps in future editions, a 2020 chapter could be added as a case study or microcosm of contagion. This may also be something Kucharski writes as a completely separate book given the extent of his expertise and knowledge on the subject matter. This would be the only potential weakness in this book if readers were looking for a current commentary regarding contagion. With this in mind, the book adequately provides the background and concepts needed for the reader to be more well informed when evaluating these current events.

Despite this one quite understandable limitation, *The Rules of Contagion* provides a quite enjoyable read linking aspects of infectious disease and social contagion with history, storytelling, and statistics. I would highly recommend this book to anyone looking to understand aspects of social and disease spread. The writing is well done, extremely readable, yet provides enough substance for even those readers already informed on the topics. In a true sense of contagion, I now spread this idea and book to you; enjoy!

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BOOK REVIEW

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Fevers, feuds, and diamonds: Ebola and the ravages of history

Paul Farmer

New York, NY: Farrar, Straus and Giroux, 2020. pp. 652. ISBN 978-0-374-23432-4.

In 2014, an outbreak of the Ebola virus swept through Sierra Leone, Guinea, and Liberia. The epidemic's high degree of devastation was due in part to Ebola's particular virulence, but also to a legacy of exploitation and neglect throughout West Africa which created what Paul Farmer calls a “clinical desert” (p. 191). Farmer explores the sociopolitical landscapes of this region to provide a more thorough understanding of how the ravages of history manifest in human bodies during times of disease. Farmer's work is characteristically exhaustive, and to aid the reader, he has separated his tome into three parts.

Part One is decidedly narrative in nature, with Farmer recalling his own experiences as a clinician working in West Africa during the 2014 Ebola epidemic. He also includes stories from Ebola's victims and combatants, who are often one and the same. In the course of developing the human element often lost in discussions of plague, Farmer establishes perhaps the most fundamental thesis of his book: That public health efforts in Africa have historically maintained a “near-exclusive focus on disease control rather than care” (p. 185) of the individual sufferer. The case of 21st century Ebola is no exception. Containment, not therapeutic treatment, was the preferred modus operandi of international healthcare organizations working on a continent with a populace that has been seen for centuries as better managed by the cold calculations of bureaucracy rather than the compassion of common humanity.

In Part Two, Farmer more explicitly links the paucity of clinical care available to Ebola victims with colonial and postcolonial African history. In discussing the Great Scramble for Africa, Western direct and indirect colonial rule of African lands and peoples, and the rampaging extractive capitalism of the postcolonial period, Farmer provides a great body of evidence to support his main point established in Part One. He also extends his thesis to a more biting critique, arguing that “[e]very chapter of the history of West Africa under European rule seems to include yet another cataclysmic outbreak of disease or conflict (or both) followed by ineffective or repressive measures (or both) and linked in an unbroken chain of profiteering” (p. 270). Peppered among this broader dissertation are some other provocative and well-substantiated ancillary criticisms: That the European Enlightenment had a decidedly unenlightened and dismissive attitude toward African history, that the alleged resistance to Western medicine by Africans was not as perspicuous as is often portrayed, and that chronicles of global health often overlook African history and the fate of Africans during periods of pestilence. Farmer closes the chapter by wading into the tragic quagmire of postindependence internecine war in West Africa, which has done little to nourish this so-called clinical desert.

Farmer's final part is a return to the mechanics of how Ebola infects and affects its victims, but it is also a state of the union on clinical care in West Africa given the historical recounting provided in the preceding pages. As one can imagine, his assessment is sober and realistic, and as such is fairly uninspiring. Reflecting not only on the academic subjects broached thus far, but Farmer also returns to his personal experiences working in Ebola-affected areas. Acknowledging his and his partners' own shortcomings, he warns against a “therapeutic nihilism” (p. 445) that he finds too common among predominantly Western clinicians working in Africa, and advocates for a brighter future where clinical care and disease control are seen as complementary elements of a robust “social medicine” (p. 438) rather than competing philosophies in epidemic care on the African continent.

Farmer's work is a great contribution to the field of medical sociology, medical anthropology, and the history of medicine. There are points in this book in which students of African history will feel as though they are re-emerged in one of their dedicated undergraduate courses, while readers with other concentrations may feel, at times, that the thread has become a bit obscured in the particularities of history. But Farmer is careful not to stray too far from his main artery, and just when the reader may feel as though a good amount of time has passed since there has been any reference to disease, suddenly a connection is made that brings a sense of cohesion to the various topics discussed. Although most proper personal stories in this work are contained in Part One, the book is essentially a long narrative that at times wanders into a thicket of historical detail. But as Farmer writes about one of his Sierra Leonian companions who seemed to drift aloft while discussing his own experience with Ebola: “He was, in that particular session, fully caught up in his narrative; it was better not to interrupt when he was on a roll” (p. 114).

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World Medical and Health Policy

BOOK REVIEW

Humber, Lee. *Vital Signs: The Deadly Costs of Health Inequality.* London: Pluto Press, 2019. $23.95. pp. 159. ISBN. 9780745338323.

Health inequality is a growing concern throughout the world and often leads to increased disease burden and reduced life expectancy. Lee Humber's *Vital Signs: the Deadly Cost of Health Inequalities*, paints a grim picture of the true cost of these inequities, moving the blame from the individual to the government and the privatization of the healthcare sector. Humber, a health and social care academic and activist, uses current and historical data to show how nature is not the leading cause of death and gives prime examples of what must be done in order to reverse our current course, save lives, and ultimately increase the life expectancy of populations.

Humber starts with the current, neoliberal model of the healthcare sector in both the United States and the United Kingdom; one that sees healthcare as a commodity to be bought and sold similar to clothing and other goods. Since this shift has taken place, healthcare workers are exploited for profit, which both furthers the market drive and commodification of healthcare. This exploitation and commodification are the dominant paradigms of the healthcare sector, which forces governments already strapped for cash to try and outperform health conglomerates that have billions in savings. Unable to provide adequate care, government entities are forced to continue the cycle of commodification, which increases healthcare spending at the same time it reduces health outcomes for patients; "[i]n this neoliberal scrambling for profitability…the health of populations comes a poor second" (Humber, p. 38).

The remainder of the text of *Vital Signs* goes on to discuss the rise of the medical-industrial complexes, the social determinants of health, and how philanthrocapitalism has cemented the privatization of healthcare, which in turn has reduced the capability of the healthcare sector to treat patients. These medical-industrial complexes are large billion-dollar, market-driven entities that lobby the government and dictate how healthcare is utilized on a global level. The commodification of health and the rise in power of these complexes are directly related to

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decreased life expectancy seen in the United States and the United Kingdom. Humber shows us the only way to avoid further decline in life expectancy, to increase healthcare and ultimately decrease health inequalities is to instead use the social determinants of health approach, rather than a biomedical approach, and to switch from a "curative" to a "preventative" health model.

The social determinants of health are an important concept to understand as our health, and the health of society is determined from many facets. The ability to be educated, find dignified work, have affordable and safe housing, and nutritional food are all factors that both influence health and are determined by wealth. Humber points to works by academics Michael Marmot, Kate Pickett, Richard Wilkinson, and Danny Dorling that helped craft this theory and how wealth and income determine how individual members of society fair, including how the lack of welfare support, in turn, exacerbates health inequalities. For instance, if the United States had a comparable welfare standard to other Organization for Economic Co-operation and Development (OECD) countries, life expectancy could be almost 4 years longer (Humber, p. 60). Humber goes on to show how in Italy, one in four children are at risk of poverty, which in turn leads to severely reduced health outcomes for these individuals; in the United States, the numbers are 1 in 6 (Children's Defense Fund, 2020). As Humber states, "In the materialist and political content that a social determinant of health approach provides us with, we have a means of both understanding where health inequality is rooted and a means to impact upon it" (p. 133).

In an interesting and eye-opening chapter, Humber delves into the formation of the World Health Organization (WHO) and the nature of philanthrocapitalism. Philanthrocapitalism is where non-profits act like for-profits, with private funding, investments, and the use of funds that are normally directed to social outcomes (Humber). These philanthrocapitalists are a leading contributor to WHO, and while WHO is known for their preventative measures for health, their aims may not always be in line with what is optimal for societies. For instance, Humber looks at the Bill and Melinda Gates Foundation (BMGF) which gives billions of dollars each year to WHO and other global organizations; however, this largely unchecked organization also exerts its influence over WHO. The BMGF's primary focus is on technology and vaccination, and while vaccination is certainly imperative for public health needs, there are other important systems that need support in terms of global health; sanitation, education, nutrition, housing, and dignified work are proven to enhance health and decrease inequality more so than simply vaccinating individuals. Humber also points to the rise of cash crops (those sold for profit rather than consumption, i.e., corn, sugarcane) and how organizations like BMGF and United Nations International Children's Emergency Fund (UNICEF) advocate for "micronutrient malnutrition," which is food supplementation and synthetic fortification rather than aiding countries to produce their own wholesome, nutrient-rich food.

With the current focus on "curative" rather than "preventative" medicine, we as a society will continue to see larger and more powerful medical-industrial complexes, more expensive but less attainable healthcare, larger and deeper health inequalities, and ultimately even lower life expectancies. Humber directs us to start questioning the status quo, pushing back against these large entities, and to open up discussions on the social determinants of health; moving from the market's view of a “biomedical” health approach to a more sustainable “holistic” approach. This view should be widely accepted by academics and health advocates as imperative and accurate, and will likely be ignored by philanthrocapitalists and conglomerates as divergent or radical. By understanding how social and societal roles influence health and healthcare, we can better support individuals and governments to prioritize health rather than markets, and reduce the exploitation that occurs in the health sectors. Humber's *Vital Signs* delves into how we got to where we are and gives us a way out, but only if we can realize our collective potential.

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World Medical and Health Policy

Book Review

Philipp Trein. *Healthy or Sick? Coevolution of Health Care and Public Health in a Comparative Perspective. Cambridge: Cambridge University Press, 2018. pp. 332. ISBN 9781108670883.*

In *Healthy or Sick?* Phillip Trein, a Senior Researcher in the Department of Political Science and International Relations at the University of Geneva, whose work has primarily focused on the coordination and integration of public policy and the politics of preventative health policies, brings to the conversation a topic that is significantly important and popular today not just in the United States, during a contentious election year; but also across the globe as governments and professional agencies struggle to contain the current COVID-19 pandemic meanwhile preparing for future outbreaks in two ways: (i) mapping out the contextualization of comparative politics of public health, concerning the connection of the intersectional dimensions health care and public health and, (ii) temporal dimensions that refer to the development of the sectors' relations amid policy divergence and convergence in five historical case studies in Australia, Germany, Switzerland, the United Kingdom, and the United States. At present, the increasing demand for more preventative health policies and curative interventions not only causes increases in health expenditures for governments but also conversations around policymaking as it relates to public health and health care.

The author conducts a historical empirical analysis between health care and public health spanning 1880–2010 using secondary literature, official documents, and recorded instances (e.g., institutional reforms and policy). To set the context for this analysis of the book, Trein initially defines health care and public health as two distinctive policy sectors that have interacted uniquely across time. In particular, defining how they differ regarding actors, policy instruments, and conflicts. Trien discusses in-depth his journey of theoretical priors and after mapping out the expansive literature, proposes the development of three hypotheses. He begins by hypothesizing three main tenants: (i) there is no distinctiveness of health care and public health if a government is unified (i.e., meaning that the national government has a relatively large discretion in changing policies and components of formal

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institutional structures without considering the opposition, for example, centralized federations, counties with few veto points, strong states, and majoritarian democracies); (ii) there exists a high level of responsiveness from health care and public health specialists if professionalism and the existence of professional organizations in that national context are high (e.g., medical and legal associations are strong and politically independent from the state); and (iii) the relationship between public health and health care remain stable over time in a nation given the context (e.g., more illness, technology, etc.) does not change significantly.

Trein then maps out a temporal theoretical four-cell diagram with two axes: responsiveness (i.e, the extent to which public health and health-care systems respond to each other) and distinctiveness (i.e., the extent to which they are organizationally, legally, and otherwise separate from each other) (p. 31). Into this four-cell typology, he places his country cases: Australia, Germany, Switzerland, the United Kingdom, and the United States. After discussing the contextual dimensions and patterns of technology and economics as they relate to health sectors across time, Trein showcases individualized case studies for the five countries in order to establish the co-evolution of both sectors along two primary analytical dimensions: (i) actor policy responsiveness and (ii) institutional distinctiveness across determine time periods. This allows readers to view how nations navigated across time and unique national (e.g., national recession) and global occurrences (e.g., Spanish Flu) that affected the two sectors.

The results of the analysis demonstrate that health care and public health co-evolved differently between the five case countries. For example, these sectors evolved from loose to tight coupling in Australia. In the United States, the development, although similar, the existence of institutional distinctiveness between the two sectors was more pronounced. In contrast, in the United Kingdom, the two sectors co-evolved from non-coupling to tight coupling. In Germany and Switzerland, the sectors co-evolved from decoupling to non-coupling. Overall, the two sectors co-evolved toward more responsiveness in all five contexts. Finally, findings on the effect of professionalism on policy sectors indicate how professionals were more politically active (e.g., medical professionals advocating for public health issues like immunization, or tobacco control policy). Furthermore, the national context subscribing to federalism had mostly impacted the institutional relationship between public health and health care. Notably, there was an overall centralization of health policy, meaning that in all five case studies, the two sectors co-evolved toward unification of the various institutions

Overall, Trein has written an intellectually stimulating book that offers a rich map of empirical basis and provides a space to address future research. The study is distinctive as the author engages and makes conversation between multiple theoretical pieces of literature and global events, which makes it an interesting read not only for public health scholars interested in health policy but also for those readers interested in theoretically informed empirical research. The books' proposed findings also contribute to the political economy literature and can be used as a platform in expanding future research efforts on the institutional conditions under which health professions take the role of public interest groups and use their reputational power and role as scientists and doctors (Ingold & Gschwend, 2014) to advocate for policies that are beyond their particular interests. Such a political activity might be particularly important in tobacco control in the United States where powerful interest groups, like the tobacco industry, have an interest and the means to delegitimize and discredit public health-related research (Grüning, Gilmore, & McKee, 2006). This book is an excellent manuscript for advanced students and scholars in the field of comparative health policy analysis. Furthermore, the scholars working in health policy integration and related concepts should particularly welcome this book as it offers a unique approach to a contemporary global conversation. The book offers insights for expansive readerships by enriching courses for graduate students or provides original research to a point of departure. Trein identified and began an important conversation in the gap in comparative politics of public health—and the organizational dynamics of integration between public health and health care. This book allows for further inquiry and examination of the two sectors moving forward.

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BOOK REVIEW

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A guide to the scientific career: Virtues, communication, research, and academic writing

Edited by Mohammadali M. Shoja, Anastasia Arynchyna, Marios Loukas, Anthony V. D'Antoni, Sandra M. Buerger, Marion Karl, and R. Shane Tubbs

Wiley Blackwell, 2020, 742 pp. ISBN: 9781118907429.

Global health is influenced by several factors including health policy, politics, health economics, medical ethics, and public health. The context within which healthcare decisions are made, and the processes, outcomes, and influences must be objectively studied. Reliable, quality evidence is needed to make proper health policy and public health decisions. Scientific research forms the bedrock of our evidence and biomedical scientists play a vital role in creating and expanding the evidence base.

As academicians, teachers, clinicians, health policy advisors, and researchers we juggle many roles ranging from large group teaching, small group facilitation, scientific research, writing for publication, research ethics, statistics, presenting at conferences, and other venues, leading research and other teams, and academic networking among others. Many of us are involved in creating evidence on which health policy decisions can be made and studying the different determinants of health. We are happy that a recently published book on a guide to a scientific career addresses many of these roles.

The chapters within *A Guide to the Scientific Career: Virtues, Communication, Research, and Academic Writing* will be especially useful to scientific researchers working in a variety of contexts. This edited collection is organized into 10 sections and 74 chapters. The sections are successful career, communication, research ethics, research regulations, research grants and proposals, research principles and methods, publication and resources, technical writing, biostatistics, and academic networking. The book has an extensive list of contributors, ranging from academicians, natural science researchers, librarians, communicators, theological scholars, psychologists, clinicians, bioethicists, and research administrators. As individuals advocating for greater visibility of third-world research and researchers, we are pleased that there are several authors from the developing world. The book can be regarded as a "guide by your side" that walks readers through the different steps of a successful academic career.

The book starts with the section on a successful career and an interesting chapter on defining and redefining success. The authors, *Mohammadali M. Shoja*, *R. Shane Tubbs*, and *Dan O'Brien* examine various aspects of success. Among the key messages are success is self-defined, opportunities are created, and failure is the key to success. *Bradley K. Weiner*, *Paige Vargo*, and *Joseph Fernandez* offer an interesting chapter on whether publishing translates to a successful career and conclude that without doubt academic writing and publishing can directly translate into a successful career. We agree. Also, in the first section, a chapter authored by *John Panaretos* and *Chrisovalantis Malesios* notes, a lot of attention has been paid of late to assessing researchers' scientific productivity and impact. Accordingly, they explain the Hirsch index and differences in an individual's indices according to different databases.

We have all had to deal with underhanded people who are skilled in the art of manipulation and evasion of responsibility, and a comprehensive chapter (in the second section Communication) by *George K. Simon* on dealing with these individuals will be useful for navigating these kinds of situations. The author draws on psychology to provide tips for setting the terms of engagement with these individuals.

In the third section on Research Ethics, a chapter by *Izet Masic* on plagiarism and how to avoid it will be of special interest. The standards on publication ethics created by different organizations and the electronic tools to detect plagiarism are discussed. Detailed instructions on avoiding plagiarism are provided.

Institutional review boards and research oversight is covered in detail, though the perspective is predominantly American. The functions of an Institutional Review Board (IRB), types of research reviewed by an IRB, different types of reviews, publishing, and the workings of the IRB itself are covered in detail.

The chapter on “Essentials of grant writing and proposal development” by *Chevis Shannon* and *Jamie Dow* in the fifth section on research grants and proposals addresses aspects ranging from the areas that a grant proposal should address, data monitoring and regulatory requirements, and budgeting and costs. We believe the chapter will be especially useful to young scientists.

The publication process is addressed in a stepwise fashion in the seventh section on publication and resources. The chapter by *Katherine G. Akers* on the quality and impact factor of journals will help readers choose suitable journals for their work. The different types of open access models and what rights authors retain are important. As we often facilitate sessions on scientific writing and publishing, we found the section on the publishing of great interest.

Section 8, on technical writing, is well-written and provides practical tips for clear and effective writing. A chapter on editors' perspectives by *Marilyn Michael Yurk* counsels to keep writing simple, use reference management software, beware of predatory journals, fully involve one's coauthors, and carefully check proofs when the article is in production.

The last chapter in Section 10, on academic networking by *Sanjay Patel*, *Petru Matusz*, and *Marios Loukas*, provides guidance on writing a curriculum vitae (CV). The CV is an important document and required frequently both in an individual's current job and when searching for new ones. The author's guidance may be useful, but readers should note that there may be some regional variations on what is included in a CV.

Each chapter in this excellent collection has a list of references and further reading. We believe, however, that a short summary using bullet points would have been helpful. The cost may be on the higher side for scientists in low- and middle-income countries but being a one-stop guide to major issues in scientific life is the book's major strength. Libraries should purchase multiple copies of this excellent book. All biomedical scientists will find vital career advice in this comprehensive resource.

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