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Understanding and Defining Healthcare Foregoing through a globally applicable model: An Academic Thesis

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Understanding and Defining Healthcare Foregoing Through a Globally Applicable Model

An Academic Thesis

June, 2018

Faculty of Social Sciences

Masters of Arts Standardization, Social Regulation and Sustainable
Development

University of Geneva

In Partial Fulfillment towards obtaining a Masters of Arts Degree

From

Aparna Pipersenia

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**UNIVERSITÉ
DE GENÈVE**

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Abstract

As one of the critical factors influencing lifespan and thus human development, healthcare is one of the chief mandates of a government. It encompasses a large range of non-utilizing behaviors stemming from motivations that are unique to a person, a society and a country. Understanding healthcare foregoing is important to resolve unintended policy exclusions, bringing overall healthcare costs down, reduce taxpayer burdens and increase longevity and wellbeing in the society. There is therefore a need to define and understand healthcare foregoing in a globally applicable way – which can be systematically applied to different countries or cultures – despite the unique differences. Through appreciation of past concepts and models, a clear definition of healthcare foregoing is arrived at. Further to this, a globally applicable model is introduced, illustrated and explained with the help of an extensive literature review of available academic papers related to healthcare foregoing. Through results and conclusions performed on empirical data of these academic papers – the healthcare foregoing model is thus described holistically with examples.

The model proves that despite economic and cultural differences between countries, healthcare foregoing as a decision is universally either an ‘individual’ one or taken as a ‘community’ and a person’s inner alignment and conviction of conventional treatment is diagnostic of the eventual reasons behind healthcare foregoing. From the state’s perspective, the healthcare foregoing can be assessed as a ‘demand’ problem – where people do not perceive the need for available healthcare or a ‘supply’ problem – where despite perceiving a need – people are not able to access decent equitable healthcare.

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Introduction

Healthcare is an important mandate and feature of any government where progressively, it is now accepted that it is a universal right of each and every human globally (Garrett, Chowdhury, & Pablos-Mendez, 2009). Especially as optimal healthcare provision is directly correlated to improving human lifespan – a key indicator to achieving development parameters for a State (OECD, 2016)

Where Governments spend a great deal of their policy making on health systems, understanding the reasons for certain individuals to actually ‘opt-out’ or ‘under-utilize’ the healthcare system is of a primary concern that needs to be addressed systematically. Understanding this human behavior that leads to foregoing of healthcare has significant implications on state policy with respect to healthcare coverage, health institutions, research into healthcare, insurance laws – to name just a few.

From the point of view of healthcare users, foregoing healthcare has a potential impact on their present as well as future health status and wellbeing. It is well documented that non-timely availing of healthcare by people for current problems leads to graver and more serious health issues for them in the future leading to greater financial instabilities and in turn poorer quality of life (Bodenmann, et al., 2014). Healthcare foregoing at any level, also results in a greater financial burden for the State and in turn on bigger burdens for the taxpayers - with more people seeking emergency services and needing hospitalizations (Galbraith, et al., 2012). In general healthcare foregoing is critical in determining overall lifespan which in turn us a significant determinant of human development in that country.

This paper is an academic pursuit to throw insights on tendencies to forego available healthcare by certain vulnerable populations and those who do so despite having all the

means. The paper's endeavor is to suggest and explore a new theoretical model to understand healthcare foregoing that can be applied globally irrespective of economic development and bring the topic under the purview of predictability and better understanding. By delving into the available academic literature and relevant empirical data, the goal is to lay the foundation by literally defining the term 'healthcare foregoing' using historical approaches and draw out the various patterns and insights emerging from this undertaking. The latter will also demonstrate that healthcare foregoing is a phenomenon that occurs through a complex interaction of interrelated factors that interact with each other simultaneously.

This paper introduces a multi-dimensional model - as it considers official care (i.e. the dominant form of medical care available to the society) versus the alternate options available and the complex interplay between decisions taken individually or from a community point of view – which results in foregoing.

Applying a few handpicked studies, this paper will seek to explain each part of the model extensively. Factors such as out-of-pocket expenditures, concerns on quality, discrimination, stigma, culture, alternative therapies among several others will be examined in detail.

The paper will start with a preamble on the current state of affairs with respect to healthcare foregoing, followed by a presentation of a few noteworthy historical models and argumentations on the topic of foregoing. Taking note of these academic papers, a new theoretical model for understanding healthcare foregoing will be introduced and explained in granular detail, employing examples of carefully curated empirical (qualitative and quantitative) research. This is followed by a discussion on the findings and insights gleaned through the aforementioned pursuit and the paper will conclude itself with the applications and relevance of the said model and its advantages as well as shortcomings.

Healthcare Foregoing Today

Healthcare under/non-utilization is defined by Penchansky et al in the context of 'healthcare access' – where such an access is a concern or is unsatisfactory (Penchansky & Thomas, 1981, pp. 127-128). This definition brings us to consider the meaning of healthcare and concept of health in our society today. Increasingly health is referred to in the context of lifelong interventions that “need permanent systems of medical assessment and treatment” (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1294). Coupled with the recent health concerns arising from new threats – such as climate disruption, population-scale health disasters, catastrophic weather events, food and malnutrition crisis and human migrations – it is imperative now more than ever to understand the basis of healthcare under-utilizations and unintended policy exclusions. Healthcare foregoing today has become a major concern in health policy, health accessibility and health management in both low-income as well as high-income countries.

From a political and economic view point, healthcare foregoing relates to larger problems of governance, risk of market failures, risk of discrimination and alienation of vulnerable populations. (Arah, Westert, Hurst, & Klazinga, 2006). Given the realities of migration and globalization of economy – the link between populations, health systems, the capacity of the global scientific community to encourage timely availing of healthcare and assess it real time is necessary.

Healthcare and welfare regimes¹ have given rise to debates about healthcare utilization for over 50 years (Anderson, 1996) when an in-depth model was attempted to understand the

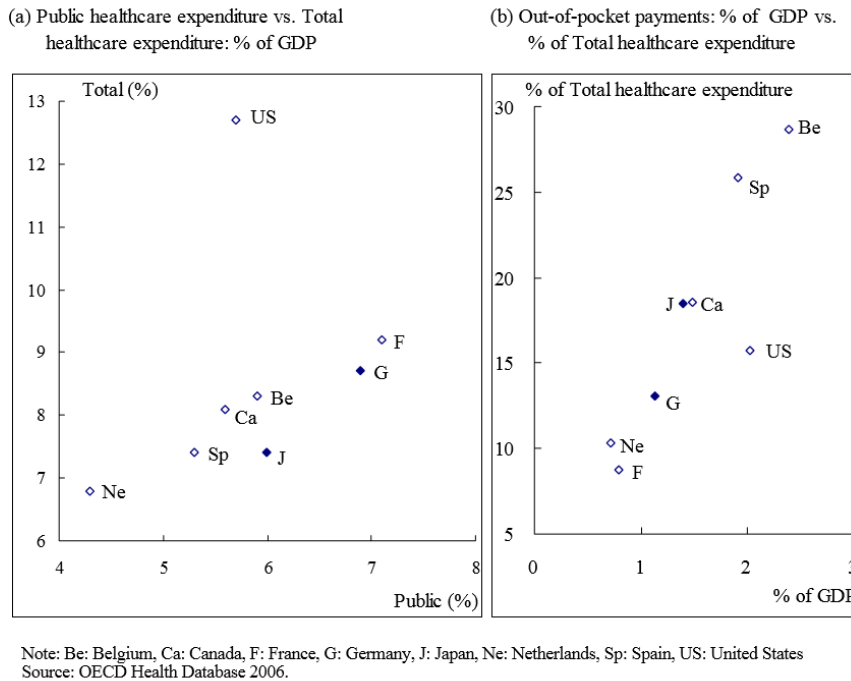
¹ Affluent capitalist Democracies are usually referred to as 'Welfare States' – where the main ingredients are seen to be Democracy and a relatively high standard of living – as per a social sciences definition. (Jolanta, 2009). The State is considered to be intimately involved in distribution and 're-distribution' of welfare among the citizens.

population behaviors of those seeking or not seeking available healthcare. As the problem has surmounted to lately a global health² debate (Allin, Grignn, & Le Grand, 2010) – it makes for a credible reason to undertake an academic research on decisions to forego healthcare— that is universal and applicable globally.

It may be imagined that richer countries would have more money to put into their healthcare systems – achieving therefore a very good score on healthcare parameters and coverage including healthcare utilization. Figure 1 presents two diagrams that illustrate healthcare spending by Governments vis-à-vis out-of-pocket expenditures by people – which prove that despite economic development, out-of-pocket expenditures for relatively well-off countries remains quite high. The first diagram plots public healthcare expenditures (by the respective governments) – expressed as a percentage of the GDP, with total healthcare expenditures (total of public/government expenditures and out-of-pocket expenditures) – also expressed as a percentage of the GDP. This gives a comparison between Government spending versus total spending – among the various countries. In the second diagram, out-of-pocket expenses – expressed as a percentage of the GDP is plotted with the out-of-pocket expenses as a percentage of the total healthcare expenditures.

² Global health in this context is defined as a series of discussions arising out of concerns around public and/or international health -which in turn have arisen out of hygiene and tropical medicine (Koplan, 2009, p. 1993)

Figure 1: International Comparisons between Healthcare Expenditures



Source: (Fukawa, 2018, p. 36)

To illustrate with an example, USA in the first diagram appears to have the highest total spending on healthcare (as part percentage of the GDP) and a somewhat lower spending on healthcare by the Government relatively. Seen from an out-of-pocket payments point of view, seen alongside other countries, US is currently leading the pack. Compared to other countries, France seems to have a very high percentage of public spending on healthcare, while its total expenditures on healthcare (as a percentage of the GDP) are lower. From the second graph, France has a much-reduced out-of-pocket expenditures vis-à-vis total expenditures on health.

Though the only aspect of healthcare this brings to the forefront is – money spent into healthcare (by the governments and out of people's pockets) in developed countries – it is

interesting to note the vast differences with respect to the out-of-pocket expenditures in spite of a high degree of economic development (Fukawa, 2018, p. 36)

To illustrate even further, USA spent \$2.4 trillion on health in 2008 (17% of its GDP) – 47 million Americans were without any sort of health coverage and further 25-35 million had an insurance that was so basic that a major medical event would result in a bankruptcy. (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1294).

“Successful health-financing schemes are an indicator of a gamut of political ideologies and philosophies; there is no one ideal system, and most feature a mix of public and private components” (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1297).

It may be imagined that non/under-utilization of healthcare occurs due “the lack of available health infrastructure” (p.28) (especially in the context of low/middle income country) – but in fact it can also arise out of the way the healthcare is organized, financially driven and implemented (WHO, 2008). It is important to consider the “fit” between the requirements of the patients with the healthcare systems (Penchansky & Thomas, 1981). There may be a significant presence of “extra fees”, “under-the-counter” charges for services that are often – not satisfactory. Healthcare with respect to patient ‘fit’ is discussed in detail in the next section (WHO, 2008).

Today many middle to low income countries experience “demographical and epidemiological transitions” (Gottret & Schieber, 2006, p. xiii), often also have limited experience in implementation and a dismal healthcare coverage. Another considerable concern for developing nations (contrary to developed economies) is the proportion of GDP that they can allocate to health (Purohit, 2014). “Although the developing countries account for 90% of the global disease burden, they only contribute 20% of total GDP and only 12 percent of all health spending in the world” (Gottret & Schieber, 2006, p. 2). This makes it exceedingly difficult for

such countries to achieve a good health coverage for their populations. According to data, only 25%-30% of the Indian population is covered by any kind of health coverage (Purohit, 2014).

Table 1: 80% Indians are uncovered by any kind of health insurance

Indian population health insurance coverage			
Scheme	Types of Insurance	No. of Beneficiaries (in millions)	% of Population Covered
CGHS (Central Government Health Scheme)	SHI	3	0.25
ESIS (Employment Scheme Insurance Scheme)	SHI	55.4	4.5
RSBY (Rashtriya Swasthya Bima Yojana)	Government Based	79.45	6.5
Rajiv Arogya Sri (Andhra Pradesh)	Government Based	70	6
Kalaingnar (Tamil Nadu)	Government Based	35	3
Vajpayee Arogyasree	Government Based	1.4	0.12
Yeshawnai	Government Based	3	0.25
Private Health Insurance	Private Insurance	55	4.5
Community Based Health Insurance	Community Based Insurance	7.5*	0.62
Total Population Covered		309.75	25.75
Total Indian Population			

Source: Purohit, 2014, p. 1239(figures of how many people are covered in community-based schemes differ with papers – as currently government backed official figures are lacking).*

Table 1 shows the coverage of Government schemes, state run health schemes, private insurances and community-based health schemes – in absolute numbers as well as percentage values. As is evident, despite several initiatives, coverage is considerably low.

This creates a significant burden on poorer households where instances of foregoing are rampant, and chances of catastrophic expenditures are particularly high (Purohit, 2014).

In emerging economies like India, it is the third parties that also provide the much-needed healthcare protection to those involved in the informal economy and who frequently get excluded from government health schemes and employer health insurance plans. “In most low- and middle-income countries, ministries of health function as national health services and generally exist alongside other risk pooling arrangements, so they are not the sole source of coverage for the entire population” (Gottret & Schieber, 2006, p. 7)

These are referred to as ‘third parties’ which are then used to cover the gap of healthcare coverage or delivery of services. Third party responsibility to achieve better healthcare coverage in form of health insurance, employer coverage etc. have worked for several countries (economically rich as well as economically poor). At least 30 million out of the 370 million workers in India are covered by a community-based health insurance scheme (Garrett, Chowdhury, & Pablos-Mendez, 2009). In a community-based health insurance scheme, the community members pre-pay for future health services. “The Community members pool their resources to share the financial risks of health care, own the scheme and control its management, including the collection of premiums, the payment of health care providers, and the negotiation of the benefits package” (Donga, Kouyateb, Cairns, & Sauerborn, 2005, p. 150). Community-based social protection schemes are great securities for poor families against ‘catastrophic health expenditures’ in countries like India where the government seldom has sufficient revenues to allocate to healthcare funding (Purohit, 2014). Because such schemes “separate time of payment from the time of use of services” (p. 150), they work just as well as insurances and are well suited to rural households who depend on seasonal incomes rather than steady monthly incomes (Purohit, 2014)

In more economically advanced economies, third party coverage refers to the cost-sharing health policy model which utilizes tools like a mainstream government regulated and approved health insurance to ensure high coverage as well as contained costs for the State. The idea is that the public would buy an insurance (mandatory or not) and pay for their health costs till a certain limit, after which all costs would be borne by the State irrespective of the treatment. There have been concerns that increasing the patient's share of contribution in the cost-sharing model significantly drives up healthcare under-utilization for low-income households (Fukawa, 2018). In Switzerland's (and many other EU states like Germany and Netherlands), availing a private insurance is made mandatory for all residents. This has helped them achieve an impressive standard of healthcare accessibility and utilization – and yet there are significant instances of foregoing related to affordability which are explored in detail ahead in this paper. In contrast, the cost-sharing model adopted by the United States does not make it mandatory for citizens to buy health-insurance – leaving various residents at the periphery of the economy without an insurance to begin with (Aroian, Wu, & Tran, 2005).

It is important to note that obtaining “high/universal rates of population coverage³” does not guarantee 100% healthcare utilization. For example, Tunisia has attained “universal coverage” but its out-of-pocket expenditure is still 45% (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1296) creating a significant deterrent to availing healthcare. This clearly points to the conclusion that – “universal health care” is not an end all solution for eliminating health care disparities (defined as “a health difference that is closely linked with social, economic, or environmental disadvantage” (Hansen, Melissa (NCSL), 2011, p. 1). Similarly, in Vietnam too, almost all the poor are covered under some health insurance, but the quality

³ Universal Health Coverage is defined as “access for all to appropriate health services at an affordable cost” (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1295) by the World Health Assembly in its 58th session in May 2005.

of care in government centers is so poor – that population health has not been able to benefit from the benevolent intentions of the government (Garrett, Chowdhury, & Pablos-Mendez, 2009, p. 1296).

The circumstances of under-utilization are usually concentrated among the financially disadvantaged and those who do end up availing – subject themselves to a significant risk of “catastrophic expenditure”. (WHO, 2008). WHO defines catastrophic expenditure as “out-of-pocket spending for health care that exceeds a certain proportion of a household’s income with the consequence that households suffer the burden of disease” (Ekman, 2007, p. 305) by getting pushed into poverty. These patterns of under-utilization (often termed also as healthcare exclusion) are rampant in emerging economies like India and middle-income countries like Colombia, Nicaragua and Turkey – where patients are made to pay prohibitively high fees for substandard services (World Health Organization, 2008).

Defining Healthcare Foregoing

According to the WHO report on Primary Health Care, non-utilization of healthcare is not only a mainstay of cost or financial burden of the vulnerable population groups but also a subset of “linguistic, cultural and gender-based barriers that are often embedded in the way in which clinical practice is conducted”. (WHO, 2008, p. xvi) – such concerns are equally applicable to not only population niches or low/middle income countries but also major population groups and high-income countries

Under-utilization or healthcare foregoing is a theme that can be explored throughout the social and economic gradient – rather than limiting to the unidimensional approach of rich vs. poor. Focus on groups like adolescents, ethnic groups, drug users, LGBT groups, stigmatized patients can offer invaluable insights into the realm of underutilization of healthcare. This is discussed in greater details, later in the paper when motivations for healthcare foregoing are explored.

The endeavor is at first to understand the meaning of ‘foregoing’ of healthcare. The need for definition arises because ‘healthcare’ as an umbrella term encompasses many stakeholders, both in the private and public sphere. (Arah, Westert, Hurst, & Klazinga, 2006). These stakeholders not only include medical professionals, rather, the term also includes government bodies, officials, NGOs, groups and people who are directly or indirectly influenced by healthcare, health policies and health management – i.e. non-medical professionals

The definition can be approached from the point of view of the state or medical practitioners -expounding the accepted medical benchmarks within the country. Therefore, the paper proposes this as the “healthcare norm” prevalent in that state. Conversely, foregoing is

proposed as the deviation from the norm in expected health behavior or obtaining compliance.

The above is particularly pertinent, as individuals feeling unwell – do usually take some measures to get back to a point of comfort and wellbeing. This generally depends on a person's 'choice of treatment' which can vary person to person and may or may not conform to standardized practices in the community or society.

In other words, *norm* is presented as *expected* behavior with respect to health in terms of *general health, preventive health, emergency health, chronic diseases, acute diseases, lifestyle diseases* and *wellbeing*.

The questions that arise therefore are; what *actually constitutes* healthcare foregoing; what prompts the individuals to get excluded from the system and opt for other (or particularly none) channels of healthcare.

Penchansky et al approach 'foregoing' as absence of healthcare access. They define access "*as a concept representing the degree of "fit" between the clients and the system*" (Penchansky & Thomas, 1981, p. 128). Healthcare access is further subdivided into four parameters – "Accessibility", "Affordability", "Availability" and "Accommodation" which together lead to healthcare access (Penchansky & Thomas, 1981). *Accessibility* is defined as the relationship between the *location* of the patients and the healthcare delivery center – considering the travel time and distance. *Availability* is defined as that part of healthcare service – that considers the volume of resources available vis-à-vis the volume and types of needs of the patients. *Accommodation* refers to the way the resources are organized (e.g. Appointment systems, operating hours among others) and their appropriateness with respect to the needs of the clients. *Affordability* refers to the patient's ability to pay, health insurance

and the patient's perception of the "worth relative to total costs" (Penchansky & Thomas, 1981, p. 128).

When one says that the healthcare has been 'foregone' – there is an inherent assumption in this statement that healthcare is fully and completely available, accessible, accommodative and affordable (as per the aforementioned definitions) – universally and without bias. It is presumed that healthcare foregoing is a demand problem – where the users due to reasons 'known' or 'unknown' to the patient, did not 'ask' for it.

However, such a narrow outlook is highly un-pertinent for middle-to low income countries where healthcare access infrastructure can be severely lacking in terms of healthcare availability, affordability and accessibility – that eventually lead to 'under/non-utilization' of such health facilities by people. The latter is a 'supply' problem rather than a demand one. It is important to ascertain whether such facilities are adequately meeting the *quality standards* of the public and generally accommodates their perception of 'appropriateness' (Penchansky & Thomas, 1981)

Another concern while arriving at a secure definition is to take in the importance of private healthcare providers and health insurance systems – which even though make care '*available*' and '*accessible*'– do not necessarily make it '*affordable*' or even assure '*accommodativeness*'. There is a substantial need to delineate what is the 'norm' as defined by the State or 'Professional Guidelines' or 'Public Health Recommendations' (depending upon the major health policy or context).

In the past, there have been two very notable exercises in defining healthcare foregoing.

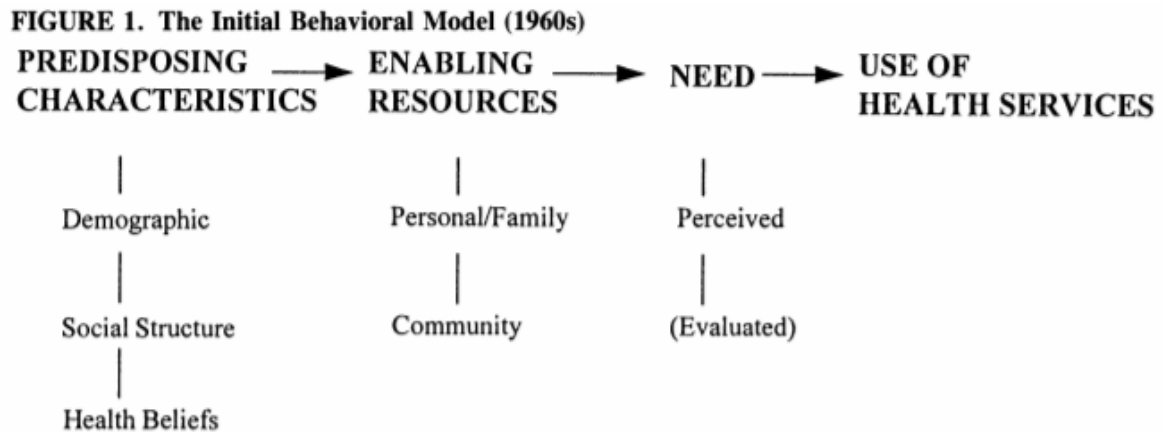
Andersen and Newman (1973) developed a 'behavioral model' with respect to healthcare utilization based on sociological and individual factors. The goal of the model was to provide measures of access to healthcare. (Anderson, 1995). This model rationally laid out the

framework for healthcare under/non-utilization as having a greater scope than economic considerations or focus on vulnerable/disadvantaged populations. The model considers the path of 'foregoing behavior' as a linear step-wise undertaking of a person with the final goal of availing (or foregoing) healthcare.

However, the Andersons model's definition of healthcare availing/foregoing is not specific in nature – that is it does not account for availing of different or parallel medical practices that can arise out of differently perceived notion of medicine and illness (i.e. different cultural beliefs, alternative medicine, traditional healing). It does not explain (though it does mention it as a 'factor') foregoing behaviors of an individual arising out of primarily being part of a certain group/community. It does not differentiate between the primary concerns of high income and middle to low income countries with respect to foregoing behaviors. Differentiation between supply vs demand side of healthcare (described and explained in subsequent sections) also requires an in-depth exploration– where the foregoing behavior may be influenced by issues of 'access' and 'availability'.

The model describes that an individual's likelihood of obtaining healthcare is based on three distinctive characteristics – such as 'Predisposing Factors', 'Enabling Factors' and 'Need – Perceived vs Evaluated' (Figure 2).

Figure 2: Behavioral model of health care utilization



Source: (Andersen, 1995, p. 2)

The Predisposing factors pertain to demographic as well as socio-cultural parameters such as age/gender along with culture, healthcare beliefs, attitudes and values. Social interactions, education and ethnicity are considered a part of this group – as belonging to all the variables of a person *before* onset of any illness/morbidity or even expectation of a particular healthcare behavior. Though culture, social structure and healthcare beliefs are mentioned – they are not defined or demonstrated in detail in the model.

Enabling factors include income, knowledge, ease of access and availability of healthcare services, quality of community and social relationships including availability and quality of health insurance.

The third parameter – ‘Need’ – measures how an individual assesses his/her existing health and the need for healthcare. This part of the model is a function of the previous 2 parts – where the individual perception of own general health and need for healthcare is greatly shaped by his/her beliefs, community, family, culture as well as his/her socio-economic status – which in turn can be seen as a function of income and education as the two most influencing factors.

The advantages of this model are many – such as introducing a three-step recognition of the measures to access to healthcare, considering a person's individuality/thought process as different from economic situation and stress community, culture, beliefs and family as additional determinants of healthcare utilization.

The two main issues that emerge with the Anderson's model are the linearity itself – that don't clearly show the interplaying factors simultaneously for healthcare foregoing and the fact that it lacks a clear definition of what is healthcare foregoing.

Another conceptual framework proposed by Allin et al (2010) approaches healthcare under/non-utilization from the view point of "unmet need". Unmet need is defined by them as "when an individual doesn't receive an available and effective treatment that could have improved his/her health" (Allin, Grignn, & Le Grand, 2010, p. 466). Allin et al. stress the importance of individuals' subjective assessment of their unmet need which in turn can complement conventional evaluations of reasons for healthcare under/non-utilization using socio-economic parameters. Allin et al. emphasize that conventional ways of thinking about healthcare utilization do not account for quality, effectiveness of treatment and even patient preferences arising out of informed choice. They divide healthcare foregoing behavior into five categories (Figure 3).

Figure 3: Different levels of unmet needs for healthcare leading to healthcare under/non-utilization

Category 1	Unperceived Need for Healthcare
Category 2	Perceived Need. Chooses to not 'demand' it <ul style="list-style-type: none"> • Seekers of alternative/complementary medicine • Usually due to an informed choice and not lack of education or other cultural factors
Category 3	Perceived healthcare need. Presence of access barriers beyond control <ul style="list-style-type: none"> • follow conventional methods of needs based utilization • but use fewer resource than what would otherwise be predicted
Category 4	Perceives healthcare need. Accesses it. Doesn't avail to the full extent <ul style="list-style-type: none"> • Healthcare is not accessed to the level expected by a healthprovider as per the norm • Can be a matter of quality or effectiveness (unknown to the patient) • Eg. Family/Routine care givers provide a far more effective care than emergency personnel
Category 5	Perceives healthcare need. Accesses it. Left unsatisfied. <ul style="list-style-type: none"> • Individual feels they deserved better care • Could be a matter of quality or effectiveness – known to the patient • Creates future barriers to utilization

(Source : Allin et al (2010, p.466))

The paper granularizes the aspect of subjectivity in unmet need – where the degree of subjectivity increases with the category. This model also subtly introduces the importance of defining the 'healthcare norm' – so that unmet needs of category four and category five can be better understood. Category four explains 'unmet need' from the point of view of the healthcare provider – against a certain norm while Category 5 – explains a subjective unmet need of the individuals against a set of personal standards.

These subdivisions of unmet need take us out of the comfort zone of assessing healthcare utilization solely from the point of view of income, cost, access barriers and socio-economic indices.

Coupled with the earlier definitions of healthcare by Penchansky et al. (1981), the importance of individual satisfaction and its perceived 'fit' with the healthcare system is of paramount usefulness while understanding the reasons for healthcare under/non- utilization.

Available literature treats healthcare utilization as a set of measurable variables/instances. (Ye, Mack, Fry-Johnson, & Parker, 2012). The variables used take into account measurable instances such as 'number of doctor visits', 'emergency room (ER) visits', 'GP consultations', 'specialist consultations' in a span of 12 months. The questionnaires go into great details defining visits to 'general practitioners'; 'family doctors'; internal medicine doctors and in some cases specialists beyond the usual obstetricians/gynecologists or ophthalmologists.

Some studies narrow down the variables to 3 categories – such as health insurance status, routine care access and sick care access. (Ye, Mack, Fry-Johnson, & Parker, 2012). Insurance status was based on whether a participant had any kind of health insurance coverage. Routine care access and sickness care access were determined on whether a participant identified a physician's office or clinic or health center for routine/preventive care and for sick care, respectively. (Ye, Mack, Fry-Johnson, & Parker, 2012).

To conclude, past attempts at defining healthcare foregoing though extensive have rarely taken a global approach which can be applied irrespective of economy, culture or country's circumstances. Anderson was the first propose a linear model in 1973 – which though quite comprehensive failed to illustrate the simultaneousness and the inter-dependence of various factors that lead to healthcare foregoing. The linearity of the model belied the otherwise organic behavior of healthcare foregoing,. Penchasky's model was the first descriptive model that provided a coherent definition of healthcare access and spoke of the "fit" between the patient's need and the healthcare provided – thereby broadening the scope. In the definition of healthcare access, we can also find a literal understanding of healthcare non-access – which in turn points us in the direction of healthcare foregoing.

Allin et al's concept introduces the distinction of perceived need for healthcare, in that there are people who do not even perceive a need. Thus examining healthcare foregoing from various angles with the aid of previous academic papers, provided for the distinctions and over-arching factors that a universal model for healthcare foregoing must contain within itself.

Model Proposed for explaining Healthcare Foregoing

In this section, the paper goes forth to present a model that has a global application in understanding the behaviors and tendencies of people that lead to healthcare non-utilization. Prima facie, the model deals with this paper's treatment of healthcare foregoing at the outset – which is built into the structure of the model – “as deviation from the norm of widely accepted/standard medical practices in a certain community/geography”. Further, there is an inherent acknowledgement built within the construct that decisions to under/non-utilize healthcare can be an individual one or arising primarily as a result of being part of a certain group or community. The model also deals with the questions of foregoing arising due to ‘supply issues’ (healthcare not perceived as available) and ‘demand issues’ (healthcare though present – is not present in the form which is considered acceptable/appropriate and hence is not being ‘asked-for’).

The model comprises of 2 intersecting axes which lead to four quadrants. The vertical axis is labelled as “Individual’ at the top and ‘community’ and at the bottom. ‘Individual’ refers to those decisions where the patient has actively and in an informed way, made a decision towards healthcare foregoing. ‘Community’ led decisions on the contrary, occurs when the patient is acting majorly from his/her “collective identity”⁴ – where the issues and situations that are affecting the community or pertain to it, by default apply to the patients also.

The horizontal axis is marked as “Non-Aligned with the Norm” and “Aligned with the norm” implying the attitudes and beliefs of the patient with respect to healthcare. This aspect applies

⁴ Collective Identity: Refers to tendency of an individual to refer to him/herself based on social identity and associations of the larger community to which they belong. It refers to the concept of individuals relating very strongly with a “common identification with some symbolic group or social category”. (Brewer & Gardner, 1996)

to the influence of external factors like culture, education, upbringing or internal convictions, values and beliefs.

Figure 4: Model proposed for explaining and defining Healthcare Foregoing



Horizontal Axis: Whether a person's internal attitudes and beliefs are aligned with the norm of their respective country is significant to assessing healthcare foregoing. It allows for a thorough deliberation, evaluation and pursuit for all the situations that can lead to a person's non-alignment or alignment with the norm – thereby having a broad scope. Hence, rather than starting with external causes to foregoing behavior – a person's inner convictions and beliefs leads this particular axis. This in turn helps us to undertake an exploration of the different influencing factors that can lead to the aforesaid 'alignment' or conviction. The left side of the axis; "Non-Aligned with the norm" corresponds to an attitude of the care-seeker

that is oriented towards health care that is non-established and non-officially institutionalized by the state – that is traditional or oriented towards methods of healing which are yet to be proven scientifically. Homeopathy, Ayurveda, folk remedies, home remedies and Chinese herbal medicine as alternatives to formal, institutionalized care can be taken as examples. Relying majorly on friends and family as an alternative to institutionalized healthcare is also an example of non-alignment to the norm.

Correspondingly, the right side of the axis; *“Aligned with the Norm”* refers to being compliant in attitude with the established/official norms in terms of the prescribed actions when relating to personal healthcare. These include an inner orientation towards physician visits, screenings, check-ups, reporting of morbidities and consistent-prescribed follow-up of the treatment plan, when faced with a certain health issue.

Vertical Axis: The vertical axis explores the individual engagement of the discerning person in the decision to forego healthcare. This axis examines the extent to which such a decision is a well-thought of, active choice by an individual person. The north side of the axis has been termed as ‘Individual’ referring to a person who took an individual decision to forego healthcare as a way of an ‘active’ independent choice – that is actively going against the course of expected behavior. The other side of the axis has been termed as ‘Community’ and refers to individuals acting as part of a group to which they belong. In the model, the ‘community’ axis can refer to people grouped together by a sense of strong cultural identity as well as groups of people grouped together due to similar economic circumstances or social disadvantage (E.g. in case of marginalization). Therefore, the ‘Community’ group of people describes those, for whom foregoing is the default non-action response owing to social norms and perhaps even circumstances and situations. The act of foregoing in such a case is *not* a premeditated well-thought of active decision – rather it’s an absence of an affirmative action towards self-care because of an overarching collective identity.

The resulting quadrants from the intersecting axis help us to determine whether the problem of foregoing is resulting from a 'supply issue' (that is majorly from lack of availability of healthcare), or a 'demand issue' (people are not even asking for or perceiving the need for the healthcare provided for various reasons).

The quadrants are named "Active Rejection"; "Foregoing by Default"; "Passive Rejection" and "Alternative Rejection".

"Active Rejection": It pertains to the intersection between "Aligned with the Norm" and "Individual" corners of the axis – alluding to foregoing situations where a person, despite being completely compliant with the healthcare system - makes an active, pre-mediated decision to forego healthcare present. Hence, the name 'Active's been accorded to this quadrant.

"Foregoing by Default": The intersection between "Aligned with the Norm" and "Community" gives rise to this quadrant. In this quadrant, people grouped by similar life/economical/social circumstances, although compliant with the system, do not end up receiving healthcare because of their prevailing circumstances – that somehow inhibit their ability to receive it. The name "default" given to this quadrant suggests a "default setting" where certain communities are not able to avail healthcare due to pre-existing attributes and circumstances – pointing towards paucity and inadequacy of healthcare.

"Passive Rejection": Created by the intersection of "Non-Aligned with the Norm" and "Community" – it refers to groups of people bound by a keen sense of cultural identity, who are not aligned with the norm and end up not availing healthcare due to their cultural beliefs, traditions and inner convictions. This quadrant is named "Passive Rejection" to describe the decision to forego healthcare which is not premeditated, rather it is centered on their

community's inclinations, viewpoints and cultural outlook, which in turn is not aligned with the norm.

“Alternative Rejection”: This quadrant is formed by the intersection of “Not Aligned with the Norm” and “Individual” sides of the intersecting axes. It alludes to people who are not aligned with the norm and who take an individual, well-thought, premeditated decision to forego institutional healthcare, often as a result of deep personal beliefs and convictions – largely based on their own experiences and outlook. The word “Alternative” relates to the “alternative” line of healing and healthcare that these individuals prefer to the institutional or major line of healthcare espoused by the state.

With the means of a few handpicked empirical and academic studies, the model is illustrated by describing each quadrant in more details with discussions related to availability, accommodative-ness, resources, location, appropriateness, affordability – as reviewed before in the Penchansky, Anderson and Allin concepts.

This will demonstrate and explain how the model can be helpful in determining instances of foregoing – in high income as well as low/middle income countries. The simultaneous distinctions between demand and supply issues of healthcare will help glean clear and actionable insights.

Quadrant 1: Active Rejection

This quadrant deals with healthcare foregoing circumstances where the foregoing behavior is resulting from people exercising *individual choice* (active decision), declining officially available medical care, while still being ‘aligned with the norm’. In this scenario, the individuals choose to opt-out of the healthcare provision for reasons that pertain to their experiences with the healthcare system, their perception of the *accessibility* and *acceptability*

pertaining to the healthcare systems. The definitions of *accessibility* and *acceptability* are from the Penchansky & Allin (1981, p.128) framework, discussed above.

To explain this quadrant, two specific instances of foregoing – namely ‘Stigma’ and ‘Quality’ are taken as examples of individual decisions to forego officially available healthcare. With help of a few selected studies – why individuals exercising an independent choice decide to forego the norm (pertaining to healthcare) will be explored.

Experiences of stigma

“Stigma is defined as a negative perception that is assigned to an individual because of an attribute that, in the eyes of others, deeply discredits and diminishes him or her from a whole and usual person to one who is tainted and discounted” (Tummala & Roberts, 2009, p. 188)

Most commonly in a healthcare setting – if the potential patient perceives for him/herself a de-evaluation by the community/friends/family – the person is said to be stigmatized. Often the case is not only regarding external judgement – but also self-judgement – the inability to actually accept the problem and the potency to label oneself as ‘incomplete’ or ‘tainted’ (Tummala & Roberts, 2009)

Diseases that arise out of potentially socially risky behavior such as tobacco use, alcohol use, sexual activity etc. are the ones that attract such a labelling – both external and internal. Additionally, diseases such as HIV which carry with them a hidden judgement towards the sufferer also create a barrier for the sufferer to avail treatment in regular public settings. (Tummala & Roberts, 2009)

Where a large number of studies are available that describe and discuss the aspect of ‘stigma’ in healthcare access, four most relevant population groups have been shortlisted

(where the behavioral patterns are the most obvious) – namely Adolescents, HIV patient community, Mentally ill and the Transgender community.

Adolescents

Lehrer et al in 2008 pointed out through an empirical quantitative study consisting of 2439 American adolescents that their predisposal to foregoing healthcare increases on account of socially-risky activities such as increased tobacco usage, alcoholism, violence or sexual activity. Adolescents who claimed issues of ‘depression’, ‘suicide ideation/attempt’, cited “confidentiality” as the biggest reason for not availing healthcare (after adjusting for race, ethnicity, income and insurance type). Adolescents present themselves as one of the most vulnerable groups when it comes to availing crucial healthcare – as a result of fear of stigma in social relationships versus stigma in healthcare system (Lehrer et al, 2008).

HIV Patient community

An in-depth primary research qualitative study with HIV patients, published by Sayles et al in 2007 - concluded after 48 focus group discussions - that fear of being discriminated or ill-treated discourages a HIV patient from visiting general public health facilities, including emergency care services (Sayles et al, 2007). The greatest fear is from the medical community itself – who despite of being supposedly the most informed and educated in the domain of medicine – can sometimes, through even subtle unspoken communication – convey a sense of bias, judgement and “profiling” (Sayles, Ryan, S. Silver, Sarkisian, & E. Cunningham, 2007).

Mental Illness patients

A qualitative study done in Belgium by Tummal and Roberts (2009) using 728 subjects in a mixed research approach found that stigma definitely colors a patient’s response towards

availing available healthcare. However, differences arose between self-stigma and public stigma⁵. Those with self-stigma had a much greater negative attitude towards approaching general practitioners and other medical providers such as psychiatrists while they were more comfortable with approaching non-medical providers such as psychologists. In a case describing public stigma - Tummala and Roberts (2009) also discuss the instance of an elected official foregoing crucial psychiatrist therapy to escape being labelled the 'psych-man'.

Transgender Community

As Poteat et al. (2013) discuss in their qualitative research involving face-to-face interviews with fifty-five transgender people and twelve medical care providers - both self and public stigma exist with respect to transgenders. The healthcare providers tend to discriminate and stereotype their transgender patients as sexually precocious and excessively appearance conscious while the transgender patients tend to be filled with inner morbidity, self-dislike and feelings of being always misunderstood - tending to visit healthcare centers only when absolutely unavoidable (Poteat, German, & Kerrigan, 2013). This study is particularly interesting as interviews with medical-care providers empirically prove an undeniable angle of discrimination and bias in the medical system which in turn propagates stigma further.

The above instances of foregoing behaviors because of *stigma* are clear examples of individuals in a community, making a conscious decision to forego healthcare over perceptions of its acceptability (to themselves) and its perceived accommodativeness. There is significant skew towards the demand side of healthcare i.e. even though healthcare is accessible (with respect to location) and available (with respect to adequacy of physicians) – individuals decide to forego on the basis of acceptability.

⁵ "Perceived public stigma refers to discrimination and devaluation by others, and anticipated self-stigma refers to internalization of negative stereotypes about people who seek help" (Elise, Mieke, Charlotte, & Piet, 2014, p. 232)

Concerns with quality

Individuals with decreased belief in the main provider's capacity to provide high quality healthcare or with doubts on the benefits of such a healthcare system may choose to not avail of it at all. Such a scenario may be hard to imagine in a high-income society but is commonplace in countries struggling with policy implementations⁶. It is commonly thought that once a policy has been 'worked out', the results would be exactly as per the ideas of the 'policy makers' while designing it. However even if a government is committed to the results, often the bureaucracy that must actually implement the policy is lacking in the capacity to do so (Grindle, 2017). This is particularly true with post-colonial countries who in order to 'catch up' have attempted sweeping social reforms without the necessary framework or infrastructure (Grindle, 2017). Hence, as discussed before, quality concerns are more commonplace in middle-income emerging economies which have privatized non-regulated parallel network of healthcare. (Garrett, Chowdhury, & Pablos-Mendez, 2009)

With help of two studies in India and Mali, this section will elaborate on how perceptions of quality can render individuals from opting out of the available healthcare system.

A research undertaken by Dalal using NHS Data in India (2009), took as sample 124385 women of reproductive age and mapped their utilization of healthcare services. The incidence of non-use of public healthcare services was a significant 58% due to reasons of 'distance', 'non-attendance of medical personnel' and basically general sub-standard quality of medical

⁶ Policy Implementation refers to the output of a "public policy process" which in turn is the manner in which public policy is formed, implemented and evaluated.

services. The 'Availability' and 'Accessibility' are parameters from the Penchansky elements that are severely compromised in this case study.

In a separate study from Mali, Mariko et al (2003) addressed further in-depth how perceived quality influences the demand for healthcare. The study is highly relevant to our undertaking in this section – because it also proves that people foregoing healthcare tend to mention cost as the reason, when in reality the real reason behind the foregoing is the 'quality'. The research identified interesting parameters to arrive at 'healthcare seeking attitude' of the patient. "Treatment at home", "Modern Treatment at Home" "public hospital", "public dispensary", "for-profit facility" and "non-profit facility" answer alternatives were used in a multinomial regression for arriving at the healthcare seeking behavior of the individual. After running various regression models, it was concluded that decreasing the cost of public healthcare facility decreases home treatment by barely 1% while, improving the quality and experience of the patient at the public healthcare facility increases their healthcare seeking behavior at the medical establishments by 136%. The paper clearly shows the association between healthcare utilization and quality of healthcare that is acceptable to the people; thereby implying the relevance of "accommodation". This in turn talks about the public's perception of appropriateness – which in this case is slanted towards high-standards. (Mariko, 2003)

Conclusion on quadrant 1

Healthcare foregoing can be an active decision by educated and informed individuals as a result of dissatisfaction with the healthcare system or issues of stigma. In this scenario – there is absence of traditional access barriers such as cost or insurance – rather it is the manner in which individuals interact with the healthcare system that matters. Issues of quality

deter availing of healthcare while perception of stigma creates a strong dissonance among individuals who perceive the need for healthcare – but feel unable to receive it in manner which is unbiased.

The issue here is therefore of accommodativeness – where the services are not organized in a manner which is seen to be ‘acceptable’ with respect to an individual. The issue of quality can however comprise access barriers - such as number of resources (availability) and waiting time, transportation etc, (the accessibility).

Quadrant 2: Foregoing by Default

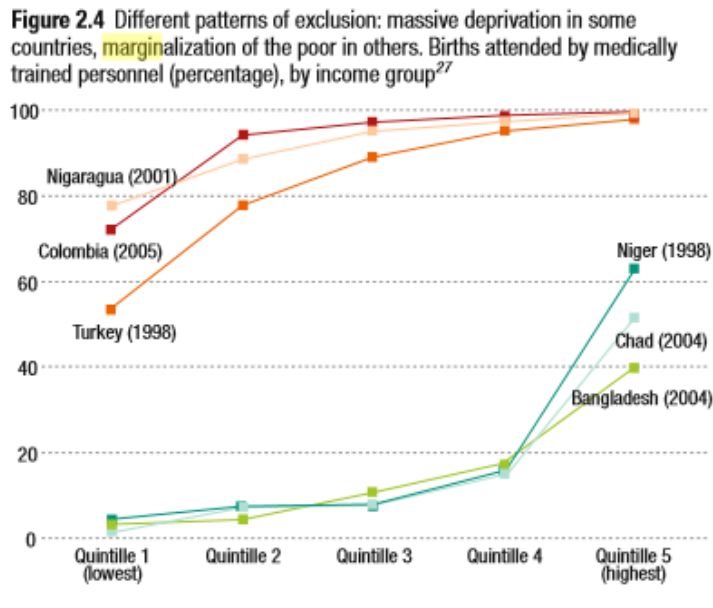
The relationship between foregoing of formal healthcare because of pre-existing life circumstances is explored here – which makes the decision to forgo – rather a perceived default choice, than an empowered individual one.

Reasons such as financial constraints, discrimination and marginalization are explored in detail within this section.

Financial Considerations

According to the WHO health report in 2008, healthcare seems to be afflicted by a phenomenon of “Inverse care” – where “people with the most means – whose needs for health care are often less – consume the most care, whereas those with the least means and greatest health problems consume the least” (World Health Organization, 2008, p. xiv). This is to state that public health policy usually tends to benefit the rich more than the needy and the poor -and this trend is consistent across advanced and emerging economies – thereby making such people ‘marginalized’ by default.

Figure 5: patterns of exclusion



Source: WHO, 2008 1: Incidence of institutionalized child birth by income quintiles

The above graph from a WHO report (2008) demonstrates how the lower income quintiles of population suffer massive deprivation – having significantly lower rates of attendance by medical personnel during childbirth. In the graph above, though certain countries like Nicaragua, Colombia and Turkey have better measures than Niger, Chad and Bangladesh – the link between wealth and medical access is undeniable in all circumstances.

Lack of social protection and forced payment for healthcare for the poor leads to “catastrophic” out-of-pocket expenditures for them (World Health Organization, 2008). WHO estimates that there are more than 100 million people in the world who are annually struck with poverty because of the aforementioned expenses (WHO, 2008).

Also, WHO notes that excessive specialization of health-care providers creates a steep climb in healthcare costs and a narrow focus discourages a holistic approach and results in health fragmentation. The steep costs of specialized care and fragmentation of health services for

poor and marginalized – leads to services for them to be severely under-resourced. (World Health Organization, 2008).

Controlling for other variables, cost still emerges as one of the most significant deterrents to healthcare accessibility. (Guessous, Gaspz, & Wolff, 2012). Even in economies with Universal Healthcare availabilities such as in Switzerland, cost is understood to be a major deterrent in healthcare accessibility, often arising out of cost of insurance deductibles (Guessous, Gaspz, & Wolff, 2012). Insurance deductibles refer to the practice of “cost-sharing” for healthcare by the insurance and the patient. The patient pays a part of the healthcare costs by themselves – till a certain limit, while all costs above that limit are covered by the insurance company. There are examples of cost-sharing health policies adopted by various governments in advanced economies such as the United States and Switzerland – where in Switzerland (unlike the United States) the need to subscribe to a private health insurance (of any convenient deductible plan) is made compulsory by the government (Bodenmann, et al., 2014)

In case of low-middle income countries, in many cases – health services require “out-of-pocket” expenditures. Such expenditures on a global average account for 19% of all expenditures on health – but for low income countries (including India, Bangladesh, Pakistan, Ghana) – such expenditures account for more than 50% of the total health expenditures (Garrett, Chowdhury, & Pablos-Mendez, 2009). Even though these economies have a national policy on health and a public health insurance – the coverage is alarming e.g. in countries like India, it is barely 5.7%. (WHO, 2008). Steep “out-of-pocket” expenditures diminish long term economic prospects and bring poverty and impoverishments in the future – particularly by decreasing expenditure on education. (World Health Organization, 2008)

Using four handpicked studies, the paper endeavors to drive the point that healthcare foregoing because of cost considerations is relevant to all – high income countries with

mandatory (or not) cost-sharing healthcare model, high income countries with universal healthcare and middle/low income countries. Various parameters have been used to understand the phenomenon of cost related foregoing of healthcare, such as “cost-related medical nonadherence”, “forgone care”, “underutilization or underuse” and “cost barriers” (Litwin & Sapir, 2009). The objective is to understand foregoing of healthcare at any stage of treatment due to financial barriers.

High Income Country – Mandatory Insurance

In a multicenter study conducted in south of Switzerland by Bodenmann et al (2014), the healthcare foregoing rate was shown to be a highly significant 10.1%. Data was collected from 2026 patients obtained from 47 General Practitioners in a cross-sectional survey (Bodenmann, et al., 2014). The study empirically shows that the question “Did you have difficulties paying your household bills during the last 12 months” (p. 1). was a far superior determinant of healthcare foregoing behavior than socio-economic determinants such as gender, age, income and educational level. The inappropriateness and stigmatizing nature of asking people their income and education level in a directly administered questionnaire is emphasized. The authors link the healthcare foregoing behavior to life circumstances such as non-Swiss nationality, younger age, lower income, poverty, receiving social grant/student grant (Bodenmann, et al., 2014, p. 1). The compelling reason for choosing this study is because it provides an actionable tool for screening patients for healthcare foregoing behavior at the GP level itself, at the beginning of the consultation itself. By targeting and training General Physicians to spot vulnerable patients early and partner with them to create a mutually acceptable plan for receiving appropriate healthcare within their means.

High Income Country with Non-Mandatory Insurance

In an original research on the effects of 'High Deductible Health Plans' (HDHPs) on healthcare foregoing, Galbraith et al (2012) conducted a study in the United States, on 578 families with children, having at least one member who suffered from a chronic disease. The study found that HDHPs are increasingly the preferred instruments for containing the rising healthcare costs for the State but often lead to under reporting or delayed doctor visitations for chronic conditions. The main objective of the study was to ascertain whether families with chronic conditions with HDHPs have a greater incidence of foregoing health care as compared to those with traditional healthcare plans. Through a multiple logistic regression analysis, they demonstrated that having a lower income and having a HDHP plan was "independently associated with higher probability of delayed/forgone care due to cost" (Galbraith, et al., 2012, p. 1105). The probability of delayed/forgone care due to economic reasons was found to be much higher in HDHPs compared to traditional plans – a difference of nearly 2.5 times [40.0% vs 15.1%] for adults while similar findings were made in the case of children.

High Income-Universal Healthcare Model

A study conducted by Litwin and Sapir in 2009, makes a point that even in sophisticated near-universal healthcare systems – access to specialists, medicine access and dental care (amongst others) are governed by an individual's self-perceived 'income-inadequacy'. The comparative study uses the database SHARE (Survey of Health, Ageing and Retirement in Europe) comprising 11 European countries and Israel. The sample includes 28,849 individuals, aged 50 and older from the various participating countries (Litwin & Sapir, 2009). This is demonstrative of the aging European population. At a foregoing rate of 14%, Israel

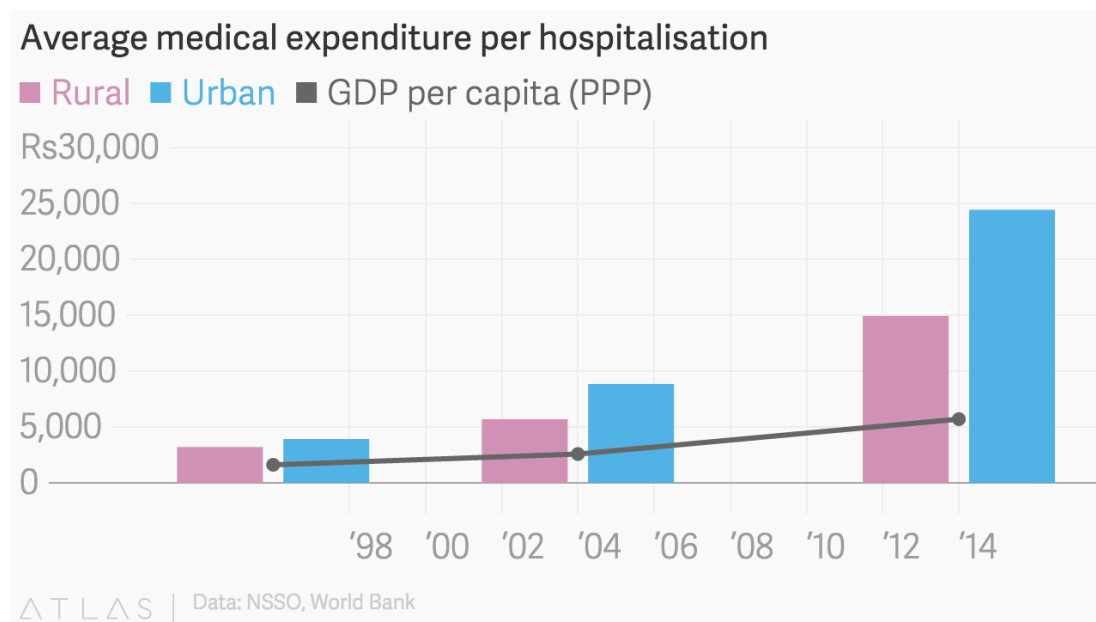
was shown as having the highest rate of forgone care, followed by France, Greece and Germany – where about 6% of its aging population claim to have forgone healthcare at some point during the previous year. The rate of foregoing was found to be less than 5% in other countries (Litwin & Sapir, 2009). The study revealed that dental care was the most foregone of all cares followed by medication follow up and specialist physician services – while foregone General Practitioner visits were relatively rarer, except in Greece (Litwin & Sapir, 2009). The author finds the subjective measures of “income adequacy” to be a significant predictor of healthcare foregoing i.e. whether the patient feels able to sufficiently make ends meet within their means (regardless of income and wealth). An unexpected insight discovered by the study is the relevance of age – which influences a patient’s attitude towards financial stability. It was found that the young-old (people in their 50s and early 60s) are far more likely to forego healthcare than the old-old. This is an interesting discovery for an aging population – where relinquishment of healthcare in ‘early old-age’ would most definitely lead to worsening health state in later years, climbing expenses and a poor quality of life. It was also found that unemployed or disabled persons might relinquish purchase of health services to a greater degree because of work-related financial uncertainty.

Low/Middle Income Country

This paper takes India as a case study with respect to low/middle income country. Though access to medical care has improved for most Indians in terms of number of clinics and quality of facilities – it has however deteriorated when it comes to cost and publicly available health facilities (Ghoshal, 2016). Using data from the Ministry of Statistics (Indian Government), some insights are presented. According to the ministry reports, more than 82% urban Indians and 85% rural Indians are uninsured for any kind of healthcare – making the situation particularly precarious to high-out-of-the-pocket expenditures (Ghoshal, 2016).

Since 2004, the rate of hospitalization in public hospitals for rural Indians has remained steady at 42% while there is a significant shift towards private facilities in the urban areas (Ghoshal, 2016). The past decade has also seen a significant increase in cost related to hospitalization and healthcare on an average, with a 176% increase for the urban patients and 160% for the rural patients (Ghoshal, 2016). Even though the Indian GDP (Gross Domestic Product) has increased by 121% in the last decade, the cost of hospitalization has increased by a greater percentage on average — thereby clearly showing a greater increase in out-of-pocket-expenditures for the population (Figure 6).

Figure 6: Average medical expenditure per hospitalization (Rural vs Urban),



Source: (National Sample Survey Office, 2014, p. 58)

The rising prosperity in certain pockets of India's population has certainly made healthcare more accessible – but healthcare remains an 'out-of-pocket' venture. "Private funds account for maximum fund flow to health sector in India and the same largely constitutes spending by households" (Ministry of Statistics - Indian Government, 2015, p. para 30.47). One can infer

hence, that this is the case for a large number of people foregoing healthcare because of costs in India.

The studies above illustrate the degree to which affordability hampers access to healthcare in all countries – irrespective of their GDP status. The rates of foregoing may vary from country to country – yet – even a 10% rate of foregoing in an advanced high-income country like Switzerland is highly significant. In advanced countries – insurance deductibles, medicine adherence, specialist visits, dental work are seen as categories leading to foregone healthcare – while in middle/low income countries – a large part of the population is at risk of foregoing primary healthcare because of tremendous out-of-pocket expenses.

Marginalization

It is important to differentiate ‘Stigmatization’ (as discussed in the previous section) from ‘Discrimination’/‘Marginalization’. Stigma pertains to the individual making a conscious decision to forgo healthcare for the fear of humiliation and ridicule. In the case of Discrimination and Marginalization – the individual is prevented from accessing standardized healthcare due to biases of the healthcare community (issues of Discrimination) or the prevalent healthcare policy (Marginalization) – that directly or indirectly curbs their intention to avail healthcare – making the decision to forgo healthcare a passive one rather than an active choice.

The Oxford dictionary defines marginalization as “Treatment of a person, group, or concept as insignificant or peripheral”.

In this subgroup of “Marginalized Populations” – the availability and access to equal and quality healthcare are explored – especially when the healthcare that is available is subpar or lacking in some aspect with respect to a community or group of people.

It would be simplistic to say that marginalized communities forego healthcare as a result of cost considerations or culture differences – as that presumes that such communities are not sufficiently well-off or educated/informed. Even though factors such as cost, fringe-society phenomenon and psychological issues are interrelated and contribute to health foregoing behavior in a society, analysis has shown that certain societal groups are more likely than others to forego healthcare – even when factors such as economic reasons or psychological issues are controlled for (Mackenzie et al. 2006).

This is different from ‘vulnerable populations’ in the previous section of ‘active rejection’ – where despite access and availability – individuals exercised an individual choice to forego available healthcare due to various reasons such as stigma etc.

To develop this section, three marginalized communities are explored in detail – mainly Immigrant Communities, Disadvantaged Communities and Gender from different geographies and from countries with various degrees of economic development. The treatment of this section is therefore, significantly slanted towards the ‘supply side of healthcare’, that is whether or not non-majority groups and communities perceive alienation from the healthcare system and have an equal chance of receiving non-biased excellent healthcare as their majoritarian populace counterparts.

Migrants

Migrants represent one of the largest populations of ‘marginalized people’. Their numbers are estimated at nearly 200 million internationally. The migrant community comprises at least 20% of the world’s population – and most of the migrants are concentrated in groups of less than a million inhabitants distributed in over 41 countries (World Health Organization, 2008). To exclude such a large population from access to healthcare – while provisioning

majoritarian populations the right – is a serious breach of human rights (World Health Organization, 2008). While many States have made significant improvements towards ensuring similar access and rights to non-citizens versus citizens – further work needs to be done in this area as migrants also represent people with significantly different languages and cultures – which may hamper their utilization of the healthcare offer severely. It is important here to reiterate that it is the issue of “supply” of healthcare to these communities, a mix of accessibility, availability and accessibility which makes the situation default. A study of Asian immigrants in the United States by Read and Smith (2017), illustrates this point.

Using the “New Immigrant Survey Data” – Read & Smith (2017) compared healthcare utilization behaviors of 2,224 immigrants from Mexico, China and India. The behaviors were compared amongst these particular immigrant groups as well as with the citizens of US, where the study was conducted. This study revealed that language proficiency was the catalyst that determined the utilization rates with respect to the gender and the national origin amongst immigrants. Among the immigrants, those that were more comfortable in English – were far more likely to avail healthcare – than those who were not – often citing reasons of ‘culture’, ‘cost’ etc. (Read & Smith, 2017)

For the migrants, the barriers to equitable healthcare are manifold – from language problems, to possible previous instances of maltreatment and indeed inadequate financial resources and issues of legal representation. According to Read and Smith (2017), immigrants may also believe that their admitting being ill would only lead to “negative consequences” for them.

Disadvantaged Classes

In a mixed methods research by Acharya & Patra (2016), qualitative in-depth interviews yielded some compelling insights. The study was performed on a community of 462 urban-

slum dwellers in New Delhi – consisting of randomized respondents with respect to age, gender, caste (in the Indian context) and education.

The authors explore the various mechanisms that Marginalization can develop. There can be a ‘partial denial’ of services or ‘selected exclusion’ (Acharya & Patra, 2016), which could manifest in various means such as – selective treatment by health providers and even co-users of the care. The ‘selectivity’ and/or ‘denial’ can manifest in providing from none/little or incorrect information and/or providing sub-par treatment at the place of care. It can even include “involuntary inclusion or exclusion” – that is, including unwilling people into certain health programs, services etc. that may appear demeaning, forced, unfavorable or derogatory. Interactions with other patients can also contribute to marginalization in the use of the waiting area, their behavior and attitudes that may be derogatory, dominating or suppressing. Acharya and Patra (2016) state that marginalization can also manifest in “touch interactions”, “perception of gentleness”, “duration of interaction”; “speaking gently”; “real or perceived usage of derogatory words or phrase”; and “long waiting times” with respect to interactions with medical professionals.

The respondents clearly articulated instances of blatant discrimination against the “Dalits” – where children from the Dalit community were made to sit separately from those belonging to higher castes while the public health workers instated by the government for poor sections of the society – visited Dalit homes far less frequently. The parts inhabited by the Dalits in the slum – were the poorest in infrastructure marked by open drains, with water supply and electricity missing. (Acharya & Patra, 2016)

According to this research – the respondents claimed that public health sector providers were the most discriminating of all, and within that context – dispensing of medicines was perceived to be the “most discriminating sphere”.

Gender

It is a well-documented fact that in advanced economies women seek healthcare more promptly and frequently than males (Read & Smith, 2017). In contrast, in developing economies, women often tend to get ignored within a household when it comes to availing healthcare. This behavioral pattern can be attributed to cultural attitudes that educate a woman from very early on in life to put herself after everyone else’s needs (Acharya & Patra, 2016). This behavior in turn is related to the out-of-pocket expenses that come with seeking medical treatment (generally high in places where there is no universal health coverage).

The above has been researched and studied in detail by a mixed study by Acharya et al (2016). In such communities, women as a group might be the last ones to seek healthcare to save on cost or ‘inconvenience’. In this situation, it is because of gender that the subject of cost gains significance in the matter of foregoing. Where free or economical treatment for maternity is not available, families would often let pregnant women deliver at home rather than make the extra effort towards institutional delivery and therefore forego antenatal and post-natal care as well. In many cases, women are culturally taught to suppress their economic needs (including healthcare) in favor of their male counterparts, to save the family the “inconvenience” and “futile cost” of “negligible health problems” (Acharya & Patra, 2016).

Conclusion on Quadrant 2

Studies described in this quadrant helped to elaborate on the circumstances that lead to people foregoing established medical care – from a ‘no-other-option’ perspective – due to reasons of affordability and availability. Healthcare foregone because of costs is clearly the most pervasive kind of foregone healthcare whether it is high income countries with mandatory or non-mandatory healthcare insurance, welfare regimes with 100% coverage or low/middle income countries. Admittedly, the extent of foregoing varies in each scenario, but in each case, it is significant. Certain groups and communities can be automatically distanced from the healthcare system due to marginalization and discrimination present at various levels in the society. Immigrants, women and certain ‘disadvantaged communities’ in some countries are few of such people – and the way the marginalization works – is explored in detail under these sub-heads. Most often – it is the issue of availability to certain sections of the society at an equal level as rest of the majoritarian population. It is interesting to note that unlike other quadrants, this particular quadrant is the only one that uniquely relates to a “supply” issue – while all others relate to a “demand” problem (where the patients are not perceiving the need for healthcare provided).

Quadrant 3: Passive Rejection

“Illness experience is an intimate part of social systems of meaning and rules for behavior- it is strongly influenced by culture” (Kleinman, Eisenberg, & Good, 1978, p. 252).

This quadrant explores the reality of groups of populations foregoing the “officially advised” modes of treatment because they have their own ‘traditional healing practices’ which are their default mechanisms of dealing with their situation.

This quadrant is termed as “Passive Rejection” to emphasize that it involves a community of people who passively forego a certain healthcare route – in lieu of another more favored healthcare practice that they may be more comfortable with.

The World Health Organization (WHO) defines traditional medicine as: “the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness” (World Health Organization, 2012, p. 15). Traditional healing has been the main source (sometimes the only) of healthcare for a vast majority of people. Its accessibility, affordability and trustworthiness make it quite attractive for health policy makers in the face of rising healthcare costs and advent of “chronic non-communicable diseases” (World Health Organization, 2012).

In countries with a strong heritage of traditional healing, there are parallel modes of treatment between traditional methods and modern medicine – with no clear scientific-empirically backed guidelines that can aid the health officials and the public to use them in a complementary way (World Health Organization, 2012). The result is a significant divide between the two modes of healing – with government health officials often tending to favor modern medicine dictates (World Health Organization, 2012).

Additionally, as the world witnesses a substantial surge in diasporic populations from various cultures, the subject of 'Migration healthcare implications' also takes an increasingly prominent place from a public healthcare perspective (World Health Organization, 2012). This is significant because the culturally diverse diasporic groups have considerable differences in their healthcare practices and health beliefs from those with whom they live amongst in their host countries.

In this section, the need to consider the cultural differences between populations will be explored – which make them perceive their physical and psychological health differently (Testi, Ivaldi, Tanfani, & Mazzino, 2006). It is known that different concepts of health and wellbeing cause certain ethnic groups to have a lower perception of disease (Testi, Ivaldi, Tanfani, & Mazzino, 2006). This is significant because it results in their healthcare seeking behavior to be remarkably different and make them prone to seeking healthcare differently at various stages of the diseases.

Health beliefs are crucial to influencing a person's perceived health and need for healthcare (Anderson, 1995). The former is significantly guided by their cultural norms and values (Aroian, Wu, & Tran, 2005). As defined by Aroian et al, perceived health refers to how people view their own health and functional state and whether they judge their problems to be of sufficient magnitude to seek professional services.

A dated – yet highly significant paper by Laura Uba in 1992, talked about the psychology and attitudes of Southeast Asian refugees with respect to healthcare and underlines the differences with the western attitudes. She discusses the unique attitude of Southeast Asians towards healthcare and their health care beliefs around the “inevitability” of suffering and the “pre-determination of lifespan”. Such orientations towards life makes Southeast Asians not access healthcare as promptly as would generally be expected (Uba, 1992). There are culturally unique interpretations about the sources of the illnesses and therefore lines of

treatment also correspond to these. This by itself creates a significant barrier to accessing western modes of healthcare. Apart from that, unfamiliarity with “western diagnostic techniques and treatments” also make them apprehensive. Altogether a general lack of trust, empathy and engagement exacerbates the phenomenon of healthcare foregoing by Southeast Asian immigrants in the USA (UBA, 1992, p. 544).

Cultural norms may manifest themselves in several ways in healthcare utilization across various parts of the world. Differences may get highlighted with respect to culturally diverse immigrant populations versus their host country; while healthcare utilization barriers may be emphasized when the majoritarian population of a certain country refuses to give up centuries old beliefs and practices in lieu of empirical studies.

Following are some handpicked studies that show the extent to which health beliefs, culture norms and traditions can influence health-seeking behaviors. The first one deals with healthcare non/under-utilization behaviors of culturally diverse immigrant populations. The second section deals with a population’s own disposition towards traditional healing practices versus government mandates. The latter is discussed in greater details to highlight the significant behavior nuances at play.

Culturally Diverse Immigrant Populations

A qualitative research by Chang et al in 2009 with 54 Southeast Asian migrants (from Hmong, Cambodia and Laos) in Rhode Islands yielded some interesting culture related barriers in their access to healthcare. The age group of the respondents was between 41 and 83 (mean age 62) with the sample equally distributed between men and women. Participants reported several culture specific barriers to utilizing healthcare in their area. The first and foremost cultural difference was in the way they looked at treatments for their chronic condition. The

Southeast Asian migrants felt there was a deep connection between diet, nutrition and their health. Their orientation was towards understanding the nutrition and diet aspect of their disease (Chang, Feller, & Nimmagadda, 2009). When asked for dietary guidance, the doctors in turn advised them not to eat rice. The respondents felt that the doctors in the west do not understand their culture. When probed, respondents were clear:

“Sticky rice...the doctor told [my dad] he can’t eat sticky rice, and my dad says ‘that is like telling a fish not to swim! I am a Laotian man; I have to eat sticky rice...” (Chang, Feller, & Nimmagadda, 2009, p. 311)

The doctors’ insistence that their culture has ‘incorrect’ nutrition – also created barriers to trust and acceptability.

“We keep hearing that our nutrition and diet isn’t correct...But things like how much fats, protein, sugar to eat—I don’t understand those things. Someone needs to tell us what to do” (Chang, Feller, & Nimmagadda, 2009, p. 312)

Even though the respondents were aware of benefits of regular screenings and doctor visits for ‘prevention’ – they found it difficult to keep the time for appointments for checkups.

The study points at the need for sensitivity when dealing with patients from varied cultures. Further research can be undertaken to understand if education at the health practitioners level as well as patients would yield better results.

A quantitative analysis by Yiali et al (2011) in the US, comprising of 2500 Asians (foreign born as well as US born), found compelling findings regarding the influence of culture in access to healthcare among people with diverse backgrounds. Foreign born Asian residents did not differ from those born in the US in income – and yet still – they were statistically more unlikely to have health insurance coverage, or a regular source of primary or routine care (Ye, Mack, Fry-Johnson, & Parker, 2012). Compared to other Asians, Asian Indians were more likely to have an insurance. The research found that herbal medicine, traditional

treatment and self-medication is widespread among foreign born Asian individuals and they are “strongly influenced by their traditional beliefs” (Ye, Mack, Fry-Johnson, & Parker, 2012, p. 735). The study opines that probably foreign born Asian Americans are less prone to having a regular source of medical care because of their preference for traditional treatments and their “perception of little to no need for western medicine and health services” (Ye, Mack, Fry-Johnson, & Parker, 2012, p. 735)

In a qualitative study by Aroian et al (2005) on Chinese immigrants in the USA, 27 Chinese elderly people, 11 adult children of Chinese immigrants (unrelated) and 12 health and social service providers were studied. This is an interesting study as it gives a holistic perspective of all involved in the care aspect. The study shows the extent to which ‘health seeking behaviors’ differ depending on cultural beliefs. Chinese elders sought professional help only when the illness or disease actively interfered with their ability to function normally. Also the aspect of “filial piety” (the inherent cultural expectation from children to actively take care of their parents at their home) and not wanting to rely on government subsidies resulted in less use of social services “unless the need was sufficiently high (Aroian, Wu, & Tran, 2005, p. 103).

In the next section, primarily African case studies are considered, as the culture of traditional healing is quite demonstrable in public life. The endeavor is to establish the tension between modern healing methods and traditional healing methods from the point of view of policy makers as well as the public at large.

Traditional Healing

In a qualitative research by Golooba Mutebi and Tollman (2007) with 55 respondents in South Africa, the complexities of parallel forms of treatment (modern medicine and traditional

healing) are described in detail. Though both modern medicine and traditional healing forms are acknowledged and authorized by the government, they are not regulated, standardized and therefore there is a lack of enforcement to streamline medical treatment – where the public can avail healthcare from both the practices in a complementary way without confusion. Given the parallel Government stance, they are tolerant of each other, though they jostle for the upper-hand during the treatment process (Golooba-Mutebi & Tollman M, 2007). It was interesting to note some of the cultural connotations that modern medicine had come to be associated with:

“Despite free treatment at primary clinics, most sufferers only attend when the illness has escalated, sometimes with chances of successful treatment considerably diminished. They are then referred to a hospital where some die shortly after admission. This is why hospitals represent places-of-death especially in the minds of the elderly – and so should be avoided” (Golooba-Mutebi & Tollman M, 2007, p. 69).

This is a striking example of non-utilization of healthcare.

Often, where traditional medicine has deep roots, the suspected cause of an illness guides the treatment. Certain afflictions and illnesses were thought to be more curable by traditional medicines and vice versa (Golooba-Mutebi & Tollman M, 2007). Basically – the greater perceived “human agency” (human interference) of a disease – e.g. relating to ritual pollution, witchcraft and others – the better it was considered to use traditional medicines. Usually most chronic afflictions (apart from diabetes and high blood pressure) were thought to result from “human agency” (Golooba-Mutebi & Tollman M, 2007, p. 66). Illnesses like “sugar diabetes” or “high blood” (hypertension) were thought to be curable only through modern allopathic medicines while illnesses like TB and HIV/AIDS could be cured by both. (Golooba-Mutebi & Tollman M, 2007, p. 66). In most cases, it is the rural patients that seek out traditional healers

– usually a mix of herbalists, healers and diviners – prioritizing them depending upon the severity of the disease.

A comprehensive study on Ethiopian health practices by Kassaye et al in 2006 revealed a similar tension between traditional healing practices versus modern medicine. Traditional healing (that integrates spiritualism, curative and surgical healings) is staunchly supported by the Ethiopian government which is committed to preserving its authenticity and heritage (Kassaye, Amberbir, & Getachew, 2006) – even though it has not been able to integrate it with the tenets of ‘modern medicine’ (Kassaye, Amberbir, & Getachew, 2006). Like in South Africa, in Ethiopian public life, ‘modern medicine’ and ‘traditional healing’ existed parallel to each other with no clear dictates over standardized lines of treatment available to medical practitioners for dealing with public health issues. There were clear instances of patients eschewing modern lines of treatment in favor of their traditional healing practices- that they would be more familiar with and would have probably easier access to (Kassaye, Amberbir, & Getachew, 2006).

In another mixed design study by Okeke in Nigeria (2010), 1200 parents of under-5 children (who had suffered Malaria less than 2 weeks before) were administered questionnaires. In this case, the government clearly favored modern medicine as the guiding principle for public health policy. This example demonstrates that in spite of government mandate, flawed enforcement of medical policies and/or staunchly embedded culture tenets, can lead to healthcare non-utilization behaviors among the public. The modern medicine vs traditional healing preference was found to follow a rural-urban skew: Rural mothers were far more likely (62%) to prefer traditional healing than their urban counterparts – who preferred private clinics and hospitals (68%). Rural women accessed hospitals only when the problem persisted or became worse. The study found that in rural communities, herbal treatments were used to treat conditions as serious as convulsions. Self-medication with modern medical

formulation was an important trend in rural areas. A substantial proportion of suspected malaria fevers were treated with modern allopathic medicine without sufficient knowledge, prescription or seeking guidance from a qualified health practitioner. Only persistence of the problem led to the child being taken to a hospital – which could lead to immense delays and prove fatal for a child. (Okeke & Okeibunor, 2010).

“in the case of convulsion, the first thing I do is to get crude oil from palm kernel (locally called ude aku), apply it on the child's body, eyes and nose. Put a spoon in the mouth to prevent the jaws from locking and then also apply some scent leaf (locally referred to as nchuanwu) to the nose. If the problem continues I will then take the child to hospital”. (Okeke & Okeibunor, 2010, p. 65)

“people in the community do go to traditionalists, to know the cause of the child's illness”. (Okeke & Okeibunor, 2010, p. 65)

Conclusion on Quadrant 3

Through the above studies, the clear deviation from expected health seeking behavior of culturally different groups is evident. Whether it is isolated pockets of culturally different people (E.g. immigrants) amongst a larger group of people or a majoritarian group of people with a strong heritage – coming to terms with a completely different set of healing practices (E.g. South Africans with respect to traditional healings versus modern healing practices). The common aspect in both is – that people who are habituated to a certain type of healing practice – would align themselves with it as their primary health solution – thus foregoing standardized/official modern health care tenets.

Quadrant 4: Alternative Rejection

“The terms “complementary medicine” or “alternative medicine” refer to a broader set of health care practices that are not part of that country’s or that person’s own tradition or conventional medicine and are not fully integrated into the dominant health-care system. They are used interchangeably with traditional medicine in some countries.” (WHO website). It is important to acknowledge the difference with the previous quadrant – in that this segment is referring to individuals – who actively and in an empowered way decide to forego the dominant healthcare system in lieu of traditional/alternative practices to which they do not culturally belong. In simple terms – this quadrant refers to individuals exercising an ‘informed choice’ to forego conventional healthcare despite complete access and affordability – in favor of alternative forms of treatment that are not endorsed by the State or medical professionals in their country.

This often pertains to an active decision by educated individuals who eschew the public healthcare services for “popular” lines of remedies – borrowed possibly from a variety of cultural practices around the world. These individuals have a ‘personal conviction’ over the ‘naturalness’ and/or the ‘ancient wisdom’ behind these alternative therapies. They actively take the decision to forgo, in their perception the more ‘chemical’ and intrusive’ cures to the ‘sublime’ and less penetrative measures. (Ramzana, Soelberg, Jäger, & Cantarero-Arévalo, 2017)

This is particularly true for relatively harmless health issues such as headaches, fatigue, cough, colds, fever – basically as a substitute to the usual first line of modern therapy.

Alternative therapy preferences may also arise from dissatisfaction from modern medicine regarding side effects and/or beliefs regarding ‘holistic’ treatment of health. Dissatisfaction

with western biomedicine, concerns regarding side-effects of drugs and also personal belief favoring holistic orientation of health promote the need for alternative therapy over conventional modern medicine – particularly in developed countries. Over the last years, the interest in alternative therapy is increasing – specifically in the domain of herbal medicines. (Ramzana, Soelbergb, Jägerc, & Cantarero-Arévaloa, 2017)

Also, homeopathy along with herbal preparations is an increasingly popular source of self-medication for both acute and chronic conditions (Rogers & Sheaff, 2000). The trend declassifying prescription-only drugs as OTC also increases the potential of “lay choice in symptom treatment” (Rogers & Sheaff, 2000, p. 55). Especially in universal healthcare regimes like in EU and UK, people usually get a sense of what doctors consider legitimate illnesses (as an occasion for visiting them) and the way the doctors respond to these illnesses. This feedback into the “knowledge derived from other lay and folk sources and influence how illnesses are subsequently perceived and managed” (Rogers & Sheaff, 2000, p. 56). Thus, combination of personal knowledge with the way the “universal care” is made available can limit or expand the way people self-treat and shape their preferences for self-treatment vis-à-vis formal healthcare services (Rogers & Sheaff, 2000).

In this section Alternative Medicine is defined as at least one of the following – (where it is used in a way as to be curative for a certain type of illness)

- Homeopathy
- Herbal Medicines/Culturally Derived Medicines
- Meditation/Yoga/Spas
- Home Remedies

This section is assessed in terms of foregoing of primary healthcare in favor of the aforementioned therapies in various degrees: “Complete foregoing of conventional treatment” and “Partial Foregoing of Conventional Treatment”.

Complete Foregoing of Conventional Treatment

A lot of research has been done on patients with life threatening chronic diseases such as cancer – who forgo conventional treatment such as chemotherapy.

A paper written by Frenkel (2013) attempts to understand the reason cancer patients give up their access to chemotherapy and other forms of cancer treatment in lieu of unverified alternative therapies. He states that “The unique patients who refuse conventional treatment are at times self-directed, confident, and active, and have thought deeply about the meaning of life and cancer and about their cancer treatment options” (Frenkel, 2013, p. 635). He states that less than 1% overall of patients diagnosed with cancer forgo all kinds of treatment and 3% to 19% of patients refused chemotherapy partially. The awareness of side effects and complications that come along with modern medical therapies/conventional therapies contribute to the confidence (or no confidence) in patients who decide to forgo treatment in favor of their value systems and beliefs.

In a qualitative study, 60 women with breast cancer, who had refused conventional cancer therapy, chemotherapy and palliative care were interviewed (Citrin, Bloom, Grutsch, Mortensen, & Lis, 2012). Breast cancer today is mostly treatable and there is sufficient evidence that those who forgo conventional treatments initially have poor outcomes (Citrin, Bloom, Grutsch, Mortensen, & Lis, 2012). The objective of the study was to understand the motivations of the women who forgo treatment and what could be done to bring them into the

fold of conventional therapy. Many of those who refused the chemotherapy completely believed they could holistically heal themselves with “raw fruits, vegetables and supplements”. However, on close questioning, it was revealed that previous experiences of the cancer diagnoses with the physician, profoundly shaped their attitude towards availing conventional treatment. *“Negative first experiences with uncaring, insensitive, and unnecessarily harsh, oncologists, fear of side effects, and belief in the efficacy of alternative therapies were key factors in the decision to reject potentially life-prolonging conventional therapy”* (Citrin, Bloom, Grutsch, Mortensen, & Lis, 2012, p. 607). The research emphasizes the need of physician compassion, patience and warmth towards patients with new cancer diagnoses as the first and the most crucial step to getting agreement on conventional therapy. Downright rejection of alternative therapy by physicians can also lead to patients ‘on the fence’ to forgo all conventional treatment (Frenkel, 2013).

In another study from urban South Africa by Friend-du et al (2008), a strong preference for alternative care was clearly shown. In spite of a high degree of education in the population of largely white settlers - and free primary healthcare for children under 6 – individuals often eschewed modern medicine in favor of traditional cures which were thought to be non-invasive, low on side effects and holistic in nature. (Friend-du, Cameron, & Griffiths, 2008). In a mixed design survey, scientists performed focus group discussions with 206 caregivers comprising of modern medicine clinics and traditional healers. The study determined that, patients tend to exercise their values and beliefs to a greater degree to what suits their needs the best. The patients believed that – it is human instinct that prevents parents from loading their babies and children “unnecessarily” with too many chemicals – that their bodies many not handle very well.

Partial Foregoing of Conventional Treatment

Partial foregoing can be classified into 2 kinds of foregoing

- Delaying accessing conventional healthcare in favor of alternative healing/medicine
- Medical non-compliance or non-adherence to conventional treatment in favor of alternative healing/medicine

Use of alternate therapies in form of herbal/natural supplements is widespread in many developed countries like the USA, UK and European countries. These may take the place of many first lines of treatments – and/or used complementarily with ongoing formal therapies. In several cases, the use of these ‘alternative’ cures are not discussed with the physician.

In a study by Jae Kennedy (2005), NHIS (National Health Interview Survey) database of the USA was used to understand usage of ‘complementary/alternative medicines. It was determined through the study that approximately 8.2 million adults (Kennedy, 2005) in the US used such treatments (in the form of herbs and supplements). A majority of the patients (>50%) claimed that these remedies were essential to their wellbeing and health. The study found a higher incidence of use amongst women and adults aged between 45-64 years (Kennedy, 2005)

In another study by Gallagher and Kunkel (2003), also in the United States – 1160 migraine sufferers were administered questionnaires. One of the criteria to qualify as a respondent was use of prescription medicines. It was found that almost 66% of the sufferers had knowingly delayed or avoided taking their prescription medicines because of their doubts over “adverse effects” (Gallagher & Kunkel, 2003, p. 36). This healthcare attitude led to delay in healthcare availing in “37% of treated migraine episodes” and to avoidance of medicines altogether in “44% of untreated attacks during the previous 6 months” (Gallagher & Kunkel, 2003, p. 36). The study showed that, 8 of every 10 sufferers are interested in trying a novel product (maybe outside their prescription) if it promises to decrease adverse effects. (Gallagher & Kunkel, 2003).

Conclusion on Quadrant 4

Through the above discussion on “Alternative Rejection”, the intention is to describe the kind of health foregoing that does not result from lack of affordability, accessibility or even acceptability. This type of foregoing is one where the patient, in spite of having complete access and a supportive healthcare system – chooses to forego available care in lieu of traditional cures or herbal medications that are borrowed from *outside of their culture*. The decision is taken individually and mostly in an informed way – as a result of cost-benefit analyses – where in their perspective the benefit of a holistic, non-invasive and chemical free treatment weighs the accuracy and specific nature of modern therapies.

Discussion

Healthcare foregoing is not a linear process as there are factors which are simultaneously at play and which interact to result in the behavior. As emphasized by Allin et al (2010), there is immense subjectivity when it comes to healthcare utilization and patient satisfaction. It is important to understand patient's subjective assessments of their met or unmet needs to holistically understand the process of foregoing. It is a phenomenon that takes place at the 'individual' level or as part of a 'collective' identity (where an individual relates more with the values and extensions of the community he/she is a part of). Acknowledging this helps to granularize the aspect of healthcare foregoing from a policy framework point of view and future actions. Though resolving any foregoing behavior in the society/country being assessed would require policy reforms and health infrastructure changes – granularizing the various touch-points for change would lead to better efficacy of easier implementations.

The model put forward in this paper, illustrates the interplay of subjective assessments of people vis-à-vis the offerings of the healthcare system and the available infrastructure. Health foregoing is shown as an interaction of 2 axes – the first assessing whether the foregoing is happening from an individual point of view or as a community-informed perspective, while the other axis gauges whether those who are foregoing the healthcare – are aligned to the official healthcare system (the norm) or believe in alternative approaches towards healing (different from the conventional approach espoused by the State)

The *norm* is taken as the accepted healthcare standards propagated by the official healthcare system and health specialists.

Considerable research has gone into the part of foregoing behavior pertaining to inadequate availability and access to healthcare (supply problem) but it is clear that it represents only a part of the foregoing behavior. It is interesting to note that out of the four quadrants, only

Quadrant two (“Default”) pertains to a ‘supply’ inadequacy’ while three quadrants pertain to behaviors arising out of a ‘demand’ problem. Where, inadequate supply stem from systemic issues with the healthcare systems, in three quadrants, patients are not even seeking healthcare as made available by the State.

WHO notes that to systematically resolve healthcare ‘supply’ issues, governments would have to go the extra mile, making structural adjustments on the adequacy of resources, their accommodativeness towards marginalized members of the society and cultural sensitization – which requires immense political will in addition to availability of financial resources for accomplishing these.

The demand problem can be a passive one (i.e. pervasive to a community like in case of foreign born migrants) or a problem of informed individuals (e.g. In case of stigma or preferers of alternative medicine) and the ways of tackling them would differ in each case.

In both cases however, it would be highly insightful for the state to undertake the exercise of classifying foregoing behaviors among its population according to the quadrants on the model. This would yield valuable information regarding whether the problem of foregoing in a respective country is majorly an ‘individual’ decision or a “collective” one and whether the people studied are in alignment with the official health standard or norm. Indeed, this could provide a broad direction to policy makers on the general direction in which they might like to concentrate their efforts. Policy decisions can then range from strengthening infrastructure, providing adequate education, imparting culture training to primary clinics etc.

In each of these cases, future research would be quite valuable in ascertaining the primary trigger in the specific health foregoing behavior – which streamlines our understanding of health foregoing behaviors further One of the biggest shortcomings of this paper is that it relies on inferences drawn from other empirical researches to explain the model – which in

turn have their own biases and limitations. As part of strengthening the model and future scope for research, further granularity can be achieved by conducting a primary research – with a research design specific to this model, having well-rounded inputs and data for analyses. Further to this, certain complex foregoing behaviors which overlap – e.g. distinctions between foregoing as a result of affordability, disadvantaged class or quality concern can be undertaken. There is ample data that suggests that people tend to mention cost as a main reason for foregoing, while the actual motivating factor may be something else altogether. Additionally, certain sub-groups of people overlap in many cases – like in the case of culturally diverse immigrants who sometimes also tend to be part of the ‘disadvantaged groups’, have low income and may be marginalized.

The future research can also include “depression” in its scope and attempt to classify it. This paper has currently not dealt with the vast topic of foregoing due to depression, as though an individual phenomenon, there is no data to support whether sufferers are internally aligned with the norm or not.

It is interesting to note that most researches have a tendency to focus on specific groups and population minorities to drive the point of their research with a significant skew towards women, disabled, immigrants and elderlies. It would be highly relevant to make a review of studies performed on larger databases without handpicking certain qualified groups to arrive at instances of foregoing which is general to a population. Indeed, the research methods can be extended to general population for further understanding on the subject.

To summarize the findings of the literature review:

An aware person, having the means and internally aligned to the norm may still desist from going to a practitioner for the fear of stigma (being labelled in a non-appropriate way) or issues related to quality. The case of HIV/AIDS sufferers, tuberculosis diagnosis, belonging

to the LGBT community, adolescents indulging in socially risky behaviors - make for a case in this scenario (Hallar, et al., 2010). The issue of “accommodation” as defined by Penchansky et al is highly relevant here - where the patients find the healthcare offer to be inappropriate and unacceptable to them – even though it is affordable, accessible (in terms of transportation and distance) and available (sufficient in terms of resources and infrastructure). This is a ‘demand’ problem for healthcare and the case can be applied across all countries. Policy recourses to deal with such kind of foregoing would may require sensitization of health personnel at grassroot level. Another recourse might also be to reassure populations at risk of ‘stigma’ to come forward and discuss their health issues anonymously.

Present alongside this in the same Quadrant, is the patient’s own assessment of the healthcare system as not providing sufficient value (especially with respect to quality) – so much so that, the best recursive is to indeed forego healthcare completely. The patient may assess the healthcare to be unavailable (lacking in high standard resources), inaccessible (too far or lack of proper transport) and even lacking in accommodation (lack of appointments, walk-in facilities etc.) Such an assessment is important particularly from a low-income country point of view – where the healthcare system has visible lacunae in the technology available and its overall implementation. However, it is interesting to note that even higher income countries – with historically well-established healthcare policies and significant resources – have individuals who forego healthcare because of quality reasons – such as inaccessibility (e.g. rural US) and lack of accommodation (e.g. perceived longer waiting times in Switzerland (Guessous, Gaspz, & Wolff, 2012)). Assessment of this type of foregoing behavior would need further examining of a person’s ‘path to healthcare’ (the various stages of healthcare access that a person interacts with and specifically enhancing the ones that would lead to greater experience improvement). This could be a combination of ‘demand’ and ‘supply’ both

– where physical improvement of infrastructure and resources may help the individual to have better trust in the quality of the available healthcare system.

Individuals may also eschew standard healthcare for conventional and alternative therapies. This is a significant demand problem - where the patient foregoes life-saving treatment (for diseases like cancer) for alternative therapies that are non-proven in their efficacy. In most cases, the individuals are aware of the treatment options, and generally have an option to access conventional healthcare. Usually, the alternative treatment options are perceived as non-invasive by them and allude to 'holistic wellbeing and care' in contrast to modern treatments which are far more 'aggressive', invasive and use chemicals which are perceived by them to destroy the body from within. The literature shows that dealing with this form of foregoing would require immense pro patient-sensitivity on the parts of healthcare providers and introduction of a well-researched health education pedagogy for health providers and individuals alike. The research points in the general direction that medical personnel 'indifference' and 'insensitivity' may cause patients to seek unverified feel-good therapies which may not be espoused by the government.

On the other hand, people may forego healthcare as a symptom prevailing for an entire community. This is a genuine problem of supply – where people perceive the need of healthcare but cannot avail due to unavailability (lack of resources), inaccessibility (lack of transport) , affordability, accommodation (present in a manner perceived inequitable). These comprise of groups of people such as migrants, disadvantaged classes, lower income quintiles. Racial discrimination and a type of “othering” of groups that do not conform to the majority (e.g. migrants, lower castes in India) also fall into this category. This is to say, it is the presence of healthcare discrimination and inequalities within the system which systematically reproduce access barriers to healthcare for vulnerable communities in a systematic way (Lee & Heinemann, 2010), (Hallar, et al., 2010), (Ye, Mack, Fry-Johnson, &

Parker, 2012). A supply problem – often communities faced with appropriate healthcare and lack of resources resort to private healthcare amounting to high ‘out-of-pocket’ expenditures leading to catastrophic expenditures that can further push them into a poverty disadvantage. Policy measures would require invigorating infrastructure, providing more resources and strengthening implementation.

Apart from this, cultural differences (UBA, 1992) and country of origin (Ye, Mack, Fry-Johnson, & Parker, 2012) are also shown to be significant predictors of underutilization of healthcare. Culturally diverse sub-populations in a host country, may tend to have distinct healthcare beliefs, values and practices from the majority population – and therefore tend to access health differently (Uba, 1992). Through the handpicked studies, language issues were shown to present a significant barrier for these groups of people in their timely availing of healthcare. Apart from language, cultural differences, such as food habits and a cultural mindset regarding ‘invasiveness’ of chemical treatment by certain communities also contribute to healthcare availing barriers in a significant way. In this case the communities are not even demanding healthcare. A suggested policy measure in this case would be investment in translators and imparting appropriate health related information to migrant groups in language of their preference and helping to reinforce specific community groups which can in turn provide knowledge and information in culturally appropriate ways.

In certain countries with strong heritage, traditional healing exists alongside conventional modern treatment, where people of the country have demonstrated higher preference for traditional healing. This brings us to consider the importance of standardized medical practices and the existence of various parallel medical therapies that exist simultaneously in the public domain. Without a clear mandate and good healthcare implementation by the Governments on the course of action - inappropriate health seeking behaviors and time lags for patients seeking the most effective remedy is rampant in countries like Nigeria and

Ethiopia. The negative cultural connotations towards modern medicine create further barriers towards timely health seeking from public health institution facilities and in some cases, patient fatalities have been attributed to such health foregoing behaviors (Kassaye, Amberbir, & Getachew, 2006). Like in case of the previous case, culturally sensitive communication in addition to robust healthcare policy implementation might be considered by the government.

Conclusion

This paper endeavors to propose a multi-dimensional model that takes into account the various motivations behind foregoing of healthcare – particularly from the stand point of, whether the decisions are individual (active) or based on a ‘collective identity’ (community based); and whether foregoing pertains to unmet healthcare needs (deviation from the norm) or an informed choice.

The motivations are further developed using examples of specific studies corresponding to major cases of healthcare foregoing seen in society, particularly within the scope of vulnerable populations. The common factors within the particular cases of foregoing behavior that are at play and the unique aspects of each are explored in detail.

The final insights are extracted from this in-depth exploration and distilled to aid health policy and behavioral health programs, by providing a detailed understanding of the meaning of foregoing, the various populations at risk and the motivations at play.

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Appendix

Tabular representation of all the studies and paper used in this literature review

QUALITY								
First author and year of publication	Place of study	Sample size	Sample Characteristic	Study design	Database name(s)	Outcome(s)	Key results	
		Age range of respondents		Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Dalal 2009	India	124 385 women (15-49 age group - reproductive age)	Women (General Population)	Quantitative. + Logistic Regression Analysis	Indian National Family Health Surveys NFHS-3 (2005–2006)	Foregoing healthcare as a result of "quality reasons"	58%	(58%) said family members did not use public healthcare facilities, because: of no nearby facilities (27%); inconvenient service times (9%); absent health personnel (5%); long waiting (17%); general poor quality (32%).
Mariko, 2003	Mali	1107	General Population	Quantitative	Original primary research	Quality is more important than even cost in determinig healthcare seeking intention and attitude	Same efficiency of public sector staff as for-profit facilities, increased utilisation of public dispensaries by 136%.	Price has minor effect on utilisation of health services, and doubling user fees and improvement of both the structural and process quality improves utilization

STIGMA								
First author and year of publication	z	- Sample size	Sample Characteristic	- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents		- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Lehrer 2006	USA	Boys: 1123	Adolescents	Mixed. Qualitative (Home Interviews) plus regression analysis	National Longitudinal Study of Adolescent Health	Foregoing necessary healthcare for reasons of 'confidentiality'	10.5% for boys	Adolescents who report health risk behaviors, psychological distress, unsatisfactory communication with parents have increased likelihood citing confidentiality as reason for forgone healthcare, compared with those who don't report these factors.
		Girls: 1315					14.5% for girls	
		(population already consisting of individuals having foregone healthcare)					(citing confidentiality as a reason)	

Sayles 2009	Los Angeles (LA)	48	HIV positive individuals (low income, minority skew)	Qualitative (Focus Group Discussions)	Primary Research (Recruitment through HIV care centers)	Foregoing healthcare due to anticipated stigma	Reported by all participants	Participants negotiate blame and stereotypes, fear of contagion, disclosure, and social contracts in the context of the medical community in addition to other areas of their life.
Poteat, 2013	USA	67	55 - Transgender 12 - medical providers	Qualitative (In-depth Interviews)	Primary Research (One time recruitment)	Foregoing healthcare due to stigma	100%	Transgender people often anticipate discrimination - often leads to their limiting their healthcare options - in order to avoid exposure to additional discrimination

Tummala, 2009	USA	4049	General Population of Transgender people	Quantitative (Logistic Regression)	National Transgender Discrimination Survey	Foregoing healthcare due to discrimination and affordability	50.40%	Healthcare postponement due to discrimination
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Financial Constraints								
First author and year of publication	z	- Sample size		- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents	Sample Characteristic	- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Bodemann, 2014	French Speaking part of Switzerland	2029	General Population	Multicenter cross-sectional survey	Primary Research (Recruitment through 47 health practitioners)	Foregoing a result of social and economic reasons	10.70%	"The question "Did you have difficulties paying your household bills during the last 12 months" performed better in identifying patients at risk of forgoing health care than a combination of four objective measures of socio-economic status (gender, age, education level, and income" (Bodemann, 2014 p.1)

Galbraith, 2012	USA	Respondents included 208 families in HDHPs and 370 in traditional plans.	General Population	Mail and phone survey used multiple logistic regression to compare family-level rates of reporting delayed/for gone care in HDHPs vs. traditional plans.	Primary Research (Recruitment through employer-sponsored insurance in a Massachusetts health plan and >12 months of enrollment in an HDHP or a traditional plan)	Foregoing as a result of cost related reasons. Higher probability for foregoing healthcare in HDHP plans compared to traditional plans	"For adult family members: 40.0% vs 15.1% among families with incomes <400% of the federal poverty level and 16.0% vs 4.8% among those with incomes ≥400% of the federal poverty level" (Galbraith, 2012)	"Among families with chronic conditions, reporting of delayed/for gone care due to cost is higher for both adults and children in HDHPs than in traditional plans. Families with lower incomes are also at higher risk for delayed/for gone care." (Galbraith, 2012, p. 1105)
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Litwin, 2009	Austria, Belgium, Denmark, France, Germany, Greece, Israel, Italy, Netherlands, Spain, Sweden , Switzerland and	n = 28,849 (Aged 50 and older)	Elderly population (50 and older)	Multivariate Regression Analyses	SHARE (Survey of Health, Ageing and Retirement in Europe)	Foregoing as a result of cost related reasons	"Relinquish- ment of care due to cost in the 12 months preceding the survey ranged from some 3– 6% in European countries, to 14% in Israel" (Litwin & Sapir, 2009, p. 174)	"Relinquish- ed care is associated in most countries with younger old age, greater health needs and perceived economic inadequacy " (Litwin, 2009, p. 175)

Marginalization								
First author and year of publication	Place of Study	- Sample size	Sample Characteristic	- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents		- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Acharya, 2014	India	462 (Women were aged between 18-45 year old)	General Population (With a skew towards disadvantaged classes)	Qualitative and quantitative techniques.	Primary Research (Recruitment in a slum in New Delhi)	Foregoing is more frequent for people of disadvantaged classes, discrimination is rampant for such groups and lower income quintiles	44 % of women did not take treatment for Reproductive Tract Infections (p.342) 60 % women did not use any assistance during birth (p.343).	Discrimination, non-availability of services due to social factors (caste, color, creed) and prevailing economic factors.
Read, 2017	USA	2244	General Population (with a 100% skew towards migrants from China, Mexico and India)	Multivariate logistic regression	New Immigrant Survey (NIS), 2003 (Multi-cohort panel survey of U.S.immigrants)	Foregoing is frequent for migrants due to English proficiency and alienation from the system	Utilization happens if children <10 age in the household, presence of English proficiency and presence of health insurance.	Migrants - high probability of no health-insurance. Strong "Relationship between gender and utilization-

								moderated by English language proficiency: (Read, 2017 p. 1)
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Culturally Diverse Immigrant Populations								
First author and year of publication	Place of Study	Sample size		Study design	Database name(s)	Outcome(s)	Key results	
		Age range of respondents	Sample Characteristic	Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Aroian et al, 2005	USA	Chinese Elders: 27	Chinese Immigrants in the USA and those involved as their healthcare providers	Qualitative (Focus group discussions, Direct interviews)	Direct recruitment	Foregoing as a result of cultural differences	100% (All Chinese elders agreed to foregoing behavior at some point)	"Chinese elders underutilize services - problems of language, cultural norms/values, preference for self-over professional care, fear, and distrust of western biomedicine, and the obligation to
		Adult Care giving children: 11						
		Health & Social Service Providers: 12						

								refrain from using formal services" (Aroian, 2005, p. 95)
Chang 2009	USA	54 participants (28 men and 26 women) Mean age: 62 (41-65)	Hmong (Laotian, Cambodian) Immigrants in the USA	Qualitative (Focus Group Discussions, Direct interviews)	Direct recruitment by RI Southeast Asian Coalition	Foregoing as a result of cultural differences	100% (All the respondents admitted to health utilization barriers and foregoing behaviors)	"lack of interpreter services contributes to adverse outcomes, including less screening and immunizations; more treatment errors; non-compliance with medication or treatment plans; missed appointments, and patient dissatisfaction" (Chang et al, 2009, p.315)

Ye, Mack 2012	USA	2500	US-born and foreign-born Asian Americans	Quantitative (Multiple Logistic Regression Analyses)	National Health Interview Survey (NHIS) from 2003 to 2005	Foregoing is enhanced if a person is foreign born	foreign-born negatively related to indicators of all indicators of healthcare utilization (office visit: OR = 0.58, seen/talked to a general doctor: OR = 0.69, seen/talked to a specialist: OR = 0.42, but ER visit (OR = 0.84) [confidence intervals have been omitted for the purpose of this table)	"Substantial differences by country of birth in health care access and utilization among Asian Americans" (Ye, 2012, p1). "study found that foreign-born Asian residents did not differ from those born in the US in income" (Ye, 2012, p.5)

Traditional Healing								
First author and year of publication	z	- Sample size		- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents	Sample Characteristic	- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Golooba-Mutebo, 2009	South Africa	55 (elderly skew)	Rural skew	In-depth interviews	Primary Research. Direct recruitment.	Preference for traditional medicine over state mandated healthcare	100% (All interviewed showed belief and varying degrees of preference for traditional medicine)	Available, folk ideas about aetiologies of disease prompt responses to affliction that point away from the formal health System
Kassaye, 2006	Ethiopia	NA	General Population	Literature Review	Systematic literature review of Ethiopian health policy documents, traditional medicine literatures, newspaper reports, journals and relevant articles	Strong preference for traditional medicine	Up to 80% prefers traditional medicine	In Ethiopia up to 80% of the population uses traditional medicine due to the cultural acceptability of healers and local pharmacopeias, the relatively low cost of traditional medicine and difficult access to modern health facilities

Okeke, 2006	Nigeria	1200	Caretakers of children under 5 who suffered malaria	Mixed Design - Qualitative and Quantitative	Primary Research. Direct recruitment.	Preference for traditional medicine above state mandated healthcare	62.7% Urban mothers patronized government/private modern health facilities. 62% rural mothers preferred self-treatment using traditional medicine or allopathic formulations	A strong rural- urban skew. Rural mothers prefer self- treatment and traditional healing while urban mothers patronized government/private health centers
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Complete foregoing of conventional treatment								
First author and year of publication	Place of Study	- Sample size	Sample Characteristic	- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents		- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Citrin 2012	USA	60	Cancer patients (skew towards preferers of alternative therapies)	Qualitative and quantitative	Direct recruitment through physicians	Foregoing in favor of alternative remedies	30% definitive foregoing 30% complemented conventional treatment with alternate remedies	"unnecessarily harsh" behavior of oncologists, fear of side effects, and belief in the efficacy of alternative therapies" (Citrin, 2012, p. 607)
Frenkel, 2013	USA	NA	Cancer survivors	Literature Review	Literature Review	Foregoing in favor of alternative remedies	Reported by all participants	"Fear of adverse side effects of cancer treatment (particularly chemotherapy), uncertainty about treatment effectiveness, hopelessness, helplessness, loss of control, denial (about their illness), psychiatric disorders, dysfunction in the health care system, and above all, issues

								surrounding communication and the patient physician relationship" (Frenkel, 2013, p. 636)
Friend-du-Preez, 2009	South Africa	206 caregivers (from public/private clinics as well as public hospitals)	Skewed towards recruitment of black South African caregivers	Qualitative and quantitative	Primary Research - Direct Recruitment	Foregoing in favor of alternative remedies	75% administered some form of traditional medicine to the patients	Care givers are at the heart of dispensing healthcare - and frequently their own beliefs and attitudes towards healthcare - influences them to suggest/administer traditional remedies to the patients they are taking care of - irrespective of the healthcare provider whom they represent.

Partial Foregoing of Conventional Treatment								
First author and year of publication	Place of Study	- Sample size		- Study design	Database name(s)	Outcome(s)	Key results	
		- Age range of respondents	Sample Characteristic	- Representativeness of the study			Prevalence of the outcome	Factors associated (explaining the outcome)
Gallagher, 2003	USA	4000 (>=18)	General Population (Pre-qualified as headache sufferers)	Quantitative. + Logistic Regression Analysis	National Family Opinion household panel	Delaying or Foregoing conventional healthcare to avoid adverse effects	66%	"Two-thirds of sufferers specifically had delayed or avoided taking a current prescription medication because of concerns about adverse effects. These concerns led to a delay in taking medication in 37% of treated migraine episodes and to medication avoidance in 44% of untreated attacks during the previous 6 months" (Gallagher & Kunkel, 2003, p. 36)
Kennedy, 2005	USA	31044	General Population	Quantitative	2002 National Health Interview Survey	Delaying or Foregoing conventional healthcare	5787 (18%) pre-qualified as herb and supplement users - of who 57.3%	"Users said that herbs and natural products were important to their health and well-being" (Kennedy, 2005, p. 1847). One thirds of the users did not

							used them to treat specific conditions	inform their conventional healthcare providers about their usage of the supplements
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