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## A Qualitative Synthesis of the Effects of Rising Cost-Sharing Requirements in the United States

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**Key words:**

qualitative synthesis; United States health policy; high-deductible health plans; access to care; Affordable Care Act; Obamacare

**Abstract:** In this review, I evaluate and synthesize thematic findings from the past decade of qualitative research on the effects of high and increasing cost-sharing requirements on health care utilization from patient and provider perspectives. Whereas most of the literature on cost-sharing and health services utilization behavior has been quantitative in approach, this synthesis helps us examine patient and provider perceptions and the lived experiences associated with high and increasing health insurance cost-sharing requirements. First, I find that high and increasing cost-sharing requirements lead American patients to forgo a range of health care services, even medically-necessary treatment for themselves and their family members, and even among employed and middle-class American families who have insurance coverage. Second, I demonstrate that high cost-sharing expenses beget intense patient confusion, fear, stress, and anxiety. These findings complement results from the RAND Health Insurance Experiment, a large experimental study of health care costs and utilization conducted from 1971 to 1986, to improve our understanding of the effects of high cost-sharing requirements on patient health care utilization in the modern context. This is critical because some policymakers continue to espouse higher patient cost-sharing requirements. Limitations and future directions for research are discussed.

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## 1. Introduction

### 1.1 Background

The Patient Protection and Affordable Care Act (ACA) of 2010 ushered in a new era in United States (U.S.) health policy. Since the ACA's enactment—the most comprehensive health reform legislation since the passage of Medicare and Medicaid in 1965 and the U.S.'s most ambitious attempt to achieve universal health coverage—the number of uninsured individuals in the U.S. decreased from 49 million in 2010 to 29 million in 2015 (OBAMA, 2016). However, despite increasing access to health insurance, the rising cost of health care spending remains a major concern to policymakers, health care providers, and patients alike (YOUNG & DeVOE, 2012). The U.S. spends more on health care than any other industrialized nation, and U.S. health care spending has swiftly risen over time—from 5.0% of GDP in 1960 to 17.8% of GDP in 2016. In 2012 alone, the U.S. spent more on health care than the entire GDP of the United Kingdom (RICE et al., 2014). [1]

ANDERSEN, DAVIDSON and BAUMEISTER (2014) classify insurance coverage as an "enabling characteristic" for "potential access" (p.43), defined as innovation that improves the probability for health care utilization. In practice, strong empirical evidence—particularly from the RAND Health Insurance Experiment (HIE), a large experimental study of American health care costs and utilization conducted from 1971 to 1986, including over 6,000 participants (MANNING, NEWHOUSE, DUAN, KEELER & LEIBOWITZ, 1987)—demonstrates that health insurance is also a pathway to "realized access" (ANDERSEN et al., 2014, p.48). That is, health insurance drives people to actually consume health care (FINKELSTEIN, 2015). Not surprisingly, total health expenditures rise as insurance coverage expands over time, highlighting the trade-off between increasing access to care and containing cost growth. In response, policymakers continue to seek ways to alter the design of health insurance plans to provide coverage but in ways that disincentivize excessive health care utilization. [2]

### 1.2 Moral hazard, the RAND Health Insurance Experiment and patient cost-sharing

From a normative ethical perspective, insurance expansion can be advantageous. Coverage promotes social equity and financial benefits (i.e., risk pooling). However, insurance coverage also introduces the economic conundrum known as moral hazard. ARROW (1963) is credited for first commenting on the dilemma of moral hazard in health care, noting "medical insurance increases the demand for medical care" (p.961). With moral hazard, insurance masks the true costs of health care utilization from consumers, incentivizes personal health care consumption, and increases the likelihood of incurring a covered loss (RICE, 1998). What was the result according to microeconomic theory under the assumption of rational behavior? Insured individuals consume care where marginal benefit falls below the marginal cost of additional consumption, and a

socially suboptimal equilibrium is reached, resulting in dead weight (inefficient and low-value) resource welfare loss (PAULY, 1968). [3]

Offering a solution, PAULY (1968) theorizes that patient cost-sharing—through deductibles, co-pays, and co-insurance—can alter the average patient's demand for health services and incentivize the patient to consume care at a more optimal level. The RAND HIE tested PAULY's theory. Conducted from 1971 to 1986, the RAND HIE researchers estimated that comprehensive health insurance yields total welfare loss equivalent to 19% to 30% of total national health expenditure (MANNING et al., 1987). More granularly, depending on the service, the RAND HIE also demonstrated that essentially free insurance yields 30%-50% additional health care consumption per person on average, when compared to plans requiring at least 25% cost-sharing (ibid.). [4]

Today, decades after the RAND HIE, the U.S. health system continues to cycle through various approaches to increasing patient cost-sharing responsibility as a method for cost-containment. One initiative—the high deductible health plan (HDHP), or the consumer-directed health plan (CDHP) variant—is currently in vogue. Nearly across the same time period as this study, from 2006 to 2016, the share of private-sector employees covered by an HDHP grew by over 400% (MILLER, VISTNES, ROHDE & KEENAN, 2018). The average deductible amount for workers in plans with deductibles tripled from \$584 in 2006 to \$1,505 in 2017, while nearly one-quarter of all workers experienced a deductible amount greater than \$3,000 in 2017 (KAISER FAMILY FOUNDATION, 2017). [5]

### **1.3 Importance and objective**

The RAND HIE findings (MANNING et al., 1987) suggest cost-sharing can constrain health services utilization; however, only to a defined cost-sharing limit. An important caveat to the HIE findings, for both physician and hospital services, the significant reduction in health services attributable to cost-sharing is only found between the 0% and 25% cost-sharing levels. On average, higher cost-sharing levels show no statistically discernable marginal consumption reductions compared to the 25% level (ibid.). This finding is critical because many policymakers continue to focus on implementing substantial and increasing cost-sharing requirements across health plans, even though the RAND HIE empirical results do not necessarily support the continuous rise of patient cost-sharing requirements over time as a viable method for reducing consumption. [6]

That said, quantitative inquiry has produced much literature on cost-sharing and subsequent health services utilization behavior. More recent (and influential) cost-sharing studies have employed observational quantitative research designs and secondary data analysis, which are often hampered by selection bias, model misspecification, omitted variable bias, and other endogeneity issues. The RAND HIE thus stands out in its design as a randomized, controlled insurance experiment. However, the RAND HIE estimates are now several decades old and may no longer fully explain patients' experience with high cost-sharing requirements in the modern health care context. [7]

In response, examining individual patients' perceptions and lived experiences with high or increasing cost-sharing requirements may help us better understand how cost-sharing affects patient health care utilization behavior in the modern context. More specifically, qualitative research can help us explore the perceptions and emotional responses of diverse groups of patients and providers, understand their lived experiences, and describe and interpret the effects of high or rising cost-sharing requirements on health care utilization behavior as a social phenomenon (CRESWELL & POTH, 2018). Such perceptions may also help us reconsider and refine the assumptions of PAULY's (1968) theoretical model of patient behavior and inform the future use of cost-sharing in insurance policymaking. [8]

The objective of this qualitative research synthesis is to therefore examine and discuss patient and provider perceptions on the effect of high or rising cost-sharing requirements on health care use in the post-ACA context. As a corollary, a two-part research question guides this study: 1. How have patients and providers recently perceived high or rising insurance cost-sharing requirements; 2. How have patients reacted to cost-sharing increases? Notably, there is limited recent qualitative research related to the effects of high and rising cost-sharing on health services use, and no summary of the qualitative findings has been conducted. As such, this study seeks to synthesize patient and provider perceptions about cost-sharing increases in the recent era. While other influential quantitative studies have been conducted over time, this study seeks to explore the qualitative insights within the context of the RAND HIE findings, which suggest that cost-sharing requirements higher than 25% of cost may not reduce marginal health care use (MANNING et al., 1987). [9]

I begin with a description of the methodological approach I conducted from February 2018 to May 2018, including a description of search methods, inclusion criteria, and data collection and analysis approach (Section 2). After that, I introduce the key findings that emerged through the qualitative research search and review (Section 3). This is followed by a discussion of the results vis-à-vis the contemporary U.S. health policy context, an assessment of the qualitative studies used in this synthesis, and considerations for future qualitative research in the field (Section 4), leading to a conclusion (Section 5). [10]

## 2. Methods: Search Strategies, Data Collection, and Analysis

This review examined qualitative studies published in the public health, medical, and health-related social science literatures. Consistent with other American health-focused studies, the primary focus was to search PubMed and MEDLINE-indexed studies, augmented by electronic searches of the Google Scholar database to capture relevant, non-PubMed/MEDLINE-indexed analyses.<sup>1</sup> All searches were limited to peer-reviewed articles, and the search was conducted up to May 2018. The following searches were conducted in both PubMed/MEDLINE and Google Scholar using the advanced search tool options with following combinations of terms:

1. cost sharing + access + qualitative,
2. cost sharing + utilization + qualitative,
3. cost sharing + barrier + qualitative,
4. high deductible + access + qualitative,
5. high deductible + utilization + qualitative
6. high deductible + barrier + qualitative. [11]

All peer-reviewed paper titles were first assessed in PubMed/MEDLINE, and all peer-reviewed paper titles were assessed for the first ten pages of search results in Google Scholar. All PubMed/MEDLINE abstracts were reviewed and assessed per the inclusion criteria (Section 2.2), whereas a Google Scholar abstract was reviewed if its title indicated either qualitative methods or study objective relevancy. Full-text articles were retrieved through the Ohio State University library online. All full-text articles were reviewed if they appeared to meet the inclusion criteria. All articles meeting the study criteria were included. [12]

There were six inclusion criteria. An included study must 1. employ qualitative methods or quantitative-qualitative mixed methods to investigate a research question related to cost-sharing and health services utilization (or access to care) for any health-related service, 2. be conducted between the years of 2005 and 2018, 3. examine individuals' perceptions, 4. be published in a peer-reviewed journal, 5. be set in the United States, 6. be published in English, and 7. examine the human species. All other articles were excluded, including duplicate titles, quantitative studies, and review articles. [13]

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<sup>1</sup> [PubMed/MEDLINE](https://pubmed.ncbi.nlm.nih.gov/) is the searchable database of references and academic journal articles on medicine, nursing, health care, and biomedical topics maintained by the United States National Library of Medicine (NLM) at the National Institutes of Health. <https://scholar.google.com/> is a free web search engine that indexes the full text or metadata of scholarly research across an array of disciplines.

Data were extracted, assessed, and synthesized for all articles. Data categories included:

1. the type of qualitative research methodology (e.g., ethnography, grounded theory, mixed-methods);
2. the type of data collection methods (e.g., interviews or focus groups);
3. the sample size and sampling approach (e.g., purposive or representative);
4. the study setting and scope (e.g., state or national);
5. key findings about the impact of high and/or increasing cost-sharing requirements on health services utilization;
6. study design limitations. [14]

Data regarding the perceptions of high and/or increasing cost-sharing requirements and subsequent health services utilization behavior were excerpted from the article results. [15]

### **3. Results**

#### **3.1 Search results**

The search yielded 79 citations through PubMed/MEDLINE and over one million citations through Google Scholar. A total of 79 abstracts were reviewed through PubMed/MEDLINE and 63 abstracts were reviewed through Google Scholar, as presented in Table 1. The search strategy resulted in ten papers that met the inclusion criteria. The included articles were published between 2007 and 2016. Sample sizes ranged from n=4 to n=722 participants (i.e., individuals participating in either a qualitative study or the qualitative component of a mixed-methods study). Study participants represented patients, providers, health care administrators, and health plan experts. Four studies were national in scope, while the remaining six studies examined participant samples from Kansas, Massachusetts, South Dakota, Oregon, North Carolina, and California. The studies focused on the effects of cost-sharing on a range of health services and conditions, including primary care and basic health services, specialty care, hemophilia, chronic illness, oncology, immunizations, and medical imaging.

<b>Searches</b>	<b>Initial Search Results</b>	<b>Title Review</b>	<b>Abstract Review</b>
<i>PubMed/MEDLINE</i>			
cost sharing + access + qualitative	45	45	45
cost sharing + utilization + qualitative	28	28	28
cost sharing + barrier + qualitative	4	4	4
high deductible + access + qualitative	1	1	1
high deductible + utilization + qualitative	1	1	1
high deductible + barrier + qualitative	0	0	0
<i>Google Scholar</i>			
cost sharing + access + qualitative	791,000	100	14
cost sharing + utilization + qualitative	263,000	100	10
cost sharing + barrier + qualitative	293,000	100	7
high deductible + access + qualitative	25,800	100	13
high deductible + utilization + qualitative	12,300	100	8
high deductible + barrier + qualitative	17,300	100	11

Table 1: Search process results [16]

A quantitative-qualitative mixed-methods approach was most commonly used (DeVOE et al., 2007; DULITZ & SCHRADER, 2013; LEE & LEVY, 2012; REED, BENEDETTI, BRAND, NEWHOUSE & HSU, 2009), while SMITH, NICOLLA and ZAFAR (2014) used a multi-method qualitative approach. Two studies (GRANDE, BARG, JOHNSON & CANNUSCIO, 2013; LIEU et al., 2009) employed grounded theory methodology. Three studies (HALL, CARROLL & MOORE, 2010; LANE et al., 2016; SHORTRIDGE, MOORE, WHITMORE, O'GRADY & SHEN, 2011) used a descriptive and thematic analysis approach. Five studies (GRANDE et al., 2013; LANE et al., 2016; LEE & LEVY, 2012; SHORTRIDGE et al., 2011; SMITH et al., 2014) conducted individual key informant interviews, while three studies (HALL et al., 2010; LIEU et al., 2009; SMITH et al., 2014) conducted focus group interviews. Finally, three studies (DeVOE et al., 2007; DULITZ & SCHRADER, 2013; REED et al., 2009) conducted inductive, latent content analysis of open-

ended free response survey items to assess emergent themes. Table 2 presents the ten articles including a summary of the data used in the final analysis.

Table 2: Synthesized qualitative findings. Click [here](#) to download the PDF file. [17]

### **3.2 Key findings on cost-sharing and health care use**

Several key themes emerged throughout the studies. In all but one (SMITH et al., 2014) of the ten studies, patients, providers, and other stakeholders confirmed that high cost-sharing led to introspection and emotional decision-making about forgoing a range of health care services, including medically-necessary treatment. Only oncology patients identified in SMITH et al. and a subset of emergency department patients identified in LIEU et al. (2009) did not forgo treatment while experiencing high cost-sharing requirements, even though oncology visit co-pays and prescription drug co-pays were financially prohibitive. For primary care, specialty care, and chronic illness treatment, high cost-sharing requirements forced patients to experience emotional turmoil upon deciding to decrease or delay their use of medical care and their children's use of medical care, even in "paradoxical" situations where working people and middle-class families had insurance coverage but still had trouble accessing care because of the high deductibles (HALL et al., 2010; LANE et al. 2016). [18]

The words of one 61-year-old male patient in HALL et al. (2010) demonstrate the prolonged and introspective contemplation patients can experience when attempting to decide which services to pursue, given their cost-sharing realities:

"If I'm not going to hit \$5000 [his deductible], I'm not getting it done. If this is a year for a shoulder surgery, okay then I'm going to get the hernia fixed, I'm going to get the glasses. You know you do that. I had a stomach wall hernia that I had to wait for 3 years until I had a shoulder surgery" (p.307). [19]

In LIEU et al. (2009), one mother shares her consternation,

"With kids, you just kind of step back and go, are you really that hurt? With 24 hours of ice, are you going to feel better tomorrow and I don't have to pay the deductible and spend the time to go? And if they obviously need it, yes ... It's if I don't have to lay out that \$150 for that, I have it for someplace else" (p.252). [20]

However, for some patients, the cost-sharing requirements were simply too prohibitive to overcome. In the pithy words of one patient in GRANDE et al. (2013), "that 20% (co-insurance requirement) can kill you" (p.39). Across the studies, patients delayed going to the doctor, received fewer medical tests, and sometimes visited the emergency room less. Providers, administrators, and health plan experts were generally fearful that future cost-sharing increases would only further force patients to forgo health services like immunizations and medical imaging (LEE & LEVY, 2012; SHORTRIDGE et al., 2011). [21]

Five studies (GRANDE et al., 2013; HALL et al., 2010; LIEU et al., 2009; REED et al., 2009; SMITH et al., 2014) also found that high cost-sharing expenses caused intense patient confusion, fear, stress, or anxiety. Complex health insurance concepts are often overwhelming, and throughout the studies, many patients did not understand how their high deductibles, co-pays, and co-insurance affected the services they needed—or even what services were covered. The words of one 51-year-old male in HALL et al. (2010) illustrate this angst:

"If somebody says you ought to do this [medical test], and all of a sudden you're saying I don't think I can do it because I can't afford it...and then you go home at night and you say, 'Well, did I really do the right thing?' I mean, that eats on people" (p.308). [22]

There was much confusion about cost-sharing requirement changes over time (GRANDE et al., 2013), as well as anxiety about potential medical bankruptcy (SMITH et al., 2014) or property loss and asset depletion (DULITZ & SCHRADER, 2013). Moreover, patients experienced stress and anxiety when they had to choose between their health care treatment (i.e., continue to pay high cost-sharing expenses) and their basic living expenses, such as food and housing (DeVOE et al., 2007; GRANDE et al., 2013). In the words of one concerned mother in DeVOE et al.: "I can't afford to pay co-pays or prescriptions when all I have is \$200 child support for rent, gas, diapers, and anything else I need for my apartment like dish soap or toilet paper" (2007, p.515). A farmer's widow further demonstrates similar emotional turmoil when she discusses almost losing the family farm during her late husband's bout with cancer,

"My husband passed away 2 years ago of cancer. I had to work off the farm to have the insurance due to his condition. I should have been home helping on the farm but could not because of cancer. During that time we paid \$1,200 per month just for the premium along with a large deductible, co-pay" (DULITZ & SCHRADER, 2013, p.410). [23]

At moments, even the health care providers expressed deeply emotional concerns on their patients' behalf, noting "We feel so helpless as there are no resources to work with. Patients are losing their homes to pay for their treatment and are forced to live in their automobiles" (SMITH et al., 2014, p.e369). However, patients were also embarrassed and reluctant to discuss cost-related concerns and uncertainties with their providers (LIEU et al., 2009; SMITH et al., 2014), fearing that financial discussions might jeopardize their treatment plans or disrupt care delivery (SMITH et al., 2014). [24]

## 4. Discussion

In this review I synthesized the findings from the past decade of qualitative research on the effects of high and increasing cost-sharing requirements on health care utilization from patient and provider perspectives. This synthesis particularly contributes to our understanding of HDHPs and the effects of higher cost-sharing in nontrivial ways, as policymakers continue to espouse HDHPs and higher patient cost-sharing requirements in attempt to mitigate moral hazard in health services consumption and in attempt to slow national health care expenditure growth. More granularly, this synthesis helps us better understand individual patient perceptions, emotions, and lived experiences with high or increasing cost-sharing requirements in the modern context, now three decades past RAND's seminal experimental study. [25]

### 4.1 Comparison to the RAND Health Insurance Experiment findings

The RAND HIE results suggest that cost-sharing requirements above 25% may not further reduce health care use for the average policyholder. As such, some health policy scholars now argue that higher deductibles and co-pays may no longer be viable cost-containment instruments. However, this qualitative synthesis suggests that certainly some patients experiencing high and increasing deductibles and co-pays do continue to reduce or delay health services utilization for both themselves and their children and across the health care spectrum. Undeniably, in the modern post-ACA context, individuals experience cost-sharing requirements far greater than the 25% level examined through the RAND HIE. Thus, this synthesis provides evidence suggesting higher cost-sharing requirements can continue to reduce health care use, which in turn likely reduces health care expenditure. However, at what emotional and personal financial costs? This synthesis finds that higher cost-sharing requirements can cause intense confusion, stress, and anxiety about health care, as well as significant monetary loss at the patient level. [26]

Recent quantitative studies demonstrate that HDHPs (or CDHPs) are associated with modest reductions in hospital and emergency department consumption and expenditure (BEEUWKES, HAVILAND, McDEVITT & SOOD, 2011; HAVILAND, EISENBERG, MEHROTRA, HUCKFELDT & SOOD, 2016; WHARAM et al., 2007), while the RAND HIE demonstrates that cost-sharing significantly decreases both unnecessary and necessary care equally (SIU et al., 1986) and disproportionately reduces spending among poorer individuals (MANNING et al., 1987). The results of this qualitative synthesis corroborate those quantitative findings (e.g., GRANDE et al., 2013; HALL et al., 2010). Thus, while we cannot speculate about the long-run effects of HDHPs and higher cost-sharing requirements on the consumption patterns of the chronically-ill, the delay or cancelation of necessary treatment among poor and chronically-ill individuals could intensify illness until the illness becomes emergent and costlier in the long run. Higher cost-sharing requirements should therefore raise concerns about patient experience, satisfaction, and quality of care. [27]

## 4.2 Assessing the qualitative study designs

It is important to evaluate the strengths and weaknesses of the qualitative studies reviewed in this synthesis. The following assessment helps to inform an overarching reflection on the explanatory power of the available studies, to methodologically appraise their significance for the research topic, and to identify opportunities for future inquiry. Notably, all but three studies explicitly stated their qualitative research methodology (e.g., grounded theory or mixed methods), which helps the reader assess the studies for rigor, credibility, validity (i.e., transferability), dependability, and reflexivity (CRESWELL & POTH, 2018; LINCOLN & GUBA, 1985). A quantitative-qualitative mixed-methods approach was most commonly used (DeVOE et al., 2007; DULITZ & SCHRADER, 2013; LEE & LEVY, 2012; REED et al., 2009), while SMITH et al. (2014) used a multi-method qualitative approach, thus permitting data triangulation and improving study trustworthiness (CRESWELL & POTH, 2018). In contrast, three studies (HALL et al., 2010; LANE et al., 2016; SHORTRIDGE et al., 2011) conducted generic descriptive and thematic analysis, though none of the three studies stated the researchers' interpretive lens, acknowledged researcher reflexivity, or demonstrated thick description, thus calling into question the credibility and authenticity of their findings (CRESWELL & POTH, 2018). Moreover, only GRANDE et al. (2013) and DeVOE et al. (2007) explicitly discussed achieving theoretical saturation in their themes, although several studies employed large sample sizes and likely achieved saturation (DULITZ & SCHRADER, 2013; REED et al., 2009). [28]

The authors of several studies also more clearly established data dependability than others (LINCOLN & GUBA, 1985). For instance, while two studies' authors GRANDE et al. (2013) and LIEU et al. (2009) employed grounded theory methodology, only GRANDE et al. discussed adhering to constant comparison as defined by CORBIN and STRAUSS (1990). In contrast, only LIEU et al. presented a theoretical model to describe the forces that affect behavior among patients with HDHP coverage. More generally, four studies (GRANDE et al., 2013; LANE et al., 2016; SHORTRIDGE et al., 2011; SMITH et al., 2014) that conducted individual key informant interviews and all three studies (HALL et al., 2010; LIEU et al., 2009; SMITH et al., 2014) that conducted focus group interviews met the criteria CRESWELL and POTH (2018) recommend for ensuring rigor in qualitative data collection, coding, and analysis. All eight studies' authors generated qualitative transcripts from digitally-recorded interviews conducted by trained interviewers, transcribed by expert transcriptionists, and organized and thematically coded via appropriate statistical software. Codes and themes were reconciled and agreed upon between reviewers through systematic, documented processes. However, LEE and LEVY (2012) and DULITZ and SCHRADER (2013) did not discuss their data coding and data analysis processes, and none of the ten studies explicitly discussed memoing or member checking during data collection or analysis. [29]

### 4.3 Future directions for research

Future qualitative inquiry on cost-sharing and health care utilization behavior can address gaps related to both research objective and methodology. First, there is much opportunity to conduct studies that examine patient experiences with the exact cost-sharing requirement increases designated in the RAND HIE (e.g., 25 percent, 50 percent, and so on). Future phenomenological studies and participatory health research studies (e.g., SPRINGETT, ATKEY, KONGATS, ZULLA & WILKINS, 2016) could directly examine the essence of experiencing incremental cost-sharing increases from 25 percent to 50 percent, 50 percent to 75 percent, and 75 percent to 95 percent. Where feasible, future studies could also retrospectively interpret the studies examined in this review to sub-analyze themes by patients classified by distinct cost-sharing requirement levels (i.e., THORNE, 1998). No such studies have yet been conducted. [30]

The studies examined in this synthesis also demonstrate a novel finding—a finding perhaps overlooked by the quantitative data analysis. That is, a range of American patients remain deeply fearful and perplexed by cost-sharing requirements, and many patients often do not understand how deductibles and co-pays work, how deductibles and co-pays change over time, or how deductibles and co-pays affect covered benefits. Observational quantitative studies seek to estimate the average patient's response to cost-sharing increases; however, said estimates about the average patient case may not fully explain the perceptions and behaviors of patients who remain confused and anxious about how cost-sharing increases affect their health care use. As discussed by WOODGATE, ZURBA and TENNENT (2017), the translation of emotional knowledge historically has not always been easily accepted by researchers and health practitioners, and the ability for health care researchers and practitioners to understand how people feel and experience their own realities is essential for developing (and implementing) meaningful interventions. [31]

There is therefore an opportunity for future mixed methods study researchers to sequentially 1. examine either administrative claims data or appropriate secondary data (e.g., National Health Interview Survey) to assess health services utilization patterns and to 2. frame qualitative examination of non-typical and outlier patients' perceptions and lived experiences with cost-sharing and health care use (LEECH & ONWUEGBUZIE, 2009). To that end, there is also much opportunity for ethnographic and grounded theoretical examination of patient interactions with providers and health care financial counseling staff, especially to examine how cultural differences and social norms affect the understanding of cost-sharing and health services use among disparate medically-vulnerable and racial/ethnic minority populations. Arts-based representations like that explored by WOODGATE et al. (2017) should also be considered to potentially enhance empathy between the patients and the health care providers and researchers, to better understand the lived experiences of individuals experiencing high cost-sharing requirements, and to help diminish stigma associated with medical debt and insurance confusion. Again, no such studies have been conducted. [32]

Second, in response to the methodological limitations discussed above, future qualitative inquiry must strive to better document dependability and credibility techniques to better ensure the rigor, transferability, and trustworthiness of future qualitative inquiry on cost-sharing and patient health services utilization behavior. In the future, researchers should strive to document auditing procedures, coding processes, member checking, and memoing efforts. Future researchers should also document the achievement of theoretical saturation. [33]

#### **4.4 Limitations of this review**

This review has limitations that must be discussed. First, in this review, I focused on relevant PubMed/MEDLINE-indexed research, only augmented by studies found via Google Scholar. Because a key finding emerged about patient anxiety, fear, and confusion about cost-sharing, it is possible that relevant, non-PubMed/MEDLINE-indexed studies exist in the psychology literature—studies perhaps not captured through the Google Scholar searchers. Second, I only considered peer-reviewed literature for review inclusion, whereas many private foundations, independent research organizations, think tanks, and government agencies have evaluated insurance- and access-to-care-related phenomena since the ACA's enactment and implementation. [34]

### **5. Conclusions**

In this review, I synthesized thematic findings from the past decade of qualitative research on the effects of high and rising cost-sharing requirements on health care use from patient and provider perspectives. Whereas much emphasis is still given to the RAND HIE empirical findings about the limits of cost-sharing, this synthesis can help us contextualize previous quantitative results and examine patient and provider perceptions and the lived experiences associated with high and rising cost-sharing requirements. [35]

First, in this synthesis, I find that high or rising cost-sharing requirements often lead patients to contemplate health services use and to make deeply emotional decisions to forgo a range of health care services, even medically-necessary treatment for both themselves and their children. Second, and related, high deductibles and co-payments can even cause introspection and emotionally-painful second-guessing about health care use among employed and middle-class American families who have insurance coverage. Third, in this synthesis, I demonstrate that high cost-sharing expenses beget intense patient confusion, fear, stress, and anxiety for a range of individuals and across the qualitative studies. Complex health insurance concepts are often overwhelming, and throughout the studies, many patients did not understand how their high deductibles, co-pays, and co-insurance affected the services they needed—or even what services were covered. [36]

These findings augment the RAND HIE results to perhaps improve our understanding of HDHPs and the effects of high and rising cost-sharing requirements on patient health services use in the modern, post-ACA context.

This is critical because some policymakers continue to espouse HDHPs, CDHPs, and higher patient cost-sharing requirements in attempt to mitigate moral hazard in health services consumption and in attempt to slow national health care expenditure growth. While the RAND HIE findings arguably do not support the continuous rise of patient cost-sharing over time, the results of this synthesis suggest high and increasing cost-sharing requirements will continue to curb health care use—although perhaps at the emotional expense of everyday patients. To that end, though, this synthesis may also remind us about the heterogeneity of individual utility functions and the change of preferences across social generations. Regardless, there are limitations to the studies examined in this qualitative synthesis, and further qualitative inquiry is necessary to illuminate the depths and essence of patient and provider experiences. [37]

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