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Evidence-Informed Health Care Transition Policy in California's Title V Programs for Medical Complexity

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Abstract

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MS, California State University Bakersfield, 2010

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Inadequate health care transition policy continues to cause interruptions or setbacks in the continuity of medical care and lapses in health insurance coverage for adolescents in California's Title V programs for individuals with medically complex cases. Yet, there is a paucity of empirical health care transition research to develop an effective health care transition policy for children with medical complexity who are enrolled in California’s Title V program. The purpose of this explanatory case study was to explore the potentiality of translating evidence from a quasi-experimental health care transition primary research project into evidence-informed health care transition policy. The research question explored how examining and translating health care transition research provides insight to inform new health care transition policy for children with medical complexity who are enrolled in California’s Title V programs. The policy process model was used to frame the translation of research evidence into the stages of policymaking. A qualitative approach was used to analyze documents, focus group data, and field notes from a health care transition primary research project conducted by a California county Title V program. The analysis showed that the translation of research evidence into the policy process model framework could inform policymaking because some processes used by researchers are shared by policymakers. Adolescents enrolled in California's Title V programs for medical complexity may benefit from health care transition policy developed from primary research projects by improving self-management and self-advocacy skills leading to positive social change.

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Dedication

To all children with special health care needs, may we find ways together for you to reach your full potential!

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I am especially grateful to Dr. B. J. Moore from California State University Bakersfield, who inspired me, and more recently challenged me, to pursue graduate studies; you were right.

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Chapter 1: Introduction to the Study

She recognized the tell-tale symptoms immediately. Having endured the recurrent cycle of wellness-sickness-recovery associated with her disease, she knew that high doses of antibiotics would again sustain her life with cystic fibrosis. Hoping to avoid the revolving door of emergency department visits that invariably result in a 2-hour trip to a children's hospital for admission, she asked her mother to contact the physician subspecialist to call in the prescription to a local pharmacy. After a day, the pharmacist informed the mother that a few days ago, her daughter aged out of the public health plan and that the antibiotics would not be dispensed until a new payer source was secured. It is Friday afternoon, near the close of business for health plans, and the mother is frantic to find a way to pay for the antibiotics. The mother and her daughter are "falling off" the health care transition "cliff" (Joly, 2015, p. 93).

I derived these composite characters in this "health care transition cliff" story from personal experiences and other stories shared by health plan administrators that demonstrate a lack of policy tools to improve health care transition for children with medical complexity. Children with medical complexity and low-income status are enrolled in Title V health plans at an early age and are case managed by nurses up until they age out of the health plans at 21 years of age (State of California, 2020). Title V programs for maternal and child health were enabled by the Social Security Act of 1935 and underpin a federal-state partnership aimed at improving the health of mothers, children, and adolescents nation-wide (Lu et al., 2015). In 2014, 3.2 million children with special health care needs were enrolled in state Title V programs (Lu et al., 2015). The

Bureau of Maternal and Child Health, the federal agency that oversees state Title V programs, promoted evidence informed health care transition strategies and listed health care transition planning as a block grant performance measure (Got Transition, n.d.). Surprisingly, there is a paucity of empirical studies that provide evidence of effective health care transition models that prevent abrupt disruption of medical care or health plan coverage as children leave their pediatric subspecialists for the adult model of medical care (Betz et al., 2015, p. 363; Joly, 2015, p. 101; Sawicki et al., 2017, p. 7).

Effective health care transition is a contemporary issue because transition efforts have not kept pace with the advances in modern medicine. In the past, children with medical complexity were not expected to live to adulthood. Advances in medicine have extended the life of children with medical complexity well into adulthood, creating a growing need to transition them from a pediatric sub-specialist-based model of care to adult-oriented health care services (McLaughlin et al., 2014).

Scholarship abounds on the problems associated with ineffective health care transition for children with medical complexity. Most prominent in the research literature are examinations of the consequences of suboptimal health care transition, which include interruptions in access to health care and the loss of functional gains attained through pediatric medical care (Inman et al., 2017). Moreover, a gap in health care transition research has been clarified: the need for a tested model and subsequent policy to establish effective health care transition for children with special health care needs, which broadly encompasses children with medical complexity (McManus et al., 2015).

I begin this chapter by defining the research problem I addressed in this study. The chapter also includes the purpose of the study; the research questions; the theoretical framework; the nature of the study; definitions of selected terms used in the lexicon of health care transition; and discussion of the assumptions, scope and delimitations, limitations, and the significance of the study. Additionally, this chapter provides context for the literature review in Chapter 2.

Background

Health care transition is an ordered series of actions and learned behaviors that are necessary for children to leave the paradigm of pediatric medical care and enter adult-oriented medical care (Chi, 2014; Sawicki et al., 2017). Learning to self-manage one's health care and self-advocate in contemporary complex health care systems is a challenge faced by an estimated 47.1 million U.S. adolescents entering the transition to adulthood (Aud et al., 2011, p. 6). Although most transitioning adolescents reported that their health status was excellent (Aud et al., 2011, p. 24), children with special health care needs face significant challenges in learning and implementing processes that maintain the continuity of medical care while moving from pediatric to adult medical care (Sawicki et al., 2017). Children with medical complexity are a subgroup of children with special health care needs, and the terms are often used interchangeably when addressing broad topics like health care transition (Cohen et al., 2018).

Former Surgeon General C. Everett Koop introduced the challenge of health care transition for children with special health care needs on a national level at the 1989 Surgeon General's Conference (Rollins, 2014). As a pediatric surgeon, Surgeon General

Koop had a career of patient encounters to draw from, coupled with the growing trend of children with chronic conditions living past their expected mortality and into adulthood (Rollins, 2014). His focus for the national agenda was two-fold: define the issue of health care transition broadly, and specifically identify challenges for youth with disabilities (Rollins, 2014). More than 30 years later, researchers continue to define the issue of health care transition and identify challenges of transition for chronic disease cohorts. In 2011 the American Academy of Pediatrics formally addressed the issue of health care transition with its historically significant consensus statement.

According to the American Academy of Pediatrics, children with special health care needs (which includes children with medical complexity) are living longer due to advances in medicine and improved access to health care services (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011). In collaboration with other physician-based groups, the American Academy of Pediatrics identified two tenets of effective health care transition: (a) health care transition planning is based at the medical home, and (b) health care transition planning starts at 14 years of age (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011).

According to the U.S. Department of Health and Human Services (n.d.), the Maternal and Child Health Bureau defined children with special health care needs as children and youth who “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally" (para. 1). In 2016, a goal of the Maternal & Child Health Bureau for the 4.3 million children with special health care needs is an effective transition to adulthood, including adult health care (Steinway et al., 2017). Taken together, this large population of children with special health care needs use more health care services than normal children and inadequate health care transition to adult health care could perpetuate the trends.

An estimated 20% to 41% of children with special health care needs successfully transition from pediatric to adult medical services each year (Chi, 2014; Lin et al., 2015). Yet, in a national survey conducted in 2016, 86% of children with special health care needs reported that they did not receive adequate transition planning services from their medical providers or health plans (Lebrun-Harris et al., 2018). Ineffective health care transition causes interruptions in access to specialized medical care for children with special health care needs, which degrades their health and prior disability-mitigating achievements (Sawicki et al., 2017; Steinway et al., 2017). The ineffective health care transition is especially impactful on minorities and low-income families with children with special health care needs (Sawicki et al., 2017).

In California, low-income families and their children with qualifying medical complexity (a subset of children with special health care needs) are case managed and financed by Medicaid Title V programs. Health care transition planning for adolescents aging out of California's Title V programs varies in California's 58 counties relative to the program's fiscal environment, caseload, and resources (State of California, 2015, p. 4). Although transition planning for California's Title V program adolescents is an annual reportable performance measure for federal Title V Maternal and Child Health funds, the California Department of Health Care Services merely offers county programs guidelines and boiler-plate form letters, in lieu of a substantive and evidence-informed health policy (UCLA Center for Health Policy Research, 2012). The guidelines and letters were not effective for 71% of families who responded to the California Children's Services Family Title V Needs Assessment Survey (UCLA Center for Health Policy Research, 2012). Improving the transition planning health policy for youths aging out of California's Title V programs would mitigate challenges to their continuity of medical care and quality of life.

Studies show that implementing effective health care transition policy for children with special health care needs is becoming more important as medical knowledge, technology, and treatments are helping children with special health care needs to live longer (Betz et al., 2015; Fernandes et al., 2014; McManus et al., 2015). However, limited evidence is available to inform effective health care transition policy (see Betz et al., 2015; Lin et al., 2015; Sawicki et al., 2017; Steinway et al., 2017). Ultimately, new policies informed by evidence are needed to mitigate an ineffective health care transition environment.

Public policy is defined as "what government does in order to meet the needs of the citizenry" (Anyebe, 2018, p. 1). Simon (2017) added to the definition by pointing out that public policy is also what the government "ought not" (p. 3) do. Smith and Larimer (2018) claimed that defining public policy precisely is allusive because many disciplines and fields of study that engage public policy make definitions from different perspectives. The working definition of public policy, which I crafted from other definitions, that I will use in this study is as follows: Public policy is the end product, created through the synergy of ideas between politicians, bureaucrats, and stakeholders, that mitigates a problem or need.

Health policy is a subset of public policy that concentrates on achieving specific health goals for a community or society (Ghaffar et al., 2016). Linking research to health policy development is a new field of study (Koon et al., 2016), and the basis for this study. This study provided an opportunity to explore the empirical development of a health care transition model for informing effective health care transition policy.

In summary, children with medical complexity enrolled in California's Title V programs are vulnerable to delays, or stoppages, in medical care and health insurance coverage during the transition from pediatric to adult medical care. The gap in scholarship suggests that using research to inform effective health policy is needed (Davis et al., 2014). In this study, I explored a health care transition model (hereinafter called the primary research) for evidence to inform new health care transition policy.

Problem Statement

As more children living with medical complexity reach adulthood because of advancements in medicine, effective health care transition policy is increasingly relevant for the continuity of disease management and maintenance of health insurance (Inman et al., 2017; Sawicki et al., 2017; Steinway et al., 2017). Effective health care transition policy is informed by evidence or based on tested models (Ferris et al., 2015, p. 36). Scholarship suggested that little and limited evidence is available to develop effective health care transition policy (Betz et al., 2015; Sawicki et al., 2017; Steinway et al., 2017). I sought to address the gap in the existing health care transition literature by analyzing and translating health care transition research to inform new health care transition policy for Title V programs in California.

Policymaking based on or informed by research evidence is an emerging field of study spanning several decades (Head, 2015). However, emotive and political factors challenge the uptake or translation of research evidence into policy (Ogbe et al., 2018). Engagement by stakeholders, researchers, and policymakers is key to overcoming these challenges in policymaking (Tomayko et al., 2019). The problem with developing effective health care transition policy is twofold: Research evidence is scarce and translating research evidence into policy is challenging.

Purpose of the Study

The purpose of this study was to address the knowledge gap in the current health care transition scholarship by examining and translating health care transition research. Specifically, I sought to explain the presumed links between empirical research and policymaking using an explanatory single-case study approach. The case was a 3-year applied research project conducted by a California county Title V program for children with medical complexity. This inquiry may provide insight to inform new health care transition policy for California's Title V programs for children with medical complexity.

Research Questions and Propositions

This study had a central research question and two related subquestions. The central research question served to guide this study whereas the subquestions mitigated the potential for research question proliferation and provided “clarity and specificity” (Miles et al., 2020, p. 24) for the inquiry. I added research propositions to focus this study’s inquiry (see Yin, 2018, p. 23) and to link the study’s data analysis back to the research question and subquestions (see Yin, 2018, p. 28). The research propositions are listed in Table 1.

Table 1

Research Propositions

Proposition	Source
Health care transition planning for children with medical complexity is more effective with participatory development from the stakeholders.	Ferris et al. (2015); Schlucter et al. (2015)
Stakeholder engagement is important for the diffusing of research evidence to inform policymaking.	Cairney & Oliver (2017); Shlonsky & Mildon (2014)
The agenda setting and policy formation stages of the policy process model provide the initial framework for policymaking and analysis.	Dodd et al. (2019); Doshmangir et al. (2019); Hillman et al. (2015); Simon (2017, pp. 106, 111)

The central research question for this study was, How can examining and translating health care transition research provide insight to inform new health care transition policy for children with medical complexity that are enrolled in California’s Title V programs? The two related subquestions, which were incorporated into a case study protocol that is fully introduced in Chapter 3, were as follows:

1. What are the perceived factors for effective health care transition policy?

2. What is the relationship, if any, between health care transition research and health care transition policymaking?

Theoretical Framework

The obscurity of information in scholarship on the use of theoretical and conceptual frameworks (Green, 2014) necessitates a formal and detailed explanation of the theoretical framework used in this study. The theoretical framework served a distinct purpose for this study. The theoretical frame provided a representation of how the analysis of the primary research was conducted from the perspectives of policymaking. The theoretical framework guided the examination of the primary research by focusing on the two phenomena central to effective health care transition planning and policymaking: stakeholder engagement in the process and the translation of research evidence into policy and practice. This general relationship between the phenomena supported the selection of the policy process model for the theoretical framework used in this study. Additionally, the policy process model was used as framework for other health policy-related studies: An evaluation of a health care transformation plan by Doshmangir et al. (2019), and a systematic review of evidence diffusion that informed health care policy by Dodd et al. (2019). Other policymaking theories were considered, and their exclusion from this study is detailed in Chapter 2.

The policy process model is a traditional theory of policymaking (Simon, 2017, p. 49). The policy process model is descriptive in its linear approach to the policymaking process by delineating sequential process stages, which scholars considered an attribute for organizing a policy analysis and applying heuristics to the inquiry (Kulac & Özgür, 2017; Smith & Larimer, 2018). In its contemporary iteration, the policy process model has five stages: Agenda setting, policy formulation, policy legitimation, policy implementation, and policy evaluation (Kulac & Özgür, 2017). Each stage of the policy process model represents the sequencing of necessary events that complete a policymaking cycle. It is the action, or inaction, provided by the engagement of various actors within each stage of the policy process model that enables a crosswalk from research to policymaking, which was the intent of this study. The policy process model's simple framework is its best attribute.

According to Hillman et al., the stages in the policy process model are appropriate for aligning research questions to the policymaking process, where misalignment impedes the articulation of research findings into policy (2015, pp. 68-69). For this study, the analysis of the primary research components adopted a policymaking taxonomy to better align the research questions to a stage in the policy process model. However, not all stages of the policy process model were appropriate for this study.

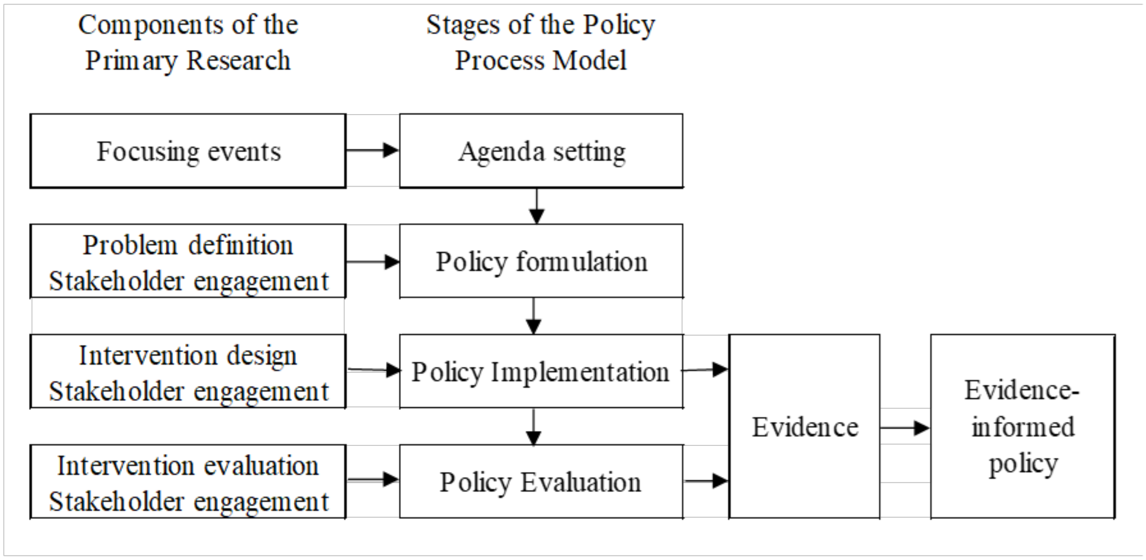
Only four of the five contemporary stages of the policy process model are included in this study's theoretical framework. The legitimation stage of the policy process model is highly occupied by political activity and public engagement (Kulac & Özgür, 2017, p. 147), which were absent in the primary research. For this study, the primary research under examination did not reach the legitimation stage or complete the policymaking process and therefore, is not included in the theoretical framework.

Some scholars do not consider the policy process model as a theory because it does not explain causality and lacks falsifiability (Smith & Larimer, 2018). However, the policy process model exhibits several policy theory characteristics, according to McCool's elements of good theory (as cited in Smith & Larimer, 2018, p. 30), which made its use appropriate for this study.

I developed a conceptual model (see Figure 1) that illustrates the relationship between the analysis of the primary research and the theoretical framework to further explain how the policy process model was used in this study.

Figure 1

Conceptual Model



Note. I applied the policy process model as the theoretical framework based on the discussion of "preferred bins" and "relationship arrows" by Miles et al. (2020, p. 22).

A more detailed explanation of how the policy process model was used to frame the analysis of the primary research and the translation of evidence to inform health care transition policy is provided in Chapter 2.

Nature of the Study

The nature of this study was explanatory single-case, within-case, case study research. A case study is an “empirical method that investigates a contemporary phenomenon in depth and within its real-world context” (Yin, 2018, p. 15). Yin suggested that case study research is appropriate when “how” and “why” questions are asked about a contemporary event where the researcher “cannot manipulate” the “relevant behaviors” (2018, pp. 12-13). This study aimed to explain how and why previously conducted primary research can inform new health policy, which was the contemporary event that cannot be manipulated. This study was explanatory because how and why research questions sought to explain the linkages between a program’s implementation, which was the outcome of the primary research, with the program effects, which may inform new health policy. Additionally, this explanatory single case study research is categorically a Type 2 design (Yin, 2018, p. 48) because there were multiple embedded units of analysis represented by the theoretical framework’s stages of the policy process model.

The phenomena under analysis in this study was the similarity of stakeholder engagement in research and policymaking domains, and the potentiality of translating evidence from the primary research, which was the case, to inform new health care transition policy for children with medical complexity in California’s Title V programs. The primary research’s products provided the data for this study.

The evolution of case study methods has improved its use for researching complex issues, identifying causality, generalizing across disciplines, and providing evidence for policymaking (Harrison et al., 2017, p. 3). There are examples of case study research dating back to the early nineteenth century, and proliferation among anthropologists and social scientists in the early twentieth century (Harrison et al., 2017). Case study research was overshadowed for a decade with the rise of positivism and quantitative methods in the 1940s (Harrison et al., 2017). During the 1960s and 1970s, case studies were often relegated to a part of a larger experimental design because the research community was critical of its ability for generalizability and validity (Harrison et al., 2017). The suggested precursor for contemporary case study research is the work of anthropologists at the Chicago School of Sociology in the 1950s and the emergence of Glaser's and Strauss' grounded theory in the late 1960s (as cited in Harrison et al., 2017, p. 2). As a result, case study research became prominent in the social sciences (Harrison et al., 2017) and appropriate for the policymaking environment.

Some case study methodology was underpinned by constructivism and interpretivism philosophical orientations when there was interaction between the researcher and study subjects (Harrison et al., 2017, p.6) however, Yin's case study design was aligned with a postpositivist approach where the inquiry seeks to generalize findings through objectivity and the use of multiple methods of data collection and analysis (as cited in Harrison et al. 2017, p. 7). This study's focus was to explain how the primary research's evidence may inform new health care transition policy and the implications for generalization across California counties; therefore, Yin's case study design and the postpositivist approach were adopted.

In this case study, I examined 27 documents in a within-case analysis of document content. The documents represented primary research, which was considered the case under study. The documents were various reports that chronicled the primary research from its inception to conclusion, spanning three years. Additionally, the reports provided analyses of qualitative data, statistical analyses of quantitative data, summaries of participant observations, and implication to inform health care transition policy.

Definitions

California Title V program: California's participation in a federal block grant program for health promotion and health care financing for mothers and children, specifically children with special care needs from low-income families (Health Resources & Services Administration, n.d.). California Title V programs are locally administered by county governments (California Department of Public Health, 2019).

Children with medical complexity: Children and adolescents with chronic medical conditions that cause functional deficits and increased use and cost of health care services that is greater than what is normal (Cohen et al., 2018). In California, children with medical complexity from low-income families are eligible for enrollment in California's Title V program, better known in California as California Children's Services (State of California, 2020).

Children with special health care needs: As defined by the U.S. Department of Health and Human Services (n.d., as cited in Cohen et al., 2018, p. 1), children and adolescents who have, or are at risk of having, a chronic physical, developmental, behavioral, or emotional condition that requires health care services or mental health services that are greater than what is normal. In the health care transition literature, the term “children with special health care needs” is exclusively used to describe the subjects of this research, who included the subset of children with medical complexity; I use the terms children with special health care needs and children with medical complexity interchangeably in Chapter 2.

Health care transition: Purposeful planning that is aimed at the seamless transfer of children with special health care needs from the pediatric model of care to the adult model of care, according to the American Academy of Pediatrics (Chi, 2014, p. 778).

Primary research: The original data collection and analysis from the intended research subjects (Oxford University Press, 2019). For this case study, *primary research* refers to the original data collection and analysis conducted by a California county Title V program where the intended research subjects were a sample set of adolescents enrolled in the program, and their parents.

Stakeholder: Individuals, groups, or organizations that participate in, influence, or are affected by the policymaking process while claiming the policymaking entity’s resources or outputs (Quick & Bryson, 2016, p. 158).

Assumptions

Stakeholder engagement, in the context of the public policy environment, was a guiding principle for this study to explore and explain how health care transition primary research informs new health policy (Cairney & Oliver, 2017; Shlonsky & Mildon, 2014). Collaterally, stakeholder engagement is vital for developing effective health care transition planning models for children with medical complexity (Ferris et al., 2015;

Schlucter et al., 2015). Taken together, this study sought to explain how and why the primary research informed health policy through the lens of the policy process model where stakeholders were engaged in all stages (Dodd et al., 2019; Doshmangir et al., 2019).

The association between the health care transition primary research and informing new health care transition policy were not easily identified; this study, I assumed one existed. The phenomenon of translating empirical research to health policy was appropriate for the explanatory case study method because an in-depth analysis of the primary research may discover evidence needed to inform new health policy. Additionally, the case study method was appropriate because I used it to investigate how and why type research questions when the phenomenon was bound in time, frozen from further manipulation, and in its natural setting (Yin, 2018).

Scope and Delimitations

There is limited evidence supporting any effective health care transition model (Sawicki et al., 2017, p. 7). Therefore, the analysis of the primary research, which claimed to have developed a best practice model for health care transition, may provide the evidence to inform new health policy.

This study was bounded by the primary research that was conducted by a California Title V program for children with medical complexity in one California county. To date, no other California Title V program for children with medical complexity have conducted empirical research on health care transition planning. The primary research's sampling frame consisted of Title V program enrolled adolescents between the ages of 14 and 20 years, representing a variety of medical complexity diagnoses.

Limitations

Yin (2018) suggested that limitations in construct validity, internal validity, external validity, and reliability of a case study diminishes its quality or methodological rigor. Incorporating the following strategies in this case study offset limitations to methodological rigor: Integrating Yin's Case Study Protocol (2018, p. 93-104), using multiple sources of evidence towards triangulation in the analysis, and the application of a theoretical framework to "overcome existing self-boundaries of interpretation" in the analysis (Wrona & Gunnesch, 2016, p. 737).

The findings from this study should not be generalized beyond California's Title V programs because the primary research's quasi-experimental design used a small convenience sample and case study's limitations forestall generalizability. Yin (2018) posited that the case, in case study research, limits generalizability because the case is not a sampling unit as used in statistical generalization. However, this study is an opportunity to explain how the primary research informs new health policy where the process is transferable to homogeneous California Title V programs.

In summary, the potential for researcher bias is explicitly disclosed and addressed through the separation and distance from the organization that conducted the primary research, the bound case (primary research) that cannot be further manipulated, and a commitment to report positive and negative findings in this study.

Significance

In 2015, health care transition policy was ineffective for 71% of children with medical complexity enrolled in California's Title V program (UCLA Center for Health Policy Research, 2012). Research suggested that there is little and limited research evidence to inform new models for effective health care transition planning (Betz et al., 2015; Sawicki et al., 2017). The significance of this study was twofold: a) exploring the potential of using empirical health care transition research to develop a best practice model for health care transition planning and b) explaining how that process could inform new health care transition policy. The implications of this study included a contribution to health care transition research and evidence-informed policymaking.

The social impacts of this case study addressed individual and organizational levels. Social change on the individual level means better health, without healthcare interruptions, for children with medical complexity that age-out of California's Title V programs. On the organizational level, California's Title V programs may realize healthcare cost savings through the efficiencies of the continuity of medical care and seamless transition from one health plan to the next.

Summary

California Title V programs for children with medical complexity need to improve health care transition planning to mitigate disruptions in the continuity of medical care and health insurance coverage (Inman et al., 2017). Health care transition policy is more effective when informed by evidence derived from research (Davis et al., 2015). Identified in Chapter 1 were a research method and theoretical framework to support an inquiry that sought to translate primary research evidence to new health care transition policy for California Title V programs for children with medical complexity. Chapter 2 reviewed health care transition research and the public policy theories the were considered for this study.

Chapter 2: Literature Review

Introduction

In this study, I explored the potentiality of using evidence, identified from primary research, to inform effective health care transition policy. Specifically, this explanatory case study focused on effective health care transition policy for children with medical complexity and enrolled in California's Title V programs. In 2010, the effects of California's health care transition policy resulted in the state being ranked 45th in a national survey of children with special health care needs (U.S. Department of Health and Human Services, 2018, p. 29). In a 2014 California Title V needs assessment family survey, the majority of parents reported that more help with health care transition would be beneficial (UCLA Center for Health Policy Research, 2012). Taken together, these statistics reinforce that improving California's health care transition policy's effectiveness is appropriate and timely. Ineffective health care transition causes loss of disease management gains made under the supervision of pediatric sub-specialists and creates lapses in health insurance coverage, research shows (Inman et al., 2017; Sawicki et al., 2017; Steinway et al., 2017).

Contemporary health care transition researchers have called attention to the paucity of empirically derived evidence to inform effective health care transition policy (Betz et al., 2015; Sawicki et al., 2017; Steinway et al., 2017). Moreover, few health care transition best practices have been "translated into policies" (Ferris et al., 2015, p. 34). The future of health care transition research is in evidence-based health care transition plan development (Ferris et al., 2015, p. 32). In this case study, I considered the future of health care transition planning by focusing on the potentiality of translating research evidence to inform new health care transition policy in the context of the policy process model.

The development of effective health care transition policy is outpaced by the advances in modern medicine that have extended the longevity of children with chronic disease (Castillo & Kitsos, 2017). The ineffective transition from the pediatric to the adult model of health care often results in significant gaps of services like medical care and health insurance coverage (Joly, 2015), or the "care gap" as summarized by Aldiss et al. (2015, p. 639). An effective health care transition model has been challenging to implement as researchers and policymakers have limited evidence to underpin health care transition interventions (Sawicki et al., 2017). Many studies are focused on a need to improve health care transition (Aldiss et al., 2015) where gaps in the research support a call for addressing how to better prepare children and their parents for the inevitable transition from the pediatric to the adult model of health care (Betz et al., 2015).

Challenges in health care transition research point to a clinical research focus on specific chronic diseases that precludes extrapolating study findings to heterogeneous populations (Beale et al., 2016; Squires et al., 2017). Additionally, emerging in the health care transition research is the recognition that effective health care transition policy needs stakeholder engagement to address the multisystemic environment of health care transition (Pierce et al., 2017). Overcoming challenges in health care transition policymaking may include strategies from an emerging field of study where research is used to inform new health policy (Koon et al., 2016).

In this chapter, I presented the rationale for selecting the policy process model as a guiding framework for this study and review other policymaking theories that were considered. This section of the chapter closes with a selection of studies on the relationship between research and policymaking. Also presented in this chapter, I provided an overview of the health care transition scholarship concerning the scope of current efforts to improve health care transition planning, the assessment tools used to measure the readiness for health care transition, and research specific to disciplines and disease categories.

The health care transition literature features the use of demographical terms to describe a broad spectrum of medical, behavioral, and social conditions that cause high utilization of medical, behavioral, and social services: children with special health care needs or adolescents with special health care needs. It is important to clarify that this study was focused on children with medical complexity, which is a subset of children with special health care needs. I found few studies in the literature search that made the distinction between children with special health care needs and children with medical complexity because the term *children with medical complexity* is an emerging subcategory in the literature used to emphasize chronic medical conditions that are high users of health care resources (Cohen et al., 2018).

Literature Search Strategy

To locate literature for the review, I conducted internet searches for peer-reviewed journal articles, government websites, and books on policy analysis authored by academics. Initially, I queried the PsycINFO, MEDLINE, and EBSCO’s Academic

Search Complete, Child Development and Adolescent Studies, and CINAHL Plus databases because, according to Nehring et al. (2015), published scholarship on the topic is predominately listed in these databases. After reviewing several peer-reviewed journal articles on the topic, the database query was expanded to include other named fields of study on the topic. A secondary query conducted through Academic Search Complete and CINAHL Plus yielded additional results. The key terms used in the database query were *health care transition*, *health care transition policy*, *children with special health care needs*, *children with medical complexity*, and *transfer of care*. Overwhelmingly, and with few exceptions, the disciplines of pediatric medicine, nursing, adolescent medicine, community health, and maternal and child health provided a majority of the scholarship for this study. The exceptions included the disciplines of education and psychology. I selected the health care transition scholarship used in this literature review from numerous peer-reviewed journal articles, which were mostly published within the last 5 years. Government website searches established the context for California's Title V programs and term definitions made by its controlling federal agency, the U.S. Department of Health and Human Services.

In selecting a theoretical framework for this study, I performed a database search of EBSCO's Academic Search Complete, using the search terms *policy theory*, *policymaking theory*, *public policymaking process*, *evidence-based policy*, and *evidence-informed policy*. A majority of the reviewed and selected peer-reviewed journal articles referenced policy analysis books authored by academics. I accessed relevant material from these books through various bookstores.

Theoretical Foundation

Public policy is defined as “what government does in order to meet the needs of the citizenry” (Anyebe, 2018, p. 1). Simon (2017) added to the definition by pointing out that public policy is also what government “ought not” (p. 3) do. Smith and Larimer (2018) claimed that defining public policy precisely is allusive because many disciplines and fields of study that engage public policy make definitions from different perspectives. Ultimately, a working definition of public policy, crafted from all other definitions, was needed here: Public policy is the end product, created through the synergy of ideas between politicians, bureaucrats, and stakeholders, that mitigates a problem or need. Health policy is a subset of public policy that is concentrated on achieving specific health goals for a community or society (Ghaffar et al., 2016).

In this section, I identify the policymaking theory that underpinned this study and explore the alternative policymaking theories that were considered, but not selected. Then, I provide a review of policymaking literature focused on linking research to policymaking. This section ends with a scholarly explanation for the transition in evidence-based to evidence-informed terminology in the policymaking literature.

Policy Process Model

Simon (2017) reminded readers that the “very traditional” (p. 49) policy process model is widely known in the public policy community and for most, easily remembered. The policy process model’s stages of policymaking demarcate dimensions, which in turn create boundaries for efficient policymaking and analysis. However, Simon also suggested that “cutting edge” (p. 33) empirical policy theories go beyond the general and simple policy process model by inclusion of variations found in contemporary policymakers and policy environments. Whether traditional or cutting-edge, contemporary policymakers and policy environments strive for scientific methods and evidence to undergird policy (Simon, 2017).

In a monograph focused on linking research in higher education with policymaking, Hillman et al. (2015) described how the heuristic attributes of the policy process model are a means for organizing ideas about the policymaking process. Additionally, Hillman et al. (2015) supported a traditionalist's approach to linking research with policymaking within the policy process framework, only when policymakers are rational; the reciprocal situation requires additional strategies because the process becomes non-linear or politically-based. The linear approach of the policy process model, when linked with academic research in higher education, can isolate politically-based policymaking in favor of evidence-based policy making (Hillman et al., 2015).

Other public policy process theories were reviewed and rejected for this study based on their applicability and complexity. For this study, my objective was to explore for a link between research and evidence-informed policymaking where the policymakers and institutions are unknown variables. Later, in a real-time public policymaking process, when these unknown variables are identified, a more applicable and complex public policy theory may be substituted for the simple and linear policy process model. Wilder (2017) conducted a comparative analysis and defined four public policy theories that are most prevalent in contemporary scholarship and were designed to replace the policy process model: advocacy coalition framework, institutional analysis and development framework, punctuated equilibrium theory, and the multiple streams approach.

The advocacy coalition framework is made highly sophisticated by using technical information in a flow through political, economic, and social subsystems (Simon, 2017; Wilder 2017). Crafting policy in each of the subsystems tends to be from technical experts that aim to influence political actors while working outside policy institutions (Simon, 2017). The primary research, used as data for this study, was conducted by the institution that was seeking to provide evidence to inform health policy on themselves and therefore the advocacy coalition framework was not applicable.

The premise of the institution analysis and development framework is grounded by the problems associated with "distant government" inaction requiring action by a local government (Simon, 2017, p. 34). Based on game theory, the institutional analysis and development framework uses a complex system of rules that government intuitions must follow to play the policymaking game (Wilder, 2017). Albeit the primary research, used as data for this study, sought to develop a best practice model for subsequent policymaking from a local institution for a distant government, the complexity of the game theory-grounded rules was not considered in the design of the primary research and therefore this framework was rejected as a theoretical framework for this study.

The punctuated equilibrium theory aims to identify changes in public policy by monitoring policy budgets (Simon, 2017). Although perfectly apt for monitoring changes in comparative studies of government and multi-government policies, the punctuated equilibrium theory does not identify the "friction" within a government or governments that caused the “punctuated pattern” or change (Wilder, 2017, p. 53). Punctuated equilibrium theory addresses change but does not address the actions leading to change and therefore is not an appropriate theory for this study that sought to explore if policy may be derived from research.

John Kingdon introduced ambiguity to the policymaking process by positing that there are multiple legitimate perspectives when interpreting problems and solutions in the public policy arena (Simon, 2017); or that policymaking is “organized anarchy” (Wilder, 2017, p. 52). Seeking to explain the non-linear and multi-structured approach to policymaking, Kingdon developed the multiple streams approach (Simon, 2017). The multiple streams approach channels policymaking and policy analysis into three streams: politics, policies, and problems (Wilder, 2017). The three streams provided enough ambiguity in the policymaking process that policymakers could relate a stream to their own policy environment variations; relatable situations to Kingdon’s streams became anecdotes for agreement (Simon, 2017). However, according to Kingdon, ambiguity must not be part of defining or prioritizing a problem (Simon, 2017, p. 39) as this is likely the strongest, and some may say headwaters, of the multiple streams for policymaking. The ambiguity of the political and policy streams caused this theory to be rejected for this study because the research and subsequent policymaking are apolitical and policy needs are straightforward and linear-without ambiguity. Scholarly research supported the initial use of the policy process model followed with the application of a more complex and synthesizing theory.

Clarke et al. (2016) performed a systematic review of political science scholarship to identify obesity prevention policy evaluation underpinned by theories of the policymaking process. The systematic review identified 17 studies that linked the development of obesity prevention policy to a policymaking process theory where all but one study used the policy process model, whole or in part (Clarke et al., 2016). Thirteen studies supplemented the linear policy process model with synthesis theories (e.g., advocacy coalition framework, multiple streams theory, and punctuated equilibrium theory), which the authors' claimed are superior to non-synthesis theories for explaining the complexity of policy decisions (Clarke et al., 2016, p. 1087). The use of evidence in policy formulation and adoption emerged as an important influencer in the systematic review (Clarke et al., 2016).

I found that evidence was imperative for underscoring the need for action and the effectiveness of alternative policy instruments (Clarke et al., 2016). Evidence of the obesity prevention policy's effectiveness provided a foundation for policy decisions however, one included study favored professional judgement or political ideology over evidence (Clarke et al., 2016). The systematic review suggested that the policy process model, on its own merit, lacks the sophistication needed to evaluate the complexities of the policymaking process and should be supplemented with an approach that constructs another dimension in the evaluation; the use of evidence is further explored in this section of the literature review. However, two studies found in scholarship support the theoretical framework for this study.

Doshmangir et al. (2019) used the policy process model to frame a qualitative analysis of a healthcare transformation plan. Their findings were categorized and then assigned to a stage in the policy process model. The stages of the policy process model provided structure and boundaries for in-depth exploration focusing on problem identification, agenda setting, policy formation and adoption, as well as policy implementation and evaluation (Doshmangir et al., 2019, p. 3). The in-depth analysis sought policy formation through an evidence-informed process where the author's claim that "evidence builds sustainability into initiatives" (Doshmangir et al., 2019, p. 5). Using the policy process model as framework for a qualitative analysis of an existing healthcare transformation plan (the primary research) was replicated here in a similar fashion for this study.

In a second study, Dodd et al. (2019) used the policy process model to establish phases of evidence diffusion that informed health policy. The systematic review analyzed 24 peer-reviewed journal articles, mostly case studies that focused on linking research to the development of health policy in South Asian, African, and South American countries (Dodd et al., 2019). The review suggested that policymakers and legislatures are more likely to enact health policy when the research included local data, real-life scenarios, and supported global trends (Dodd et al., 2019). The authors clarified that the policy process model was considered simplistic in contemporary policy analysis research. However, it did provide a linear flow with phases to frame their analysis (Dodd et al., 2019, p. 470). The identification of evidence in research using the policy process model framework was replicated here in this study. Moreover, the analysis of the primary research was local data and real-life scenarios; and was supported by a universal advocacy for the improvement of health care transition.

Linking Research to Policymaking

Pressure from the public and economic environment for more effective and efficient public service delivery caused policymakers to seek evidence from the development and outcomes of public policy. Finding evidence to ground public policy improved the perception of legitimacy and thought to increase the public’s trust (Head, 2015).

Ogbe et al. (2018) conducted interactive workshops using subject matter experts to evaluate three case studies that linked applied research to policy development. The study’s impetus was the paradox that policy formulation and implementation are not always based on empirical evidence, and that research provides evidence needed in formulating and implementing effective policies. Tantamount to the study was an emphasis on the importance of collaboration between the researchers, stakeholders, and policymakers in the agenda setting stage of the policy process model. The collaborative importance increased when stakeholders were from the low-income context (Ogbe et al., 2018). The findings of the case study evaluations suggested that engagement of stakeholders during the research phase increased the likelihood that research evidence would be included in subsequent policy implementation (Ogbe, et al., 2018).

Tomayko et al. (2019) developed a six-step model to address the research-to-policy paradox that Ogbe et al. (2018) identified in their research. Working under a similar premise, Tomayko et al. (2019) sought to close a communication gap between researchers and policymakers by developing a model to facilitate the transfer of research evidence to policymaking. Tomayko et al. (2019) found that organizational differences (structure, culture, purpose, and operations) between researchers and policymakers created a “community dissonance” that impeded the transfer of research evidence into policy making (p. 734). With an aim to improve communication and eliminate community dissonance, a six-step model created a venue for researchers and legislators to synthesize the agenda setting and policy formulation stages on their own terms and paradigms (Tomayko et al., 2019).

Peterson (2018) fully confronted the challenge of the acceptance of research evidence in policymaking by focusing on political factors at every stage of the policy process model. While creating paradigms for how research is produced and how research is consumed, Peterson (2018) defined research evidence as having an element of something observed or experienced in its production (p. 343) and having less objectivity to “assuage political concerns” in its consumption (p. 346). However, Peterson (2018) does examine environments when political factors have diminished dominance; when substantive learning resulted from evidence production and when technocratic leadership readily consumed evidence for policymaking. Although Peterson (2018) is not explicit, his research suggested that the level of political factor dominance in consuming research evidence for policymaking is contingent on the level of government. Peterson (2018) concluded that research evidence has a positive benefit in policymaking under the right circumstances.

In an opinion piece, Cairney and Oliver (2017) explored a perceived divide between researchers and policymakers. When comparing the close relationship between clinical researchers and practitioners using the evidence-based medicine approach with researchers and policymakers using the evidence-based policymaking approach, Cairney and Oliver (2017) found that policymakers were constrained by bounded rationality and a scientific knowledge deficit when interpreting or applying evidence provided by the researcher. In comparison, when clinical researchers and practitioners share a field of study, a shared base-knowledge for evidence interpretation and application exists. On the other hand, policymakers are limited by a scientific knowledge deficit where researchers must adopt an approach to fill the knowledge gap caused by unfamiliarity with the researcher's branch of knowledge.

Cairney and Oliver (2017) suggested three models that researchers use to diffuse evidence into the policymaking process: a) patrician model where the researcher dominates the process, b) advocacy model where the researcher persuades the policymaker, and c) facilitational model where the researchers and stakeholders work together in process (p. 4). The primary research that provided data for this study used the facilitational model by including stakeholders in the research process.

The analysis of research for the purpose of developing health policy is a new field of study (Koon et al., 2016). Health policy and systems research seek to connect policymakers, bureaucrats, and researchers in a common goal of solving health systems' problems (Koon et al., 2016). In a scoping review, Koon et al. (2016) analyzed 52 studies for frameworks that influenced health policy. Frames were defined as "a central organizing idea," or "a package of ideas" (Koon et al., 2016, p. 803), which is a simplification of theoretical and conceptual frameworks. Of the 52 studies analyzed, 94% effected the policymaking process and 40% of the studies used either a case study or content analysis approach for document reviews to explain how research translated to health policy. The authors concluded that research and analysis grounded in an ideational approach increases the use of frames in methodology, especially in the evidence-based literature.

In contemporary hospital operations, improving outcomes for transitional care (hospital to home) through evidence-based interventions are gaining popularity and decreasing hospital readmission rates (Rouse et al., 2019). A transitional care model was developed and tested using a person-centered perspective for high-risk older adults that were post-hospital care and returning home (Rouse et al., 2019). The underpinning concept of the evidence-based interventions used in the transitional care model is facilitating self-manage skills (Rouse et al., 2019).

The transitional care research and evidence later identified from the research were used to frame a new health policy that was sanctioned by a nonprofit advisory group, the Coalition for Evidence-Based Policy (Rouse et al., 2019). The similarities in method, concept, and output, in the development of the transitional care model to health policy, support the method, concept, and output, of this study.

Horne (2017) studied evidence-based best practices in social services from the perspective of social service program funders and their use of evidence-based program registries that identify best practices for replication. Evidence-based program registries were established to provide government and private funders with program evaluations of evidence-based practices (Horne, 2017). The content analysis of program evaluations (*N* = 55) was narrowly focused on youth development programs using a rubric that ranged from the absence of variable descriptions in the program evaluation to the best rating that included an empirically supported causal relationship (Horne, 2017). Horne (2017) concluded that the evidence-based program registries provided technically adequate program evaluations but lacked in providing the optimal context for implementing the evidence-based best practice: environment, agency, and type of personnel.

This study explored a primary research project conducted in the context of a California county with an aim to inform new state health policy. The primary research's goal was to develop a best practice model that could be generalized to the other California counties; the context issue identified by Horne (2017) was not present here.

Evidence-Based to Evidence-Informed Policymaking

The origins of evidence-based policymaking rests with the development of evidence-based medicine. Evidence-based medicine used the top tier of the scientific methods hierarchy, which included the determination of evidence through randomized control trials and replicated testing to generalize findings (Cairney, 2017). Absent from the development of evidence-based medicine was the challenges evidence-based policymakers face with the availability of resources, the availability of time, and sampling frames robust enough for randomization (Cairney, 2017). Additionally, evidence-based policymakers have a confounding variable to consider; the influence of political ideals (Cairney, 2017).

Cairney (2017) identified specific characteristics that diminish the scientific rigor of evidence-based policymaking: A range of influencing actors, rules from different venues, relationships between policymakers and powerful actors, beliefs that dominate the policy discussion, and conditions or events that usurp time in the policy environment (p. 5). Although Cairney (2017) focused on the challenges with evidence-based policymaking compared to evidence-based medicine, he concluded that using evidence in policymaking is pragmatism over idealism and is worth pursuing.

Sheingold and Bir (2020) suggested two domains for evidence-based analysis: Process evaluation and summative evaluation. The process evaluation focuses on the engagement, content, and procedures used to implement an intervention (Sheingold & Bir, 2020, p. 12). The summative evaluation investigates the outcome of the implemented intervention and the impact on the program under analysis (Sheingold & Bir, 2020, p. 13). Aligned with Sheingold & Bir's (2020) domains for evidence-based analysis are two overarching research questions:

1. Did the target outcomes for the program improve, for whom did thy improve, and under what circumstances? and;
2. Can the findings demonstrate in a scientific credible manner that the program, as opposed to other environmental factors, contributed significantly to the observed improvement? (p. 4).

The scholarship provided by Sheingold and Bir (2020) is the foundation for the research questions of this study.

Shlonsky and Mildon (2014) traced the origins of evidence-informed policymaking to the application of the evidence-based medicine principles to educational contexts in social services. Social services research often included stakeholder engagement through interviews and observational studies bounded by the environment under study, which produces qualitative data not recognized as a top-tier scientific methodology by evidence-based practitioners (Shlonsky & Mildon, 2014). Additionally, the scarcity of top-tier scientific evidence caused stakeholders to evaluate evidence from the perspective of how local policy decisions were made, and therefore limited the generalizability of the evidence (Shlonsky & Mildon, 2014). The shift from evidence-based to evidence-informed policymaking is most prevalent in social services research. Other primary factors that differentiate evidence-based and evidence-informed policymaking were explored further in this review of the literature.

Head (2015) reviewed the literature for policy research that used evidence as a factor in policy evaluation, development, and advice. Head (2015) found a developmental transition from evidence-based policymaking to evidence-informed policymaking based on novel assumptions that policymakers have not maintained the rigors of scientific inquiry but relied on the “best available evidence” and that “political interpretations of evidence” are a significant and unavoidable factor in policymaking (p. 473). These assumptions explained why, in some instances, scholarship has moved from using evidence-based to evidence-informed terminology when describing the use of evidence in the development and evaluation of public policy in the social services and health domains.

Evidence-based policymaking is grounded in randomized control studies that are replicated, holding to the tenets of its origins in evidence-based medicine. Evidence-informed policymaking is quasi-experimental where convenience sampling often replaces randomization, and generalizability is decreased because the best available evidence may be from a unique population constrained by geography, environment, politics, and public service eligibility requirements. Political priorities and competition were additional factors in the shift from evidence-based to evidence-informed policymaking terminology.

La Brooy and Kelaher (2017), using a multi-case study approach, further explained the shift of terminology from evidence-based to evidence-informed policymaking. While focusing on the decision-making process of policy implementation, La Brooy and Kelaher (2017) found that differences in evidence identification in the research process caused the shift. For example, evidence-based policymaking emphasized outcome-based evidence where evidence-informed policymaking emphasized process-based evidence; a formative-summative paradox. Process-based evidence interpretation included the political factors of decision-making, especially when there are competing political priorities or competing research evidence (La Brooy & Kelaher, 2017).

The transition from evidence-based to evidence-informed policymaking terminology was significant to this study because the primary research used a quasi-experimental research design and the best available evidence to develop a health care transition best practice for children with medical complexity. Additionally, the primary research used an advocacy model to guide the relationships of the researcher, stakeholders, and policymakers, as well as the inclusion of qualitative data bounded by time and a local research environment. Taken together, these conditions, sans a political factor, are indicative of evidence-informed policymaking.

Literature Review

Health Care Transition Research

The signs and symptoms, or what is observed and what is passed on, of ineffective health care transition for children with special health care needs are acknowledged by practitioners of medicine, the administrators of service systems, and the parents and youth themselves. The literature was rich in pointing out the issues and challenges for health care transition. In a query of scholarship and grey literature, Davis et al. (2014) sought to identify effective health care transition programs that were grounded in research.

Davis et al. (2014) used key informants to refine their research questions, controlled vocabulary terms and words to search peer-reviewed literature and limited their search to evaluative studies focused on transition programs for children with special health care needs from the years 2000 to 2013. The query identified 699 studies where 25 were evaluation studies. The finds by Davis et al. (2014) were repeated in all subsequent reviews of scholarship pertaining to health care transition for children with special health care needs: a) more empirical research is needed, and b) the establishment of research goals and outcome measurements are key contributors to the body of literature.

The literature review by Davis et al. (2014) suggested a need for more substantive and methodologically rigorous research for how to provide health care transition; only 2 studies were considered randomized control studies. Additionally, the researchers found that health care transition studies tended to be restricted to specific chronic diseases where diabetes is the most studied. The generalizability of health care transition research across a broad spectrum of childhood diseases could prove challenging for future researchers.

Joly (2015) conducted an integrative literature review with broad key terms used to describe health care transition for adolescents with complex and chronic medical conditions, which exemplified the vernacular of contemporary pediatric sub-specialists treating medical complexity. The selection of search terms narrowed the field of children with special health care needs to those with chronic medical conditions and comorbidities, excluding those with only behavioral or mental problems. Joly focused on a subset (medical complexity) of children with special health care needs closely represents the eligibility criteria for California’s Title V programs for children with medical complexity and therefore provides this study with some congruence with her work.

Joly (2015) used Meleis’ transitions theory and Bronfenbrenner’s ecological systems theory of development to inform her review. Transitions theory provided focus on the organizational and service delivery aspect of health care transition where ecological systems theory provided focus on the individual’s development and social interactions associated with effective health care transition (Joly, 2015). Taken together, Joly’s integrative literature review was framed in the context of aligning healthcare provider practices and adolescent development. Of the 594 studies found in the initial query, 11 studies (ten qualitative and one quantitative) were selected for analysis because they limited the study subjects to children with medical complexity, and were not literature reviews, theoretical in nature, or expert opinion pieces.

Joly (2015) found three predominant themes in her integrated literature review: a) health care transition is characterized by the transitioning adolescents and their parents as “It’s like falling off a cliff!” (p. 93), b) self-management and self-advocacy skills needed by the transitioning adolescents produced a paradox of independence (p. 97), and c) the guidance and support needed for effective health care transition of children with medical complexity “takes a village” of medical providers, support systems, and parental and family support (p. 98). Joly (2015) concluded that health care transition needed improvement because pediatric sub-specialist services seem to abruptly end, and parents of the adolescents have grown increasingly dependent on a system that should facilitate a handoff (transition) from the pediatric to the adult models of care.

Through a systematic review of scholarly literature, Nehring et al. (2015) sought to define the state of health care transition for children with special health care needs from the perspective of the clinical practice or provider. They found 745 articles pertaining to health care transition of children with special health care needs published between 2004 and 2013. They used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines to narrow the review to 55 studies. All the studies used a descriptive design. The researchers used a “provider defined” category to group studies that described health care transition activities for a specific pediatric chronic disease and discipline of medicine, and a provider combined category to group studies that were interdisciplinary in nature. Significantly, most health care transition research from the clinical practice or provider perspective is restricted to the provider defined category, which suggests that each medical discipline is conducting health care transition research specifically for the diseases and conditions they treat and not necessarily for the general population of children with special health care needs.

Nehring et al. (2015) found four major themes in their systematic review from a clinical practice or provider perspective: a) transitioning from a pediatric to adult medical provider has limitations because some adult providers are not prepared to medically manage transitioning youth with special health care needs, b) a clinical practice or provider have their own perspective about health care transition, c) a clinical practice or provider have attitudes about the challenges and barriers of health care transition, and d) exploration of existing health care transition service models.

In summary, Nehring et al. (2015) found that health care transition planning is in the beginning stages of development for an emerging practice focused in medicine. Their findings included an absence of empirical-based data that leads to best practice models and a need for rigorous research design and methods for filling this gap.

Healthcare service systems do not adequately prepare the parents of children with special health care needs; therefore, the parents are unable to fully conceptualize the future for their children. In another extensive systematic review, Betz et al. (2015) focused their research on parental needs and issues from the perspective of the parents. Their review found 47 studies from 2004 to 2013. Using an inclusion criterion of parent-defined studies, meaning that parental findings were discovered and reported separately from their children, thematic findings were drawn from 30 studies. Of the parent-defined studies, only one used an experimental design to test intervention strategies. The remaining studies were predominately qualitative and to a lesser extent a secondary analysis of other data studies. Betz et al. (2015) suggested that the thematic foci findings should be incorporated into the development of evidence-based models aimed at improving the effectiveness of health care transition planning.

Betz et al. (2015) identified seven thematic foci from their systematic review: a) parents experience a change in expectations related to planning for health care transition of their children, b) parents are confronted with changing their parental role, c) parents recognize changes to the children's role, d) parents have positive and negative experiences in the health care transition process, e) parents have new stressors caused by health care transition, f) suggestions by parents pertaining to support and services needed for health care transition, and g) parents perceptions of what their child experiences during health care transition. Overall, Betz et al. (2015) provided a systematic review of scholarship focused on the parent's perspective of health care transition of children with special health care needs and identified that themes could be used in the development of evidence-based models for improving health care transition.

In another systematic review, Chu et al. (2015) found five studies that addressed the impact of transition programs for adolescents with chronic illnesses. Inclusion criteria for the systematic review was hinged on Got Transition™ core principles. Got Transition is nonprofit research collaborative between the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, and the National Alliance to Advance Adolescent Health (Got Transition, n.d). The studies selected by Chu et al. (2015) had to use at least one of the six Got Transition core principles in their transition program implementation. Of the five studies, one was conducted in the U.S., which was the only study to use a pilot randomized control trial. The remaining four studies were conducted in clinical programs using small non-randomized convenience samples where Chu et al. (2015) suggested that more rigor would likely be provided for studies conducted by research programs.

Chu et al. (2015) supported the emerging claim in the literature that there are few studies that address the evaluation of health care transition programs for children with chronic and complex medical conditions. Chu et al. (2015) found that limitations in the research included methodological limits, non-randomization and convenience sampling. Additionally, the suggestion that limitations may be caused by where and who is conducting the research is an important point; research conducted in the clinical setting is limited by the practice's patient load and are typically in a sub-specialty field, which cohorts the research participants into siloed disease groups (Chu et al., 2015). Chu et al. (2015) implied that research programs, over research conducted in the clinical settings, may increase the number and rigor of health care transition research.

Ladores (2015) searched the literature and performed a concept analysis on 50 studies that included health care transition and children with chronic medical conditions going back to 1994. Using the Rodgers evolutionary method (as cited in Ladores, 2015), Ladores (2015) identified two critical concepts in the domains of attributes and consequences of health care transition for children with chronic medical conditions.

The attributes domain represented a consensus among scholars about the positive characteristics of a concept. A characteristic from health care transition that garnered the most consensus was viewing the process of health care transition as continuous or on a continuum. Ladores (2015) associated the concept of the continuum of health care transition with implications for nursing practice, which is supported by Meleis' transition theory but initially excludes the necessary collaboration between patient, family, health plans, and other social systems from the health care transition continuum.

The consequences domain represented the possible outcomes of implementing the concept of health care transition. Ladores (2015) suggested that effective health care transition must be operationalized when the adolescent's health status is stable and not in crisis. Furthermore, Ladores (2015) reminded us that adolescence is a transition period in it of itself and the stressors of health care transition may impact normal life-span development.

Strickland et al. (2015) examined the results of the 2009-2010 National Survey of Children with Special Health Care Needs. Strickland et al. (2015) added to research that Strickland conducted with others in 2009, using the same survey and earlier time period of 2005-2006 (Lotstein et al., 2009). The framework for the evaluations was a core performance outcome set by the Maternal and Child Health Bureau. The core performance outcome is a measure of whether or not the adolescent survey respondent received effective health care transition services. The National Survey of Children with Special Health Care Needs was subsequently absorbed by the broader National Survey of Children's Health in 2016 and went from a four-year cycle to an annual cycle where the results of the 2018 survey are not yet available (Johns Hopkins University, n.d.). This may be the only chance to broadly compare survey results from survey period to survey period.

Comparing the core performance outcome between 2005-06 and 2009-10 showed a 1% decrease in how many survey respondents met the criteria for meeting the core performance outcome (41% to 40%). There was a slight increase in two of the core performance outcome objectives: a) providers discussed health care transitions (42% to 43.9%), and b) providers discussed changes in health insurance (34% to 38.1%). This comparison of the core performance outcomes suggested little progress towards effective health care transition programs for children with special health care needs over a five-year period. Additionally, as researchers learn more about health care transition, new challenges and mitigation measures are revealed. New to the National Survey of Children's Health, in the category of health care transition, is *anticipatory guidance*.

Syverson et al. (2016) defined anticipatory guidance as a medical provider's responsibility where the provider discusses with the adolescent patient: 1) the transition to adult health care services, 2) the change in health insurance, and 3) the changing health care needs as one approaches adulthood. Syverson et al. (2016) conducted a randomized control study using a convenience sample of patients from an urban academic health center, which was embedded in a pediatric tertiary healthcare system. Using linear regression analysis, the researchers found that a large segment of the study participants did not receive anticipatory guidance (49%) and those that did reported their perception of health care transition readiness were rated significantly higher. Syverson et al. (2016)

suggested that the low rate of anticipatory guidance was similar to the rates of the 2009-10 National Survey of Children with Special Health Care Needs examined by Strickland et al. (2015). The similarity in anticipatory guidance rates were weighted by the differences in the sample demographics where in Syverson et al. (2016), the impoverished minority groups experienced significant disparities.

Coyne et al. (2018) performed the most current systematic review of scholarship with a focus on the use of the National Survey of Children with Special Health Care Needs as an outcome variable in health care transition research. Fourteen research articles, using the PRISMA search strategy, were included in the systematic review; scholarship that was previously cited in this literature review were included (Lotstein et al., 2009; Strickland et al., 2015). The National Survey of Children with Special Health Care Needs datasets reviewed were from years 2000-01, 2005-06, and 2009-10.

Coyne et al. (2018) found several limitations. First, the core performance outcome set by the Maternal and Child Health Bureau was not consistently applied resulting in various claims of attaining the outcome. Second, although the National Survey of Children with Special Health Care Needs datasets draw from a national stage, some researchers narrowed their focus to a specific disease or condition resulting is small sample sizes that prevented generalization across the population. Lastly, the National Survey of Children with Special Health Care Needs limits the sampling frame to youth ages from 0 to 17 years, which is inconsistent with guidelines from the American Academy of Pediatrics (2011) that determined health care transition efforts and the transfer of care from the pediatric model to the adult model should be implemented in the age range of 14 to 18; the researchers were using data that was not aligned to the suggested health care transition readiness practice. Moreover, the National Survey of Children with Special Health Care Needs solicited the perceptions of parents and caregivers, excluding the adolescents themselves.

Coyne et al. (2018) did find value in using the National Survey of Children with Special Health Care Needs for transition research because of its low cost, the national-level sample size, and the inherent ability to study trends over time. However, the research community has developed and tested alternatives to the National Survey of Children with Special Health Care Needs, which are introduced and described later in this literature review.

Just as anticipatory guidance was introduced into the health care transition lexicon, Strickland et al. (2015) were first to suggest a “life course approach” be incorporated into health care transition planning for children with special health care needs. The life course approach, already prominent in the maternal and child health literature, would extend health care transition planning outside the clinical practice to include the adolescent’s family, social network, community, and other systems of services.

The life course approach is a simplified reference to the life course health development model, which was developed and currently being refined by multiple fields of study and disciplines. The life course health development model broadens the determinants of good health outcomes by considering the social and physical environment as influencers and considers the transitions and resiliency between different life stages as important contributors (Halfon et al., 2014). The life course approach mirrors some concepts in Bronfenbrenner's ecological systems theory of development.

In a research commentary, Bethell et al. (2014) suggested that the life course approach addressed the current shortfalls of the health care system in preparing adolescents with chronic conditions for transitions between life stages. The tenets of the life course approach specifically branch out to social, psychosocial, and behavioral domains where the paradigm of health care transition is mainly based in the clinical practice and addresses the transfer (not transition) of care from the pediatrician to the adult provider. In other words, Bethell et al. (2014) identified a need for the life course approach when medically managing children and youth with chronic or complex medical conditions because the health care system does not utilize a cross-systems approach, which missed a holistic transition preparation opportunity.

Although adolescents are typically carved-out of maternal and child health studies, Shlafer et al. (2014) pointed to the importance of linking prenatal, infancy, and the phases of childhood to the transitional phase of adolescents to adulthood. Compounding the issue of ineffective health care transition for adolescents with chronic and complex medical conditions is the life course complexity of a series of parallel transitions; adolescent to adult, school to work, exuberant growth, changing roles and relationships with parents, and cognitive and emotional growth associated with a still-developing brain (Shlafer et al., 2014). The life course approach largely remains a theory where practical applications are being developed.

Where Strickland et al. (2015) suggested that a life course approach be applied to health care transition planning for children with chronic and complex medical conditions, Burton-Jeangros et al. (2015) illustrated that the life course approach is a long-term approach, which is inappropriate for the short-termed events and the abrupt changes in health care transition. The aim of the life course approach is to conduct an in-depth analysis of human development over time, which requires longitudinal studies (Burton-Jeangros et al., 2015). In the context of health care, health care and social support systems have yet to achieve interoperability and connecting social and psychosocial determinants of good health are not yet available to monitor or let alone predict an individual's health trajectory (Burton-Jeangros et al., 2015). Given that our current health care system cannot support the full integration of the life course approach, health care transition readiness for children with medical complexity should be guided by clinical practices, health plans, or other social services agencies. It is reasonable to postulate that a child's pediatric sub-specialist leads the guidance for health care transition preparation because of the importance and authority of their position.

Guidance for implementing health care transition planning in clinic practices has been around since 2002 (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011). Davidson et al. (2015) evaluated the status of guideline implementation through a survey of 376 general and sub-specialty pediatric practices at an urban healthcare network. The survey response rate was 28% ($N = 105$). Overall, the pediatric sub-specialist reported greater compliance with the guidelines than the pediatric generalists. A majority of all the providers worked with children and youth with special health care needs in identifying an adult provider to transfer care to. The study's dismal findings showed that utilization of the guidelines was incomplete. The researchers suggested that the absence of an accepted and tested transition planning model hampers the implementation of the guidelines, which many viewed as workflows that may not fit the practice's model. Clearly, the guidelines published in 2002 did not resound with practitioners. Although the response rate and sample size of the convenience sample were small, the findings are telling in the context of the passing of time since the guidelines were published.

The reviewed literature was rich in suggesting that the transitioning adolescents, and their parents or caregivers, needed to be included in the health care transition planning because they provide valuable and practical insight for challenges and solutions in the process. But how much health care transition knowledge do they possess?

Assessing Health Care Transition

It is general knowledge that the first steps in addressing a perceived problem were to assess if the problem exists and its severity. Without the first assessment, interventions or mitigation cannot be adequately developed and implemented to resolve a problem. Assessing the adolescent's readiness for health care transition is the first measure for addressing the lack of effective health care transition planning. Additionally, assessing for transition readiness facilitates temporal precedence and allows the clinician or program to prioritize scare resources designed to improve the readiness transition, and subsequently evaluate and monitor those interventions. Three health care transition readiness assessments tools were prominent in the literature: STAR$_x$, TRAQ, and UNC TR$_x$ANSITION Scale.

Ferris et al. (2015) tested the STAR$_x$ (Self-Management and Transition to Adulthood with R$_x$=Treatment questionnaire), which was an 18 question self-report questionnaire used to assess self-management and health care transition skills for adolescents with chronic medical conditions. Unlike most other health care transition readiness assessment tools, the STAR$_x$ was not disease-specific (Ferris et al., 2015). The STAR$_x$ was comprised of six domains: a) medication management, b) communicating with the medical provider, c) engagement during medical appointments, d) general disease knowledge, e) adult health responsibilities, and f) resource utilization (Ferris et al., 2015). The testing was conducted in three phases at pediatric sub-specialty clinics, teaching hospitals, and community-based agencies (*N* = 1,219). Ferris et al. (2015) concluded that the STAR$_x$ was a reliable health care transition assessment tool, with internal consistency and test-retest reliability, for adolescents with chronic medical conditions. The STAR$_x$ was not the first health care transition assessment tool widely accepted in health care transition scholarship.

Cohen et al. (2015) compared the STAR$_x$ to the TRAQ (Transition Readiness Assessment Questionnaire). The purpose of the comparison was to validate the STAR$_x$ further use of the TRAQ as a benchmark. The TRAQ is a 20 question self-report questionnaire used to assess self-management and self-advocacy skills pertaining to health care transition of adolescents with chronic medical conditions (Cohen et al., 2015).

According to Sawicki et al. (2011), the TRAQ was the first validated assessment tool for measuring the readiness for health care transition.

The seminal work by Sawicki et al. (2011) and Wood et al. (2014) contributed to the canon of health care transition research. Their collaborative work developed the most widely used health care transition readiness assessment instrument. The TRAQ was developed through a literature search from existing clinical checklists and questionnaires used in preparing adolescents with chronic diseases for health care transition (Sawicki et al., 2011). The final iteration of TRAQ was based on five domains: a) managing medications, b) medical appointment keeping, c) tracking health issues, d) talking with medical providers, and e) managing daily activities (East Tennessee State University, 2018). The questionnaire's response options were developed using a transtheoretical model, which represented the continuum from pre-contemplation to maintenance of change model behavior (Sawicki et al., 2011). The developer's validation of TRAQ through factor analysis (*N* = 192) provided clinicians, health plans, and social service programs, with a no-cost easily accessible assessment tool to measure the readiness for health care transition for adolescents with chronic medical conditions.

In an ongoing study, the TRAQ was further tested by Wood et al. (2014). Using an exploratory factor analysis (*N* = 269) and a confirmatory factor analysis (*N* =178), Wood et al. (2014) showed that TRAQ had good internal validity and criterion validity (α = 0.94). Moreover, the TRAQ was further validated for a reliable self-report assessment tool for measuring the readiness of health care transition. The TRAQ assessment tool was ubiquitous in the literature when the need for health care transition data collection is suggested. In a commentary by Sharma et al. (2014), the TRAQ was suggested for longitudinal studies where outcome measures for health care transition have yet to be defined. I found that the TRAQ was the most prominent assessment tool in the health care transition research.

Anelli et al. (2019) conducted a confirmatory factor analysis on a carefully translated Brazilian Portuguese iteration of the TRAQ. Pilot testing revealed a cross-cultural difference in the translation from English to Portuguese centered around the concept of a loss of health insurance; question number 10 was amended to reflect a Brazilian national guarantee for health insurance coverage (Anelli et al., 2019). Although the TRAQ was designed and tested to be a disease-neutral data collection tool, Anelli et al. (2019) administered the survey to a large convenience sample of adolescents with rheumatologic diseases. Significant findings from the confirmatory factor analysis included a demonstrated reliability when the TRAQ was administered by non-clinician lay interviewers, and a universally accepted moderate internal consistency (Anelli et al., 2019, p. 185).

Kiziler et al. (2018) performed a confirmatory factor analysis to determine the TRAQ's validity and reliability in Turkish for adolescents with type 1 diabetes. Content validity was established after the Turkish translation of the TRAQ by expert evaluation in place of pilot testing (Kiziler et al., 2018). The Turkish TRAQ was administered through face-to-face interviews by clinicians at two endocrine clinics to 109 adolescents with type 1 diabetes and proved to be a valid and reliable instrument for assessing the readiness for health care transition (Kiziler et al., 2018). Other researchers used the TRAQ for cohorts of adolescents with type 1 diabetes.

Chan et al. (2019) used the, by now, validated TRAQ to explore if relationships between demographic factors and clinical indicators contributed to the readiness for health care transition of adolescents with type 1 diabetes. Using a convenience sample of 19 adolescents with type 1 diabetes, the TRAQ was self-administered and demographic data and clinical markers were collected from a retrospective chart review (Chan et al., 2019). Taken together, hypothesis testing was performed comparing the TRAQ scores to other variables. Included in the findings were that females managed their diabetes better than males, self-management of medical provider engagements improved with age, and that a correlation between the gold standard clinical marker of hemoglobin A1C and readiness for health care transition was inconclusive, needing more study (Chan et al. 2019). The significance of the research performed by Chan et al. (2019) is recognized as a novel approach to use the TRAQ and associated demographic factors and clinical markers to design interventions that improve the readiness for health care transition of adolescents with type 1 diabetes. Other researchers have focused on using TRAQ to determine health care transition outcomes.

Jensen et al. (2017) sought to measure health care transition outcomes by performing a longitudinal study using the TRAQ to create a baseline reference and follow up interviews to monitor progress to successful health care transition. Jensen et al. (2017) followed 89 adolescents with various diseases from a single health care facility for three years. A TRAQ score was compared to the time of medical care transfer to an adult sub-specialty provider, which represented a successful outcome. Jensen et al. (2017) found that in their study, successful health care transition outcomes were not predicted by TRAQ scores. Although the TRAQ has been validated in health care transition research as an assessment instrument, using it to predict health care transition outcomes needs further study.

The UNC TR$_x$ANSITION Scale is a 33 question provider-administered survey that results in a score that places the respondent on a scale. The scale has 10 domains: a) type of chronic illness, b) medication management, c) adherence to treatment plan, d) nutrition, e) self-management, f) issues of reproduction, g) education, h) insurance issues, i) ongoing support, and j) new health care providers (Cohen et al., 2015). Research suggested that a weakness of the UNC TR$_x$ANSITION Scale manifests through misalignment between the clinician's ratings and the adolescent respondent's perception of their self-management skill set. However, in a focused study by Cantú-Quintanilla et al. (2015), the UNC TR$_x$ANSITION Scale received further validation through a Spanish language version administered to 163 adolescents with chronic kidney disease in a pediatric hospital in Mexico. Missing in the research was the provider's commitment of resources for administering the survey, which includes a medical record review. The self-report assessment tools may provide a better option for providing meaning to the perceptions of the adolescent respondents and with less clinical resources.

School-Based Transition Research

Human development is comprised of many simultaneous transitions. Basic transitions include the time and situations when adolescents are biologically turning into adults while they leave school for the workforce. Health care transition is significant to adolescents with chronic and complex medical conditions because it is an added stressor to normal transitions. Hirano et al. (2018) conducted a qualitative meta-synthesis to identify barriers that families of children with disabilities face in the basic transition from school to adulthood. Although the gathering of qualitative evidence across studies did not focus on health care transition, Hirano et al. (2018) contributed to health care transition scholarship because they addressed those health care situations and processes found in the school system from the perspective of special education in accordance with the Individuals with Disabilities Education Improvement Act of 2004. In other words, Hirano et al. (2018) introduced processes and context different than the health care community, which supports Bronfenbrenner's ecological systems theory where the developing adolescent influences, and is influenced by, distinctive separate actors in the microsystem (schools and health care services). A significant amount of existing health care transition scholarship was from the medical provider's perspective, Hirano et al. (2018) broaden the scholarship used to inform this study.

After a quality appraisal of identified research, Hirano et al. (2018) reanalyzed qualitative data from 405 family members from 22 studies. The qualitative reanalysis used Bronfenbrenner's model of ecological development to assign context to the associated micro-, meso-, and macro-systems, and Bourdieu's theory of social and cultural reproduction to identify codes that represented barriers to and involvement in the transition process (Hirano et al., 2018).

Hirano et al. (2018) found three categories that parents of children with disabilities face when seeking involvement in health care transition planning. First, the family category included stressors that usurp time and resources away from health care transition planning. Included in the family category were issues with transportation, living paycheck-to-paycheck, a lack of cultural capital, and low self-efficacy. The second category identified the school context where families perceived racism, discrimination, and paternalism, in their interactions with school staff. Finally, the third category was the adult systems that the adolescent with disabilities is expected to navigate when their parents admitted they could not do it themselves. All in all, Hirano et al. (2018) exemplified the importance of incorporating the school context in health care transition planning of children with disabilities because challenges mitigated there translate or crosswalk to success in the health care context.

Disease-Specific Transition Research

Health care transition research included several studies that focused on specific chronic illness. Epidemiological profiles and factors of pediatric chronic and complex illnesses provide considerable variability in the needs and wants of adolescents facing health care transition; a one-size-fits-all transition plan is not practical. According to Davis et al. (2014), diabetes was the most prevalent pediatric chronic illness studied in the context of health care transition.

Davis et al. (2014) conducted a literature review to identify empirical evidence of evaluative studies of health care transition programs. Twenty-five evaluative studies met strict inclusion criteria where 32% of the studies focused on insulin-dependent (type 1) diabetes, 20% focused on organ transplant (mostly kidney), 8% focused on sickle cell disease, and the remaining studies focused on adrenal hyperplasia, epilepsy, HIV, arthritis, spinal bifida, cystic fibrosis, and inflammatory bowel disease (Davis et al., 2014). This literature review did not provide a reason for the prevalence of health care transition research that was focused on adolescents with diabetes. However, a reasonable explanation is deduced indirectly: Adolescents with type 1 diabetes have three clinical markers well supported by research for monitoring disease management, and therefore, the diabetes cohort is easily and economically studied.

Davis et al. (2014) identified that a laboratory test in common use by type 1 diabetics (glycemic control marker) was used as an outcome measure for successful health care transition of adolescents with diabetes, as well as the frequency and severity of in-patient hospitalization and interactions with adult molded health care providers. The glycemic control maker laboratory test, or the hemoglobin A1C test, provided quantitative data for trend analyses and correlations studies. Moreover, glycemic control was the best indicator for effective disease management, which is used to confirm self-management for effective health care transition. As promising as it may seem, glycemic control is a poor indicator of disease and self-management for adolescents with diabetes because of social determinants that create confounding (extraneous) variables. Adolescents from minority or low-income families are predisposed to poor clinical outcomes due to social determinants that pose challenges against the norm (Sawicki et al., 2017; McManus et al., 2015). Research by Lemke et al. (2015) supported this claim. In a quasi-experiment that compared the effectiveness of interventions between a control group to a treatment group, Lemke et al. (2015) found that "low socioeconomic minorities" had an increased risk for ineffective health care transition (p. 7). Additionally, Lemke et al. (2015) provided a framework for quantitative analysis of an intent-to-treat study design using repeated measures testing. Conversely, one diabetes health care transition study was conducted using an all-Caucasian sample from affluent families.

Babler and Strickland (2015) interviewed 15 Caucasian adolescents from western Washington state, comprising a convenience sample in pursuit of a deeper understanding of living with diabetes. Although findings from the Babler and Strickland (2015) study are not generalized across populations (p. 658), there were many similarities with studies that included low socioeconomic minorities: support is needed from parents and providers and is crucial to facilitating diabetes self-management, programs (interventions) are needed to develop self-management skills, and the paradigm of health care transition is a *normalizing* evolution concurrent with other normal developmental milestones. Some diabetes health care transition research focused on transition programs or interventions aimed at improving self-management skills.

Polfus et al. (2015) evaluated the perceptions of adolescents and their parents as to the effectiveness of programs or interventions designed to promote self-management skills and the readiness for health care transition. In a unique cross-sectional study design, dyads (adolescent and primary parent) were used to gain an understanding of the complex relationship between the developing adolescent and the support provided by parents and diabetes medical clinics at a mid-western children's hospital. Polfus et al. (2015) used current scholarship to establish two assumptions about health care transition for type 1 diabetics in the design of the data collection surveys: Effective health care transition 1) is measured by an increase in the levels of self-management and less supervision by the parents, and 2) has decreased oversight by the medical provider. Glycemic control was used to measure the level of disease management skill. The use of dyads provided the opportunity for paired samples t-testing.

The study's findings included a strong correlation between the adolescent's and the parent's self-efficacy scores and self-management skills, where self-efficacy was defined as the belief one has in their abilities (Polfus et al., 2015, p. 753). Here, the adolescents showed a higher level of self-efficacy perception over what the parent reported, and the relationship between the adolescent's self-efficacy and perception of the ability to self-manage diabetes clearly supported other health care transition research that targeted interventions or transition programs aimed at improving health care transition through developing self-management skill. Although Polfus et al. (2015) provided compelling insight into the perceptions of adolescent-parent teams, the one that directs the medical care of adolescents with diabetes was not present in their study. Garvey et al. (2016) took a complementary approach by focusing on the endocrinologists.

In a qualitative study that involved a national survey of endocrinologist in the U.S., Garvey et al. (2016) identified a need for enhanced information transfer between the pediatric and adult providers of transitioning adolescents with type 1 diabetes. Additionally, the endocrinologists that responded to the national survey identified a need for more mental health referrals for transitioning adolescents where a need to assign blame for having diabetes by newly diagnosed adolescents was prevalent in their practices. In our present-day health care system, the pediatric endocrinologist often manages the medical care for type 1 diabetics until the patient transitions to the adult model of care. The advent of the health maintenance organization model made the primary care physician the gate-keeper of services provided by specialists, like the endocrinologist, thereby making the primary care physician the manager of the transitioned adolescent diabetic; the paradigm shift is the factor for endocrinologists wanting to enhance the transfer of information from specialist to general medicine. Remarkably, the endocrinologist had little input into scholarship about health care transition of adolescents with type 1 diabetes. The transfer of medical care from the pediatric-based endocrinologist to an adult model primary care physician exemplified a situation where *trust* between the transitioning adolescent and health care provider is must be started anew, which is contradictory for the needs of the transitioning adolescent with type 1 diabetes.

In a published paper selected from health care transition research, Bridgett et al. (2015) provided a retrospective review of an innovative service line established at an Australian children’s hospital. The new service line was developed using a person-centered approach where the patient, in this case the adolescent with type 1 diabetes, was central and involved in all aspects of their health care planning. The person-centered approach was reported to facilitate trust-building between the adolescent with type 1 diabetes and the medical provider, which was necessary for effective health care transition (Garvey et al., 2016). The new hospital service line provided comprehensive care coordination where comprehensive included all life issues experienced by the developing adolescent, and care coordination included services provided by primary and specialist medical care, mental health and social services providers, and services provided by the health plan. The retrospective review interviewed two adolescents with type 1 diabetes enrolled in the comprehensive care coordination clinic.

Bridgett et al. (2015) found that attributes of the new service line identified by the consumers included the initial psychosocial assessment, which allowed for proactive mitigation of broad issues that often overlapped among the service providing entities, and the availability of clinical data, like glycemic control, which provided baseline and trending data used to monitor self-management skill development and the readiness for health care transition. Moreover, Bridgett et al. (2015) emphasized the point that health care transition was an evolution requiring skills development and not just an event like the transfer of care from the pediatric endocrinologist to the primary care physician.

Health care transition research was dominated by scholarship that emphasized the readiness for transition without established outcome measures (Sharma et al., 2014). Developing health care transition outcome measures requires input from all those involved in the process and longitudinal studies to test them. Pierce et al. (2017) identified constructs for developing health care transition outcomes. Using qualitative semi-structured interviews with open-ended questions, Pierce et al. (2017) collected data from a broad mix of stakeholders related to health care transition of adolescents with type 1 diabetes. The stakeholders included adolescents and parents that were randomly selected (*N* = 19), pediatric and adult medical specialists found through a purposeful sampling technique (*N* = 18), and health care transition subject matter experts (*N* = 9).

The research subjects were accessed through large children's hospital systems in Florida and Pennsylvania and were English language speakers. The data analysis developed the following constructs:

- Maintaining favorable glycemic control.
- Successfully navigating the adult model of type 1 diabetes specialty care.
- Demonstrating type 1 diabetes self-management skill.
- Integrating type 1 diabetes into emerging adult roles.
- Accepting or owning the prioritization and responsibilities that come with successfully managing the disease (Pierce et al., 2017, pp. 975-979).

The authors claimed that the constructs developed by their research could be transferred to other chronic diseases. Health care transition research for other chronic diseases included congenital heart disease, kidney disease, cerebral palsy, epilepsy, cancer, sickle cell disease, and HIV infection.

Pediatric chronic diseases vary in pathological features, treatment regimens, and the discipline of medicine that directs medical care. Health care transition research reflected these variances in pediatric chronic diseases by limiting some studies to specific diseases (Fernandes et al., 2014). Congenital heart disease has a unique feature in that the growing and developing body from a child to an adult, in it of itself, increases the risk for cardiac complications (Asp et al., 2015). The risk of cardiac complications has exacerbated because the survival rate of pediatric congenital heart disease has increased from 25% to 95% in the last forty years; more children are transferring to adult services where the risk of complication is regularly monitored (Hays, 2015). Health care transition research for congenital heart disease has an additional domain that must be mastered by the transitioning adolescent.

Hays (2015) reviewed the current research to identify recommendations for the management and treatment of adult congenital heart disease. Hays (2015) found that unlike most health care transition research that uses age as a trigger for the transfer of medical care, adolescents with congenital heart disease should use clinical instability, or the domain of increasing risk for cardiac complications going into adulthood, as the trigger (p. 63). Additionally, the health care transition readiness of the adult cardiologist needed to be improved because the pediatric cardiologist managing congenital heart disease did not historically transfer medical care for patients that had a shorter life span (Hays, 2015). Asp et al. (2015) supported the identification of the new domain in health care transition research for adolescents with congenital heart disease.

Asp et al. (2015) conducted a descriptive qualitative study using individual interviews of sixteen young adults from two Swedish cardiac clinics. Based on the assumption that as a child with congenital heart disease develops to adulthood, the risk of cardiac complications increases with age, the study aimed to describe the experiences of the study subjects that had transferred their medical care to adult providers. The data analysis revealed some categories common with general health care transition research: Experiencing trust and security with the new provider and assuming more responsibility and involvement in the planning and managing of medical care (self-management). Unlike most general health care transition research, the study subjects were concerned about the increased risk of cardiac complications and expressed a need to learn the symptoms that portend the event (Asp et al., 2015).

The differences in health care financing and delivery between the U.S. and Sweden is an obvious limitation for generalizing the finding from the Asp et al. (2015) study. However, it is clear, due to the risk of cardiac complication domain that adolescents with congenital heart disease have specific requirements for effective health care transition.

The health care transition literature contained several studies restricted to specific diseases that unlike the congenital heart disease's additional domain, contributed to the general scholarship for health care transition that was applied across all chronic childhood illnesses. The following studies are examples of general research contributions from specific chronic disease groups.

Cantú-Quintanilla et al. (2015) tested a disease-neutral health care transition readiness survey (UNC TR$_X$ANSITION Scale™) on Mexican adolescents with chronic kidney disease. The author's claimed that their study was first among Latin-American countries and compared the findings to similar studies conducted in the U.S. The convenience sample of 163 adolescents from low-income families were Spanish language speakers with an average age of 15 years old. Cantú-Quintanilla et al. (2015) found that the survey tool was reliable, correlations between the survey scores and age and gender were consistent with studies in the U.S., and that assessing the readiness for health care transition is an important first step for providing effective health care transition programs for adolescents with chronic kidney disease. Disease-specific health care transition research was not limited to testing transition readiness surveys.

Carroll (2015) used a phenomenological reduction to explore the lived experiences of adolescents and young adults with cerebral palsy after transitioning from pediatric to adult medical services. The nine study participants were not cognitively impaired but were all mobility challenged. Similar to other health care transition research, Carroll (2015) found that the differences between the pediatric model and the adult model created uncertainty for the transitioning adolescent, which could be mitigated using the inclusive patient-centered approach to plan medical care and prepare for health care transition. Moreover, providing early orientation, introduction, and awareness to the transitioning adolescent of the transfer of medical care from the pediatric to the adult model would mitigate uncertainty about the process. Similar to other health care transition research, Carroll (2015) found that medical providers needed to offer support through transition programs and initiatives to improve the process of health care transition.

Different than other disease cohorts, adolescents in Carroll's study (2015) described a necessary interdependence with parents and friends that transcended health care transition related to their mobility challenges. Although self-management and self-advocacy are goals for the transitioning adolescent, mobility challenged individuals may still need assistance from others in all forms of mobility and transportation. This necessary interdependence is not unique to adolescents with cerebral palsy.

Disabato et al. (2015) focused on another neurological-based disease cohort that included adolescents with mobility challenges. Focusing on the health care transition of adolescents with epilepsy, Disabato et al. (2015) took a quality improvement project approach and therefore used pediatric and adult neurology clinics as the study's settings. Working with the assumption that most adolescents with epilepsy, and their pediatric providers, lacked confidence in the adult providers to maintain seizure control gains made by the pediatric providers, one goal of the quality improvement project was to improve the communication and time to transfer between the providers (Disabato et al., 2015). Additionally, the quality improvement project sought to improve the self-management skills of the transitioning adolescent. The adult neurology clinic group reported that transitioning adolescents with epilepsy lacked the preparation necessary to meet the level of independence needed in the adult setting and that often the transfer of medical care included unreliable medical history documented in medical records (Disabato et al., 2015). Clearly, the quality improvement project, in it of itself, improved communication just by exposing the challenges between the pediatric and adult providers.

Disabato et al. (2015) found that improving health care transition for adolescents with epilepsy included institutionalizing the transition process (communication and transfer of medical information) and incorporating educational interventions into the medical care plans aimed at developing self-management skills (developing an appropriate level on independence); these findings support what was found in the general health care transition research, which was disease-neutral in nature. Exemplifying the differences between disease cohorts, where Disabato et al. (2015) conducted their research in specialty clinics dedicated to epilepsy, Overholser et al. (2015) explored the use of specialty clinics for individuals with childhood cancer.

Rates of surviving a childhood or adolescence diagnosis of cancer had improved to 84% (Overholser et al., 2015). The improved survival rates caused pediatric oncologists to seek effective health care transition models to maintain continuity of care and surveillance into the adult primary care setting (Overholser et al., 2015).

Adolescents with epilepsy had the opportunity in some settings to participate in a disease-specific clinic, which Disabato et al. (2015) found to be a beneficial venue for improving the readiness for health care transition. Overholser et al. (2015) tested the model in a descriptive study of a newly-established disease-specific clinic for adult survivors of childhood cancer. Unique characteristics of the clinic included the participation of pediatric oncologists working alongside adult primary care physicians, the adoption of a single electronic medical records system platform, and the addition of a psychologist to the care team. These unique characteristics of the clinic were developed to mitigate perceptions in scholarship where pediatric oncologists thought there was a knowledge gap about cancer by the receiving adult primary care physician, the transfer of medical history and treatment information was challenging, and psychosocial sequelae were not effectively addressed (Overholser et al., 2015). By placing the transfer of medical care squarely in a clinic setting with the transferring physicians working side-by-side, and using a common electronic medical records system, along with the adding a psychologist to the care team, the cancer clinic under study sought to address the pediatric oncologists' perceptions of problems associated with health care transition documented in the literature. Overholser et al. (2105) have plans to evolve the research from a descriptive study to an evaluative study of their clinic model.

Disease-specific specialty clinics were a popular setting in the literature to conduct health care transition research. In another example of disease-specific research, Maturo et al. (2015) tested a clinic protocol specifically designed to facilitate effective health care transition for adolescents with HIV infection. The clinic protocol was developed by medical practitioners, adolescents, and young adults from an HIV clinic embedded in a medical school. Using a retrospective medical records review, a purposeful sample (*N* = 38) of post-health care transition young adults that were exposed to the clinic protocol was evaluated for completion of the final phase of the protocol, which demonstrated successful health care transition to the adult model. Maturo et al. (2015) found that when adhering to the clinic protocol, 69% of the study participants successfully transitioned to the adult model (p.33). Unsuccessful clinic protocol fulfillment was primarily caused by disengagement from the process by the study participant. Despite the small sample size, Maturo et al. (2015) demonstrated a process for evaluating a structured health care transition protocol or model. Additionally, Maturo et al. (2015) demonstrated that health care transition research is firmly grounded in empirical methods when data from medical record reviews are included. However, medical records do not entirely encapsulate the health care transition experience for adolescents with HIV.

In a qualitative study of adolescent with HIV-parent dyads (*N* = 18), Fair et al. (2015) investigated the congruence of dyad responses for the expectations, anticipated benefits, and concerns related to health care transition. The convenience sample was drawn from an HIV clinic in the U.S. Using semi-structured interviews for data and grounded theory for theory development, Fair et al. (2015) found that dyads shared the same perceptions about the expectations for health care transition but varied in their responses as to when parents should relinquish control and adolescents assume more responsibility in managing their care. Another area of congruence in the dyads was related to the concerns or loses of health care transition.

Fair et al. (2015) supported other general health care transition research by finding congruence in the dyads about concerns in the transfer of medical care from the pediatric provider to adult provider as this signified the ending of a long-termed relationship and the beginning of a commitment to an unfamiliar system of care and provider. Fair et al. (2015) suggested that concerns related to ending the pediatrician's long-termed relationship may be the reason for hesitancy to begin the health care transition process earlier rather than later.

In the last example of disease-specific health care transition research, Speller-Brown et al. (2015) conducted a descriptive correlational study to identify the perceived readiness for health care transition by adolescents and young adults with sickle cell disease-parent dyads. Using the Readiness for Transition Questionnaire, developed by Gilleland for adolescents with kidney transplants (Speller-Brown et al., 2015), a convenience sample (*N* = 60) of English-speaking patients between 14 – 21 years of age was surveyed. The sample was drawn from a large urban children's hospital in the U.S.

Speller-Brown et al. (2015) found variance in the descriptive statistics pertaining to the dyad's perception of health care responsibility. The adolescents and young adults with sickle cell disease reported that they were involved with the treatment regimen, which included compliance with laboratory appointments, scheduling specialty and primary care appointments, filling prescriptions, and communicating with their providers. On the other hand, parents reported that they were involved with all aspects of the treatment regimen (Speller-Brown et al., 2015). This variance in the dyad's perception of health care responsibility is attributed in the general health care transition research to a need to recognize role-change in that as adolescents become more responsible for their health care, parents need to assume less responsibility. Remarkably, due to its utter importance, the dyads agreed that the adolescent or young adult had no responsibility in navigating the health insurance environment (Speller-Brown et al., 2015).

Correlation between health care responsibility and the readiness for health care transition exemplified the misunderstanding of role-change between the transitioning adolescent or young adult and their parent. The study found no significant correlation between the adolescent's or young adult's perception of their health care responsibility and their readiness for health care transition (r = -14 to .08). Conversely, there was a strong positive correlation (r = .837, p = .000) between the parent's perceptions of their health care responsibility and their adolescent's or young adult's readiness for health care transition (Speller-Brown et al., 2015, p. 792). This study contributed to the general health care transition research by providing evidence to show that interventions designed to increase self-management skills, which are applicable to assuming more health care responsibility, should include a path for parents to decrease their role in managing health care to facilitate role-change.

Summary and Transition

Three interconnected concepts underpin health care transition. Medical providers are focused on a seamless transfer of medical care responsibility from the pediatric subspecialist to the adult model of medical care. A seamless transfer of medical care requires the development of self-management and self-advocacy skills by transitioning adolescents. The third concept involves health policymakers that seek to implement effective health care transition policies and models to mitigate the additional health care costs, and use of scarce resources, that result from ineffective health care transition.

The review of the relevant literature revealed themes of consensus:

- Health care transition policies or models are ineffective for a majority of children with special health care needs, including children with complex medical conditions that are enrolled in California's Title V programs.
- Ineffective health care transition causes gaps in medical care and lapses of health insurance coverage.
- Effective health care transition policies and models are grounded in rigorous empirical research, which is the current gap in health care transition research.
- There are many stakeholders in the health care transition policymaking arena; none more critical than the transitioning adolescent.

- Interventions that improve health care transition readiness are different for each socioeconomic environment, age group, and disease, or complex medical condition.
- Translating health care transition research to inform health care transition policy requires a synergy of research and policymaking models.

In this case study, I sought to contribute to filling the health care transition research gap by examining a case of primary research aimed at developing a best practices model and informing new health care transition policy. In Chapter 3, I provided an overview of the primary research that is the single case of this study and a case study protocol that guided this research.

Chapter 3: Research Method

Introduction

The literature suggested a lack of empirical research to ground new and effective health care transition policy. Ineffective health care transition policies cause breaks in the continuity of medical care and lapses in health insurance coverage for children with special health care needs (Aldiss et al., 2015; Joly, 2015). The literature review in Chapter 3 revealed a need for translating health care transition research to inform new policies (see Ferris et al., 2015). Over the years, policymaking experts have developed models and frameworks for diffusing research evidence to policy (Koon et al., 2016). The purpose of this study was to provide insight for informing effective health care transition policy through examination and translation of health care transition research.

In this chapter, I provided a description of the research design and the rationale for selecting a qualitative approach and case study method. I described my role as the researcher. In the methodology section, I defined the case under study and break down the data collection and analysis phases. Issues of trustworthiness of the data and analysis are addressed as well as ethical implications for this study.

Research Design and Rationale

The central research question for this study was, How can examining and translating health care transition research provide insight to inform new health care transition policy for children with medical complexity enrolled in California’s Title V programs? Two subquestions complete the inquiry: (a) What are the perceived factors for effective health care transition policy? and (b) What is the relationship, if any, between health care transition research and health care transition policymaking? The research questions bring two disciplines together: research and policymaking.

I observed the phenomena explored in this study in the literature review. Similar process characteristics between the research and policymaking communities have become evident in the participatory development of health care transition research and the stakeholder engagement in the first phases of policy development. Health care transition planning and development is more effective with participation from the stakeholders (Ferris et al., 2015; Schlucter et al., 2015). Furthermore, stakeholder engagement is necessary to diffuse evidence to inform new policy (Cairney & Oliver, 2017; Shlonsky & Mildon, 2014). The phenomenon of stakeholder engagement is paramount to effectiveness for the research and policymaking communities. Evaluating evidence to inform policy is also “deeply intertwined” (Gallo, 2017, p. 244) between the researchers and the policymakers.

In the scholarship I identified several influencing factors for evaluating evidence to inform policy; power relationships between the researcher and the policymaker, along with their perceptions of authority and expertise, influence how evidence is evaluated (Gallo, 2017). Additionally, the institutions involved in the research or policymaking process may directly or indirectly influence the evaluation of evidence, based on funding priorities and stakeholder pressures (Gallo, 2017). These influencing factors manifested in the agenda setting and policy formation stages of the classic policy process model where philosophical differences may divide researchers, policymakers, and stakeholders in policy choices and priorities, as well as policy goals, alternatives, and solutions

(Simon, 2017). Stated in other terms, the phenomenon of evaluating evidence is not the only process to inform policy; there are several other inputs to consider (Gallo, 2017, p. 243). The phenomena are embedded in the primary research under examination. I selected a postpositivist paradigm to guide this qualitative study.

The selection of the epistemological orientation supported the purpose of this study by increasing the potentiality for external validity. For guidance, I explored three seminal methodologists in qualitative research with different philosophical orientations. Robert E. Stake and Sharan Merriam suggested a constructivist's viewpoint where reality is a construct by individuals in their natural setting (Yazan, 2015, p. 137). Robert K. Yin, on the other hand, conveyed without claiming a postpositivist viewpoint that focus on empirical inquiry from a realist perspective that maintains objectivity through a structured methodology underpins the quality of case study research (Harrison et al., 2017). Yin's (2018) structured methodology includes the use of theoretical frameworks and propositions, triangulation of data, pursuit of rival explanations, and adherence to a case study protocol.

I based the rationale for selecting a qualitative methodology on the research problem of this study and the inquiry that answered the research questions. According to Sale and Thielke (2018), qualitative researchers focus on the interpretation and meaning of data that come from exploring a social or human issue (p. 129). The research problem pointed to a gap in scholarship where empirical studies are scarce and translating research evidence into policy is challenging (Betz et al., 2015; Ogbe et al., 2018). The research questions were focused on an examination of health care transition primary research to explore the possibilities of informing new health care transition policy. The interpretation and assignment of the meanings for the primary research's data align with qualitative methodology and matched some common features of qualitative inquiry according to Miles et al. (2020): The primary research had a strong qualitative component through the intensive and prolonged engagement of the study participants, and most of the collected data were words, phrases, stories, and dialog. Additionally, the primary research documents, which were the focus of this study, are comprised of textual material, appropriate data for qualitative methodology (Yin, 2018).

Explanatory Case Study Design

I used a qualitative method because the case study evidence provided words to analyze and a case study approach to explore “how” and “what” research questions. Methodology and approach methods are defined and linked through research traditions (Durdella, 2019). Case study, a traditional qualitative method, is empirical research that is used to investigate a contemporary phenomenon in-depth and in its real-world context (Yin, 2018, p. 15). Additionally, case studies are favored for retrospection of a contemporary event that cannot be further manipulated (Yin, 2018, p. 15). The primary research (e.g., the case), which was central to this inquiry, was a contemporary event and could not be further manipulated in this study. The phenomena of stakeholder engagement in research and policymaking, as well as the factors that influence research evidence evaluation, were bounded within the primary research. Yin (2018) suggested that bounding the case helps to bring about an alignment between the research questions and propositions, which is another characteristic of case study (p. 31). Yin continued to define case studies by developing a typology for single-case study and multiple-case study designs.

This study had the characteristics of single-case study design with multiple units of analysis. Yin (2018) described the rationale for using a single-case study design when the case is unique and critical (pp. 49-50). The primary research was unique in that it was conveniently available for examination; it was produced by a California county Title V program for children with medical complexity, which was a sample of the population for this study. The criticalness of the primary research is supported by scholarship that suggests there are gaps in empirical health care transition studies (Betz et al., 2015; Sawicki et al., 2017; Steinway et al., 2017). The primary research was comprised of focus groups, surveys, educational interventions, correlational studies, participant observer field notes, events, and research reports, all providing multiple units of analysis within the case. Yin categorized a single-case study with multiple units of analysis as a Type 2 single-case study (p. 47). Yin further assigned typology to case studies by their purpose and type of research questions.

For this study, the explanatory case study approach facilitated an in-depth examination of complex activities. In the in-depth examination, I sought to explain how the primary research activities might translate to a new health care transition policy. Yin (2018) suggested that inquiries using "how" and "why" questions are more explanatory and "likely to lead to the use of case studies, histories, or experiment as the preferred research method" (p. 10). The objective of this study was to explain how the research process and empirical evidence may translate to inform new policy. Characteristics of the explanatory case study design supported the research objective of this study by affording a postpositivist research perspective in a review of the primary research's operational processes, complex activities, and events, while recognizing that "reality exists but can be challenged" (p. 91) and explanations attempt to minimize those challenges (Durdella, 2019).

Often cited as a detractor for conducting case study research is "its lack of generalizability" (Harrison et al., 2017, "History and Evolution" section, para. 2). Yin (2018) expounded that generalization is not produced from a single-case study (pp. 20-21). However, the context of generalizability is applied to broad applications of different types of situations and people. The applicability of this study was limited to California county Title V programs for children with medical complexity, which share homogeneous characteristics in operations, administration, policies, and demographics of the children served. The context of generalizability could arguably be different by limiting generalizability to California's Title V programs for children with medical complexity.

Role of the Researcher

The case study researcher's role was to act as an instrument "within the inquiry process" (Alpi & Evans, 2019, p. 1). As the researcher's personal and professional experiences shape perceptions and interpretations, some subjectivity is ineluctable and considered a key feature of qualitative research (Damaskinidis, 2017; Durdella, 2019; Harrison et al., 2017). However, the study's potential for subjectivity must be openly acknowledged (Harrison et al. 2017).

Researcher's Position

My objective as a researcher of effective health care transition planning was to explain the possible linkages between health care transition research and the development of new health care transition policy. My interest in health care transition policy was peaked when I served as a director for a California county Title V program for children with medical complexity. Over the years of administering the program, I found that most adolescents aging-out of the program were not prepared for their entry into the adult model of health care. Although anecdotal, the frequency of health care transition issues and challenges caused me to address the lack of effective health care transition planning. I addressed the issues and challenges by establishing strategic goals and objectives for improving health care transition planning and conducted a grant-sponsored primary research project.

Researcher Bias

As an individual who was directly involved with the primary research under examination in this study, I am obligated to address researcher bias (experimenter bias). First and foremost, the challenges of backyard research bias were addressed by my separation and distance from the organization that conducted the primary research; Three years have passed since I left the public-sector organization that conducted the primary research. According to Durdella (2019), backyard research bias is mitigated through case selection that meets the specific criteria for the inquiry. The primary research under examination in this study is unique in that it is the only known empirical health care transition study conducted by a California Title V program for children with medical complexity and is conveniently available by the research grant sponsor for this study. The selection of the primary research for this study aligned with the research problem, purpose, and research questions.

According to Yin (2018), research bias manifests if the researcher's aim is to use a case study for substance applied to a preconceived position (p. 86). Additionally, Flyvbjerg suggested that inherent bias in case study research is a "misunderstanding" (see Longhofer et al., 2017, p. 191). Taken together, the role of this researcher was to conduct this study without a preconceived position while relying on the Yinian case study method and postpositivist orientation to explore the primary research in an objective fashion.

Methodology

Defining the Case

The case for this study is an applied research project, referred to as the primary research, conducted by a county Title V program for children with medical complexity. The primary research was funded by a foundation associated with a children's hospital and conducted from January 4, 2016, to July 27, 2018. The primary research was a quasi-experimental design underpinned by grounded theory to develop a best practices model for health care transition planning. The participants in the primary research included a convenience sample of 493 adolescents enrolled in the program and 216 parents or caregivers, nine participant observer research assistants, a university faculty advisor, and five local stakeholder representatives. Explaining the participant selection logic of the primary research is part of the case study analysis because this study was retrospective in nature.

The selection of the primary research conducted by the county Title V program as the case for this study was based on three characteristics. First, the primary research records were conveniently available from the research grant sponsor. Second, the primary research was relevant to the purpose of this study. Third, the primary research provided rich case evidence with multiple units of analysis, which are prime characteristics for data triangulation.

Case selection for this study was limited to the availability of applied research projects conducted withing California’s Title V programs for children with medical complexity. Up to now, the county Title V program’s primary research is the sole applied research project conducted by a California Title V program for children with medical complexity that addressed the challenges of effective health care transition planning. Throughout the United States, Title V programs for children with medical complexity vary in medical eligibility requirements, organizational structure, and funding streams (Lu et al., 2015). Due to the nature of federal block grant programs, States have the flexibility and "do many different things with their Title V dollars." (Lu et al., 2015). Therefore, variations in Title V programs for children with medical complexity preclude a multi-case study and indicated that a within-case analysis single-case study of the county Title V program’s primary research was appropriate for this study.

The single-case study design for this study was supported by Yin (2018). Yin suggested that the rationale for a single-case study design included characteristics like criticality, uniqueness, and relevance for answering the research question (p. 49). The primary research is explicitly critical for providing evidence to inform new health care transition policy, unique in its existence and availability, and relevant to the research questions of this study. However, Yin (2018) also suggested that a single-case design was "vulnerable" to omitting replication in the analysis, which impacts external validity (p. 61). Increasing the potential for external validity was addressed by adopting Yinian postpositivist analysis techniques.

The case study evidence, available from the primary research, includes planning documents, research reports and logs, focus group and interview transcript excerpts, field notes from participant observers, a database of survey data, and unpublished correlation and evaluation studies. In case study research, a principle of data collection is to establish the study’s case study database (Yin. 2018, p. 130). The case study evidence is cataloged, typed, described, and presented in a case study database in the analysis phase of this study.

Case Study Protocol

The purpose of using a case study protocol was two-fold. Using a case study protocol “is a major way of increasing the reliability of the case study” and guides the researcher in “carrying out the data collection” (Yin, 2018, p. 96). Yin (2018) compared the case study protocol to a data collection instrument and suggested they share a similar focus on data collection (p. 93). Although case study protocols “have been largely absent from the literature (Whitmore et al., 2018, p. 2), Yin described the case study protocol as a formal document that outlines the procedures for the inquiry and lists questions, directed at the researcher, to illustrate the relationships between the research questions and propositions. Use of a case study protocol aids in identifying relevant data for analysis (Yin, 2018).

Yin (2018) provided in-depth instructions on developing a case study protocol in his work *Case Study Research and Applications: Design and Methods* (pp. 93-105). Yin's instructions were used to develop the case study protocol for this study. The case study protocol is in Appendix A.

Data Collection

I obtained all of the data for this research from a foundation associated with a regional children's hospital. The foundation sponsored and funded the primary research and owns the rights to its products. The primary research products include planning documents, research reports and logs, focus group and interview transcript excerpts, field notes from participant observers, a database of survey data, and unpublished correlation and evaluation studies. Permission to use the primary research products was granted by the foundation through a data use agreement.

I also collected some data from publicly accessible websites. The websites provided explanations for the organization and structure of California's Title V programs. According to Yin (2018), there are six sources of case study evidence (p. 113). In this study, I examined four of six case study evidence categories, which provided ample opportunity to triangulate data in the analysis phase of this research. According to Patton (2015), data triangulation, or using multiple sources of case study evidence in multiple measures of a phenomenon, increases construct validity and the quality of the case study.

Data Analysis Plan

The first phase of the data analysis for this study was selecting, cataloging, typing, describing, and storing the case study evidence into a formal case study database. Yin (2018) suggested that a case study database "preserves [the] collected data in a retrievable form," aides in the replication of the study, and "markedly increases the reliability" of the research (p. 131). Miles et al. (2020) provided a sound argument for using a computer-assisted qualitative data analysis software (CAQDAS) to store and maintain qualitative data. Additionally, a CAQDAS assists the researcher in analyzing the data (Miles et al., 2020). Due to broad functionality and popularity among qualitative researchers, NVivo™ (version 12) served as the case study database and assisted the research in phase two of the data analysis (Paulus et al., 2017).

In the second phase, the case study evidence represented multiple units of analysis (e.g., individuals, groups, documents, organizations, and events) that required different analysis methods. Document analysis was used for units of analysis that represented organizational plans, research reports and logs, and studies. Document analysis is a qualitative research method that uses a systematic approach for “identifying, analyzing and interpreting the content and context of documents” (Spitzman & Balconi, 2019, p. 6). The process used pre-determined categories based on the research propositions and the policy process model to answer the research questions. Other units of analysis used in this study required a different approach of analysis.

Units of analysis that represent individual interviews, focus groups, and participant observer field notes, were comprised of words and phrases. The data was raw and needed coding before interpretation. Miles et al. (2020) provided a method that uses first and second cycle coding for raw textual data. First and second cycle coding serves as a heuristic model for analysis where first cycle coding (category and theme) informs the second cycle coding (patterns), and the interrelationships of the cycles develop assertions in the context of the research's propositions and theories (Miles et al., 2020). Interpretation of the data analysis was synthesized to answers the research questions.

Other research, independent of this case, was used to examine rival explanations. Yin (2018) posited that "examining plausible rival explanations" in the data analysis phase is a "general analytic strategy" in case study research (p.172). The literature review revealed some scholarship that had similar propositions and theoretical frameworks as this study, and these were used to consider rival explanations for assertions made in the data analysis phases. The synthesis of the data analysis was guided by the questions in the case study protocol and the central and sub-research questions.

Issues of Trustworthiness

Yin (2018) suggested that spurious effects and incorrect inferences by the researcher threatened the internal validity of explanatory case study research (p. 45). For this study, the identification of causal relationships and inferences were supported by data triangulation and active consideration of rival explanations. Both techniques were suggested by Miles et al. (2020) to offset internal validity's weaknesses through "converging conclusions" (p. 306).

Some have argued that a weakness of case study research is its inability to generalize findings (Yin, 2018). The counter-argument reframed the strengths of case study research by pointing to its value of improving understanding with thick descriptions and transfer of knowledge through analytical generalization, and not statistical generalization (Yin, 2018). Analytical generalization focused on the "lessons learned" from the case study and contrasted with a generalization of empirical studies or statistical generalization (Yin, 2018, p. 37). One distinguishing trait of this study aligned with Yin's principle of analytical generalization, where the primary research's characteristics are similar to every other California county Title V programs for children with medical complexity; sharing the *lessons learned* within the California Title V community aligned with the purpose of this research.

Miles et al. (2020) listed the underpinnings of dependability in qualitative research as consistency, stability, quality, and the integrity of a study (p. 305). Yin’s (2018) proclivity to a postpositivist orientation and efforts to specifically develop the field of case study research addressed reliability through the use of a case study protocol. This study's design incorporated a case study protocol that guided the inquiry, in step, with the study’s propositions and theoretical framework, thusly maintaining focus on answering the research questions.

Reflexivity, in the context of this study, was the active process of recognizing one’s underlying beliefs and values and the potential to allow them to impact one’s research (Reid et al., 2018). Reflexivity is a strategy to support the qualitative research standard of objectivity or confirmability (Miles et al., 2020). Other strategies that supported objectivity include structuring the study’s methods in explicit detail with attention to sequences of data collection and analysis, the exploration of rival explanations, and a study structure that allowed audit, replication, or reanalysis (Miles et al., 2020, p. 305). This study intended to use the aforementioned strategies to maintain the highest possible level of objectivity.

Ethical Procedures

The Institutional Review Board (IRB) at Walden University approved this study after a review of my plan for research and confirmation of an executed agreement for data sharing with the primary research sponsor. This study's IRB approval number was 08-28-20-0368061. This study did not collect data through direct intervention or interaction with human subjects or use identifiable private information. The de-identified products of the primary research are stored in a cloud-based document sharing software platform between the research sponsor and myself because I was the lead investigator of the primary research used in this study. Continued access to the products of the primary research is anticipated for other research and uses.

In the analysis phase of the primary research, I found that the primary researchers had their own IRB process. The *procedural ethics* of the primary research are embedded in the research reports, and their discovery was part of this study. *Process ethics* describes the ethical guiding principles for this study. According to Reid et al. (2018), the challenges for transparency in the research process and the potential for researcher bias are mitigated by a reflexive approach to the process. Additionally, in the context of this study, the "practitioner-researcher position is valuable in developing [programmatic] insights" but also comes with the risk of researcher bias (Reid et al., 2018, p. 70). Strategies to guide ethical behavior are of two domains. This researcher used the ethical principles of beneficence and nonmaleficence to ground ethical behavior. Additionally, a strong mitigation strategy existed in the framework of the dissertation process, where a supervising committee lends their expertise and experience to guide the doctoral candidate, which was the environment for this study.

Summary

The purpose of this study was to provide insight for informing effective health care transition policy through the examination and translation of health care transition research. Stakeholder engagement and the evaluation of evidence are phenomena that are present in applied research and policymaking. A qualitative explanatory case study approach was selected to examine and translate data collected from a primary research project and interpret the analysis within a policy process model framework. Data, from multiple units of analysis, were provided by the primary research's sponsor and publicly available websites. This study was retrospective in nature and did not collect data through direct intervention or interaction with human subjects. The data was analyzed through document analysis and content analysis by coding to identify categories, themes, and patterns. The synthesis of the data used triangulation and the consideration of a rival explanation, so assertions are supported or refuted by more than one data source. This study aimed to explain how the primary research data may inform new health care transition policy and what factors make the policy effective. Strategies to strengthen the quality of the study included the use of a case study protocol and a reflexive mindset against researcher bias. Chapter 4 introduces the case study database, an in-depth analysis of the primary research data, and synthesis of the data analysis in the framework of the policy process model.

Chapter 4: Results

Introduction

Children and adolescents with special health care needs face a transition from the pediatric model of care to the adult model of care. Additionally, there are common milestones associated with age that comprise a successful transition (Sawicki et al., 2017). In California, children from low-income households with qualifying complex medical conditions (a subset of children with special health care needs) are managed by a state-mandated Title V program until they age out of the program at 21 years of age (State of California, 2020). As part of a federal requirement for Title V program funding, California's Department of Health Care Services identified a need to improve health care transition planning for adolescents aging out of county Title V programs for children with medical complexity (UCLA Center for Health Policy Research, 2012). Ineffective health care transition of adolescents with medical complexity causes interruptions in medical care and health insurance coverage, and sometimes a loss of functional gains made in the pediatric model of care (Inman et al., 2017). Scholars suggested a scarcity of empirical research for informing effective health care transition policy (Betz et al., 2015; Joly, 2015; Sawicki et al., 2017).

The purpose of this qualitative explanatory case study was to provide insight for developing evidence-informed health care transition policy by examining and translating a case of health care transition research. I examined a primary research project conducted by a California county Title V program for children and adolescents with medical complexity using the policy process model as a framework. The case study evidence analysis included a wide range of primary research documents and qualitative data from focus groups and field notes.

I developed a conceptual model, identified research propositions from scholarship, and adhered to a case study protocol to guide the analysis of data. The conceptual model provided a process for translating coded units from the primary research data to stages in the policy process model. I used research propositions to identify relevant information in the coded units, which I applied appropriately to the conceptual model's processes. The case study protocol was my constant companion in that it provided procedures to follow and additional questions to identify relevant coded units, which kept me focused on this study's topic. The case study protocol was a constant reminder that my purpose for this study was not to evaluate the primary research but to translate why coded units were considered the evidence and how they could inform health care transition policy.

In this chapter, I described the setting, demographics of the study subjects, and methods used to collect data relative to the primary research, which were explored in this study. Additionally, the processes used to analyze the case study evidence are provided. This chapter also addressed the quality criteria and rigor of this study and concluded with the analysis of the case study evidence.

Setting

The case study evidence analyzed for this study involved products from a primary research project conducted by a California county Title V program for children and adolescents with medical complexity. Engaged in the primary research project were personnel from the county Title V program and grant-funded research assistants. Additionally, stakeholder groups were engaged in the primary research, which included a faculty consultant from the health care administration graduate program at the local university, local and regional medical providers involved in the care of the Title V program's enrollees, two local Medi-Cal (Medicaid)-managed care organizations that resume health insurance coverage for transitioning adolescents, and 376 adolescents and their parents. The California Department of Health Care Services, which provided the policies and procedures for county Title V programs, was not involved in the primary research but is indirectly part of the research setting. The department is the public policymaking system that could benefit from this study because health care transition is an ongoing topic according to the latest state-wide Title V program needs assessment (The Regents at the University of California, 2012). The primary research was bounded by time and jurisdiction. The primary research started on January 11, 2016, and ended on August 13, 2018, and was conducted in one California county Title V program.

Demographics

I based the case study analysis on a primary research project that used a convenience sample of adolescents enrolled in a California county Title V program for medical complexity. The research subjects' demographics are essential to detail here because some characteristics of the sample influenced the primary research processes. In the analysis, the primary research processes were associated to stages of the policy process model to translate research to policymaking. The overarching demographic characteristics common to all in the sample was low-income status where the adolescent's annual family income was $40,000 or less, California residency, and 21 years of age or less. These common characteristics in the sample represented the Title V program's eligibility requirements (State of California, 2020). Other demographic characteristics that did not influence the primary research processes were age ranges and gender. Adolescents and new adults represented 98% of the sample, and gender was almost evenly split (see Table 2).

Table 2

*Primary Research Demographics: Age and Gender (*N *= 376)*

Age			Gender Identity		
Range in years	Frequency	Percent		Frequency	Percent
10-13	7	.02	Female	199	.53
14-17	178	.47	Male	177	.47
18-21	191	.51			

Demographic characteristics that influenced the primary research processes were the language that the research subjects self-reported as the primary language spoken in the home, identity with an ethnic group, and whether the research subjected lived in a rural or urban community (see Table 3). Language and ethnic group demographic characteristics influenced the primary research processes because the researchers had to accommodate the characteristics by developing additional processes to produce formal consent documents, educational materials, live presentations, and interviews and focus groups in the research subjects' primary language with culturally sensitive delivery. Additionally, the disparity of health care and available community resources between urban and rural areas in the primary research caused the researchers to significantly focus their efforts in rural areas where the primary research findings showed the greatest need.

Table 3

*Primary Research Demographics: Language, Ethnic Group, and Location (*N *= 376)*

Language			Ethnic Group			Location: Urban or Rural		
	Frequency	Percent		Frequency	Percent		Frequency	Percent
English	242	.64	Hispanic	273	.73	Urban	232	.62
Spanish	134	.36	White	53	.14	Rural	144	.38
			Black /African American	15	.04			
			Asian	9	.02			
			Not reported	26	.07			

In the analysis, I translated the primary research evidence into stages of the policy process model realizing that variances in the study subjects' demographics were mitigated by the primary researchers through their use of Spanish language interpreters and culturally sensitive translation of informative materials. However, the underrepresentation of Black/African American and Asian participants was not addressed in this study but needs further research because stakeholder engagement should include a representative sample of the community demographics, which is clearly not represented by the case study evidence provided by the primary research. I addressed, what I see as an expanding definition of stakeholder engagement, in Chapter 5.

Data Collection

The primary research sponsor provided secondary data that became the case study evidence for this study. After the IRB protocol was approved, and a data use agreement was executed, de-identified limited datasets were transmitted from the primary research sponsor to me through a cloud-based document sharing software platform. A complete inventory of the case study evidence is in Appendix B.

The primary researchers collected data from three sources. First, there was focus group data where open-ended questions that specifically addressed health care transition domains were asked at three focus group meetings and 36 adolescents and their parents. Second, a Transition Readiness Assessment Questionnaire (TRAQ) was administered to adolescents ($N = 376$) and readminister to adolescents if they completed interventions designed and deployed in the primary research; this served as the pretest-posttest survey for correlation studies (paired samples, $n = 34$). Lastly, 11 research assistants produced direct observation field notes following the evolutions of the deployed interventions. The field notes played a role in improving the deployed interventions by incorporating feedback from the research assistants in a reflexivity practice; three of the research assistants brought powerful insight into the primary research because they had aged-out of a county Title V program previously transitioned to the adult model of care.

Data Analysis

I analyzed the data analysis by using a computer-assisted qualitative data analysis software (NVivo) and Microsoft Excel. I uploaded the case study evidence into the NVivo software for coding and storage. I coded germane content of the case study evidence in two cycles using a deductive approach and “a priori codes,” or concept-driven coding (Miles et al., 2020, p. 74). First cycle coding assigned content to categories established by the study’s conceptual model: agenda setting stage, policy implementation stage, and policy evaluation stage. In the second cycle, the coded content was transferred to Excel workbooks where sub-codes were developed from the coded content from each of the first cycle coding categories. After reorganizing the coded content in Excel spreadsheets, themes emerged and were assigned inductive codes. A list of a priori conceptual categories and primary codes are displayed in Table 4. Taken together, I synthesized the coded content and identified themes in the first three stages of the policy process model to illustrate how research evidence could inform policymaking.

Table 4

A Priori Categories and Codes

Conceptual Categories	Codes
Agenda setting stage	Problem definition Stakeholder engagement Policy formation
Policy implementation stage	Development of interventions Stakeholder engagement Deployment of interventions Development of policies
Policy evaluation stage	Correlation studies Identifying best practices

The analyzed case study evidence varied in type and volume. I found it necessary to differentiate between who produced the content to clearly address the study's propositions and help triangulate the data analysis. For example, there were two originators of content for the Problem Definition theme in the Agenda Setting Stage, the primary research documents and qualitative content from stakeholder focus groups. The primary research documents provided content from a programmatic perspective by bureaucrats that administered the Title V program. The stakeholder focus group content provided a Title V program services consumer perspective. By differentiating the origin of the coded content, I identified a level of stakeholder engagement and agreement for establishing a problem definition code supported by bureaucrats, which addressed the study's propositions and the use of multiple data sources triangulate a comprehensive meaning of the content.

I had to develop profiles for the primary researcher participants to reveal where the quoted data originated and which role the participants served in the study. The case study evidence was mostly reports and spreadsheets and the number of stakeholders at focus groups and interviews were reported in aggregate. Statements made by adolescents represented the role of adolescent stakeholder (AS), and statements made by the parents of the adolescents represented the role of parent stakeholder (PS). Research assistants employed by the county Title V program provided field notes for the primary research. Filling the role of participant observer, the research assistant (RA) provided quoted material for examples in the findings section. There was one principal investigator (PI) whose role was to draft the reports for the primary research sponsor.

Evidence of Trustworthiness

Credibility

Where the case study evidence allowed, I triangulated the data analysis by adding labels to identify different origins and data sources that converged on the same theme. Different data sources included coded units from documents produced by researchers and bureaucrats, and focus group content produced by stakeholders.

Pattern matching was used to explain rival explanations found in the analysis, which were limited to the theme of developing interventions. The predicted process for developing effective interventions supported by the study's proposition, a large volume of coded field notes from research assistants reflected that improving interventions were done by the bureaucrats, without engaging the stakeholders. This plausible threat to the study's credibility was explained by the primary research documents that outlined a prescribed process for using the research assistants to solicit stakeholder feedback for improving interventions and document the input in field notes, therefore indirectly providing stakeholder engagement and the original proposition remained the rule.

Transferability

This study has prospects for analytical generalization to other California county Title V programs for children with medical complexity. California county Title V programs for children with medical complexity are the operational arms of the state's controlling administrative agency and operate under the same set of policies and procedures (State of California, 2020). This homogeneity logically facilitates the transference of this study's findings and recommendations from the county, where the primary research was conducted to other California counties. Additionally, while the state's controlling administrative agency sets the policies for county Title V programs, transferability is likely to happen through diffusion from the state-level policymaking arena.

Impeding this study's prospects for analytical generalization are delimitations related to the primary research sample. A convenience sampling technique was used, and the sample size was small. Providing a representative sample was a challenge for the primary researchers and was documented in the case study evidence. However, this study's focus was on how and why research evidence may be used to inform new policy, and the case study evidence abundantly demonstrated that research processes translate to policymaking.

Reliability

This study's design relied on the structure provided by a conceptual model, propositions, and a Case Study Protocol (see Appendix A). The structure focused, and at times refocused, my data analysis. The Case Study Protocol questions were not modified in the data analysis phase of research and contributed to building reliability into the study (Yin, 2018, p. 96).

The structure in this study’s design provided consistency for interpreting data from multiple sources and was reasonable in the same methods used by other case study researchers. Miles et al. (2020, p. 305) suggested that consistency and using accepted processes across research are hallmarks of dependability.

Confirmability

During the data analysis phase of this study, I frequently reflected on the purpose of this research. It was vital for me to acknowledge, through reflection, that having first-hand knowledge of the primary research could bias this study. Reflecting on this study's purpose reinforced that I was not addressing the validity and effectiveness of the primary research but exploring its processes for translation to policymaking.

I found jargon in the coded content easily recognizable and interpreted appropriately, which is one benefit from having first-hand knowledge of the primary research. Another benefit was adhering to this study’s built-in structure, which played a significant role in alleviating the potential for researcher bias by focusing the data analysis on the research and protocol questions.

Results

Category: Agenda Setting Stage

The initial step in the policymaking process is agenda setting (Simon, 2017). Agenda setting encompasses identifying a salient social problem and what priority policymakers give it (Hillman et al., 2015). The case study evidence analysis started with a review of documents produced by the primary researchers, which represented the advocacy coalition framework policy instrument in action. According to Simon, the advocacy coalition framework involves a calculated and methodological activity to set an agenda for a problem that is perceived stable by the bureaucracy, political leaders, and other stakeholders (2017, p. 105). Initially, coded units were extracted from the primary research documents that represented the Title V program's strategic plan, and interim research reports drafted for the primary research sponsor. Next, coded units were extracted from focus group content. The primary researchers conducted three focus groups with a convenience sample of the Title V program's adolescent members and their parents (*n* = 36). It was clearly identified in the triangulation process that defining the problem of ineffective health care transition included participation of stakeholders.

Code: Problem Definition

The county Title V program that conducted the primary research responded to the findings of a Title V Needs Assessment report, which identified health care transition planning as an area in their operations that needed improvement. The county Title V program’s response was to further define the problem of poor health care transition planning by developing a strategic plan. The strategic plan documented that the county Title V program’s health care transition efforts consisted of “mailing prescribed transition materials to adolescents” and “retroactively mitigating the issues that typically result from poor transition planning” (PI). Additionally, the county Title V program admitted that “transition planning was not a priority in the normal workflows” (PI). The Title V program conveyed in the strategic plan that the existing health care transition policy was ineffective.

Essential for defining the problem of ineffective health care transition policy was feedback from the adolescent members of the Title V program. During focus group meetings, adolescents who were enrolled in the county Title V program responded to how they felt about health care transition. The responses revealed trepidation about health care transition: “scared. don’t know anything,” "feeling lost, worried about follow-through," and "parents have not spoken about transition" (AS). At other focus group meetings when parents were included, the responses to the same question revealed inadequate understanding of health care transition: “don’t know what to expect,” “confused, want to learn more about transition,” “concern to [*sic*] what it is,” and “what happens after?” (PS).

Code: Stakeholder Engagement

Stakeholder engagement and participation are at the heart of developing effective health care transition policy (Ferris et al., 2015; Schlucter et al., 2015). In the primary research, internal stakeholders were represented by adolescents between the ages of 14 and 21. According to the American Academy of Pediatrics, health care transition planning should start at 14 years of age (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011). California’s Title V program for children with medical complexity ends when the member reaches 21 years of age (State of California, 2020). Additionally, the parents of adolescent stakeholders were included in the primary research.

The county Title V program planned to engage the internal stakeholders by establishing “a venue for …adolescents, and their families, which regularly and exclusively pertain to transition planning to adult medical care,” and through “informed consent meetings convened by the Principal Investigator,” which satisfied the informed consent and assent requirements of the primary research’s human subjects research protocol (PI).

The county Title V program operationalized regular engagement of stakeholders through an annual transition conference: “Thus far, we have established an annual venue that brings together our…adolescents, their families, and organizations that they would be transitioning to, to meet, hear presentations, and receive materials” (PI). In another way to engage stakeholders, and directly related to the primary research, informed consent meetings were convened where program adolescents and their families were introduced, inducted, and subsequently participated in the research: “The meetings were set up in an outreach fashion using family resource centers, youth centers, hospital meeting rooms, and government facilities in all the major cities and towns of (the county Title V program service area),” and “The Research Assistants contributed by securing the meeting venues, providing healthy snacks, providing certified Spanish interpreter services, and helping families review and sign the packet of informed consent documents” (PI). Thus far in the primary research, the county Title V program went beyond their standard operational functions to engage internal stakeholders in the primary research. However, the internal stakeholders were not as engaging as anticipated by the primary research.

A function in the data collection process performed by the research assistants was to monitor internal stakeholder engagement by tracking invitations made by research assistants and attendance to meetings by internal stakeholders. There were 10 informed consent meetings conducted at various locations in the county Title V program’s service area where the concept of health care transition and the purpose of the primary research were introduced to internal stakeholders. The initial attempt to engage internal stakeholders resulted in 7% of those contacted attended the meetings (see Table 5).

Table 5

Title V Program Initial Telephone Campaign for Stakeholder Engagement

Initial Engagement Meetings	Frequency	Percent
Contact attempted with families of adolescents 14 to 20 years of age	1,810	100
Successful contact with families of adolescents 14 to 20 years of age	1,287	.71
Families that committed to attend the engagement meetings	287	.22
Families that attended the engagement meetings	96	.07

Note. Unsuccessful telephone contacts were due to disconnected or wrong telephone numbers. Unit of analysis is one telephone contact for one adolescent member.

The primary researchers did not define or establish a measure for stakeholder engagement. Bowen et al. (2017) suggested that event attendance is a measure of stakeholder engagement, but additional corroborating data is needed to determine the engagement's quality and extent. I found that event attendance and punctual attendance were emerging themes for how to measure the level of stakeholder engagement by the primary researchers. I further supported this assumption when coded units for other primary research events were analyzed.

Code: Policy Formation

The county Title V program initiated two internal policies after a strategic planning evolution before collecting data for the primary research. In line with the advocacy coalition framework and policy formation, the county Title V program worked within their policy subsystem (a county within a state system). It used empirical methods and technical information to establish new procedures to define a policy goal (Simon, 2017, p. 111). The new internal policies established a level of commitment from the county Title V program and were broadly supported by health care transition scholarship.

To further define the problems with the existing health care transition policy, the Transition Readiness Assessment Questionnaire (TRAQ) (East Tennessee State University, n.d.) was adopted to measure the readiness for health care transition of the program adolescents: "We will assess for readiness for transition to adult care by administering the Transition Readiness Assessment Questionnaire (TRAQ) and analyzing the data," "TRAQ is especially helpful in monitoring the progress of readiness to transition and lead (the program) in developing educational interventions that improve the readiness for transition, “ and “TRAQ surveys are digitized and entered into the (program’s) case file [*sic*]" (PI). The TRAQ was introduced to program adolescents and tested during an annual transition conference, and "adolescents responded favorably" (RA7).

Another new internal policy established the employment of research assistants for the primary research. Research assistants were recruited from a local university's health care administration program and hired into civil service classifications by the county Title V program: "In an effort to decrease interviewer bias, we are using graduate student interns to administer the (TRAQ) questionnaire after they receive an orientation to the (program) through immersion” (PI).

Taken together, the TRAQ assessment and research assistants from the county Title V program, were well on their way to identifying changes or additions to the program that might improve or replace the existing health care transition policy.

Category: Policy Implementation Stage

The primary research implemented several policies for the county Title V program. These policies were enabled through a bottom-up approach by local county Title V program administrators. They were contained within the policy subsystem of the California Department of Health Care Services. The implementation of new policies created revisions to workflows, new funding requirements, and new opportunities for the county Title V program to approach stakeholders for input. The policies were related to interventions aimed at improving health care transition of adolescent program members.

The analysis of documents authored by the primary researchers disclosed that the development of interventions to improve the readiness for health care transition was based on two processes of the primary research. First, the program adolescents and their parents were asked questions correlating to the TRAQ survey domains: managing medications and medical appointments, tracking health issues and talking with medical providers, and situational questions related to domestic functions and perceived future needs. Second, the respondent's answers in the TRAQ survey were assigned a numerical value rendering a TRAQ score. The primary researchers reported:

> TRAQ scores are the sum of 19 answers that have values that range on a scale from 1 to 5. The original TRAQ survey contained 20 questions, but question 15 was removed from the study in collaboration with the survey's lead developer.

TRAQ scores in the range of 76 to 95 are achieved when survey questions are answered by ‘yes’ choices, which reflects that transition readiness is on track. TRAQ scores less than 76 will require attention or intervention—if they do not improve on their own. The mean TRAQ score for Dataset 7 is 72.5 (PI).

Code: Development of Interventions and Stakeholder Engagement

The design of several interventions was based on an analysis of TRAQ scores and focus group feedback from program adolescents and their parents.

Pharmacy Class Intervention. The primary researchers analyzed the TRAQ survey data and reported that "40% (of program adolescents in the study) needed an intervention to improve in this area" (PI). Moreover, from an analysis of focus group data, the primary researchers reported: "Focus group input conveyed that pharmacy dealings where [*sic*] a mystery to most adolescents” (PI). Some program adolescents revealed why they were not managing their pharmacy visits, “Mom does everything” and “Mom likes doing it” (AS). The dependence on an adult to manage pharmacy visits was echoed by “I am afraid to get the wrong medications” (AS). Other program adolescents revealed why they managed their pharmacy visits, “I do it because my mom [*sic*] doesn’t speak English. So, I have to do it,” and “I want to know the side effects of the medications” (AS). The adolescent focus group data related to the TRAQ domain of managing medications suggested a convergence with the primary researchers’ conclusion to develop an intervention focused on: “a pharmacy orientation by a pharmacist, with a field trip to a pharmacy” (PI). When the program adolescents were asked about the benefits of a pharmacy class in the focus group, they responded, “Yes, want to come to class,” “Yes, need a workshop,” and “(I) would like to actually go to a pharmacy” (AS).

Care Notebook Intervention. The primary researchers addressed a low TRAQ score in the domain related to tracking health issues: “Seventy percent of respondents report their medical history and allergies at medical appointments and keep a calendar of appointments. However, 60% of the respondents do not go to doctor’s appointments with prepared questions” (PI). Without many bases, the primary researchers created a policy to distribute care notebooks, "To improve this domain, care notebooks have been introduced program-wide" (PI). Care notebooks were described in the primary research documents:

> Care Notebook: A three-ringed binder organized with tabs that provide one place to store information for the (program) member. (Program) members are given tangible items and documents at every intervention or outreach meeting, which promotes the use (of)the Care Notebook. (Program) members are encouraged to use the Care Notebook at their provider visits and come to the (Program) office for refreshing the documentation needed to support their care (PI).

Minimal focus group responses from program adolescents or their parents supported the care notebook intervention because some adolescents had a method of managing documents that are needed at medical provider visits: "stores documents in (a) briefcase," and "uses (a) binder (that is) color-coordinated" (PS). A single response reported, "Yes, we need a care notebook" (AS). I reasoned that the divergence of data sources that support the adoption of the care notebook by the primary researchers was based on a widely-accepted practice prominent in the gray literature for things parents can do for their child with special health care needs.

Medi-Cal Managed Care Intervention. The primary researchers reported that “80% of the respondents did not know what their health plan covered or how to apply or re-apply for health coverage” (PI). Health insurance, in it of itself, is complicated and incredibly complicated for adolescents enrolled in California's Title V programs for children with medical complexity. California's Title V programs for children with medical complexity are part of the state's Medi-Cal program (California's Medicaid program). In some counties, the Title V program is entirely carved-out of the local Medi-Cal managed care system (State of California, 2020). What this means for the program adolescents in the primary research is that they have double-coverage in Medi-Cal-based health plans requiring separate enrollment and reenrollment cycles, as well as different processes and jargon to authorize treatments and medications; the Title V program covers medical treatments, medications, and therapy only for the program’s medically eligible condition, and the Medi-Cal managed care organizations cover conditions typically associated with primary care. I found little focus group contributions from the program adolescents. However, the responses from parents supported participation from the local Medi-Cal managed care organization in the primary research: "Sometimes it feels that (the Title V program), Medi-Cal and (the local Medi-Cal managed care organization) bounce the responsibility to one another," "Want to know more of the differences between ... (Medi-Cal managed care organization) vs. (Title V program)," and "Would like (the Medi-Cal managed care organization) to be present so they are aware of the problems" (PS). Some parents requested: "Please bring in (the Medi-Cal managed care organization) to these workshops (focus groups)" (PS).

Diabetes Management Education Intervention. Early in the primary research, focus group feedback indicated "a need for local support groups that (are) disease-specific" (PS). The primary researchers addressed the basis of the focus group feedback:

> A literature review using health care transition as the search term yielded an abundance of scholarship that was separated into disease cohorts. What seems apparent from the literature review is that transition planning needs to consider the unique issues and characteristics of the different disease groups; one transition planning model will not satisfy the diversity of diseases. Therefore, cohorts were developed using primary ICD 10 codes (disease classification) to establish disease groups that could be assigned a priority by the number of members, and specific expertise brought into the focus group meetings. The first priority, by the numbers in the TRAQ database, was diabetes (PI).

Organizations need to prioritize work when resources are limited. The primary researchers, through the county Title V program, prioritized program adolescents with diabetes for the development of a diabetes management education intervention: “Reinforcing the decision to start the interventions with a diabetic cohort (was) a comparison of a fairly static caseload against an increasing rate of healthcare used by (program adolescent) diabetics” (PI). Seeking more engagement from internal stakeholders, the primary researchers conducted additional inquiries: “Diabetic members and their families were interviewed and surveyed. The result was the establishment of a diabetes education project aimed at educating members to self-manage their disease and prepare for the transition" (PI). There was a strong convergence of data sources that supported the development of diabetes management education intervention with stakeholder participation.

Code: Deployment of Interventions

Identified in the primary research documents were two interventions that were highly specialized by incorporating external stakeholders in curriculum development: the pharmacy class and diabetes management education. The county Title V program policy to issue care notebooks to program adolescents was deployed with little feedback from internal stakeholders. On the other hand, the inclusion of the local Medi-Cal managed care organization was strongly supported by internal stakeholder feedback:

> Early in the qualitative data collection phase, (program adolescents) and their families identified a disconnect between (the Title V program) and (the) Medi-Cal Managed Care organizations. Since most, if not all, (program) members in (the county) transition to (a Medi-Cal Managed Care organization), a partnership was established where the Medi-Cal Managed Care organization participated in all the … interventions with staff, educational materials, or funding. The (local Medi-Cal Managed Care organization) has turned out to be an active partner bridging the gap between health plans (PI).

Additionally, in keeping with the commitment to engage stakeholders, the primary researchers used the research assistants as participant observers "at two deployed interventions; the diabetes management class and the pharmacy orientation class" (PI).

The purpose for including the research assistants in these classes was to gather data through a "reflexive" writing technique where their field notes provided "a valuable source of data," which was "formative in nature" (PI). The research assistants were tasked with reflecting after each class and documenting what they observed and what improvements could be made.

Pharmacy Class. A description of the Pharmacy Class was extracted from the primary research's final report to the research sponsor:

> A monthly class taught by a pharmacist. The two-hour course aims to indoctrinate the (program) adolescents to use pharmacy services on their own. The curriculum includes how to read drug labels, how to interpret a (Title V program) SAR (service authorization request) and Medi-Cal Managed Care TAR (treatment authorization request), as well as role-playing to exemplify how to interact with pharmacy staff. The class is attended by adolescents and their parents, where typical attendance is 15-30 (PI).

There were 12 pharmacy classes between January 2017 and January 2018. The research assistants described the first class's attendance as "well attended" and "most of the kids came with their parents" (RA1). However, the subsequent pharmacy classes brought out different responses from the research assistants: “Two families showed up, the lowest number since we started these classes. We need to improve outreach efforts” and “The class is really good the only problem seems to be getting families out to the classes” (RA9). Attendance for the pharmacy class was considered a measurement of internal stakeholder engagement by the primary researchers. Although the research assistant’s field notes reported that “overall again, a great class with great families” and “It was a positive atmosphere” (RA11), attendance for the pharmacy class was lower than expected (see Table 6). At this point in the analysis, I created a thematic code for the emerging *level of engagement* theme that presented in focus group meetings and pharmacy class invitations.

Table 6

Title V Program Pharmacy Class Engagement

Pharmacy Class	Frequency	Percent
Successful contact with families of adolescents 14 to 20 years of age for pharmacy class invitation	552	100
Families that committed to attending the pharmacy class	214	.39
Families that attended the pharmacy class	62	.11

Note. Unsuccessful telephone contacts were due to disconnected or wrong telephone numbers. Unit of analysis is one telephone contact for one adolescent member.

External stakeholders engaged the primary research by participating in the pharmacy classes. The research assistants recorded in their field notes: “Representatives from (the local Medi-Cal managed care organization) and (a local hospital) gave their presentations” and “I enjoy having (the local Medi-Cal managed care organization) at this class; the families always have questions … it is a good way to get the dialog going about what transition to an adult healthcare plan might entail” (RA2). As the pharmacy classes went on, the research assistants documented a decline in external stakeholder engagement: “Representatives were missing from (the local hospital) and (the local

Medi-Cal managed care organization), but they managed to send goodies (educational literature) for the families" (RA3) and "The (local Medi-Cal managed care organization) representative was not there, but (the local hospital) sent a person to represent them" (RA6). For those program adolescents and families that attended the pharmacy classes, the research assistants made favorable field notes and valuable suggestions for improving the classes.

The pharmacy classes were led by a local pharmacist: "He was able to engage the audience in the class," "kids and parents asked a lot of questions," "kids were sent in a separate group to conduct this [*sic*] role-playing activity with the pharmacist," and "families appreciated learning they have the power to choose pharmacies as well as (medical) providers" (RA6). The research assistants also made suggestions to improve the pharmacy classes in their field notes: "There was one family who brought 3 [*sic*] younger siblings…a breakout area (is needed) where they can do some fun activities" (RA6) and "I felt it was necessary to spark a conversation with…commonly asked questions to make the families feel comfortable asking question" (RA11).

Diabetes Management Education. The diabetes management education intervention was extensively developed and improved through local external stakeholder participation and reflexive field notes by research assistants. The intervention was named "Chews Wisely" by the county Title V program. External stakeholder participants included teams from the local public health department, and local Medi-Cal managed care organization. Emerging from the data analysis were characteristics that align with the institutional analysis and development framework for policy development and implementation. Simon (2017) suggested that the institutional analysis and development framework was a reasonable choice for policy development and implementation where policy is created and improved on a local level by the policy stakeholders. Additionally, the institutional analysis and development framework support the inter-agency collaboration for managing pooled resources; the primary research grant did not fund the Chews Wisely initiative. Local agency collaboration included the county Title V program, elements from the local public health department, and the local Medi-Cal managed care organization. The California Department of Health Care Services filled the role of a "distant government" that did not adequately address effective health care transition planning for program adolescents with diabetes (Simon, 2017, p. 34). The diabetes management education for the county Title V program adolescents was a novel concept locally developed and implemented through the primary researchers' leadership.

A description of Chews Wisely was extracted from the county Title V program’s final report to the primary research sponsor:

> A quarterly class taught by a nutritionist and a nurse, with a cooking demonstration by public health educators. The name of the class is Chews Wisely. The class is two-hours long for five weekly sessions. The class provides (program adolescent) members and their families with an introduction to diabetes management, a cooking demonstration with replacement foods deemed better for diabetics, icebreaking activities to facilitate a support network and medical guidance for better diabetes management (PI).

The research assistants recorded their attempts to engage and track program adolescents and their families' attendance for the initial focus group meetings and the pharmacy classes. However, I did not find any such documentation in the case study evidence for the Chews Wisely classes. The research assistants' field notes for the Chews Wisely classes conveyed a consensus that program adolescents and their families' attendance were below expectations. Without a data source other than field notes, I deduced that the participation capacity of a Chews Wisely class was up to seven program adolescents and their families: “There was a great turnout at tonight’s class, 7 families totaling 26 participants” (RA1). All other research assistant field note entries described low attendance: “three families showed up” (RA2), “three families showed up again,” (RA9), and “two families showed up, the lowest number since we started these classes” (RA10). Similar to other internal stakeholder engagement opportunities, Chews Wisely exhibited a low level of engagement and thematically, was subject to the attendance phenomenon.

I made a reasonable assumption about resources expended by the county Title V program, the local public health department, and the local Medi-Cal managed care organization for the Chews Wisely classes. The primary researchers' final report describes the Chews Wisely teaching staff as a public health nutritionist, a public health nurse, and public health educators, working past regular working hours and at various remote locations in the county. Additionally, equipment and supplies included technology for delivering the presentation, mobile cooking equipment, and food ingredients for diabetic designed meals. The Chews Wisely classes required inter-agency cooperation and coordination and extensive resources, which, according to the primary research budget documents, were not funded by the primary research sponsors. I equated the concern for Chews Wisely classes' punctual attendance by program adolescents and their families to the extensive efforts in coordination and resources made by the county Title V program and others. The research assistants expressed the concern for punctual attendance, who were active participants in the Chews Wisely classes.

The concern for punctual attendance was a frequent coded unit in the research assistants' field notes related to the Chews Wisely classes; some examples included: "our families did not arrive on time" (RA1), "it was a little nerve wrecking in the beginning because at 5 p.m. we had no families" (RA3), "one family was punctual, remaining 3 families showed up after class began" (RA9), "half of the families were punctual; the other half arrived after class started" (RA10), and "(we) decided to start class so our other families were not kept waiting" (RA6). Adding to the concern for punctual attendance was a dense curriculum requiring inter-agency coordination.

Gleaned from the research assistants' field notes were comments about the Chews Wisely curriculum and its delivery. The bilingual capacity of the staff delivering the curriculum was an issue: "the class is bilingual" (RA2), "when the parents began to speak in Spanish the translator [*sic*] had to translate to the nurse in English, the moments of silence could be the cause of why we didn't have more in-depth (discussions)" (RA1). Although the portion of the Chews Wisely curriculum dedicated to a cooking demonstration of replacement foods for diabetes was well received by the program adolescents and their families, there were problems with the cooking equipment: "the replacement theme is a brilliant idea, and I hope we can execute it well enough for our families" (RA2), "there were some issues with the burners during cooking, but these were handled" (RA3), and "the burner(s) (are) not heating as fast and effectively" (RA9). There appeared to be some friction between the research assistants and the public health educators, which was apparently resolved: "This PowerPoint presentation was a little more organized than the last one, but there was still no interaction with the presenter and the families" (RA1), "If we continue our partnership with (the public health educators), we need to improve the topics integration so they fit more congruently" (RA3), "I also sense some tension between (personnel from the county Title V program) and (the public health educators)," and "I did feel a bit of uneasiness from (the public health educators) but dismissed it" (RA9). Different from the other field note entries was this compliment, which likely represents a change in personnel: "(the public health educator) did an outstanding job making (program adolescent) members and their families feel welcome, gaining their trust, and engaging their participation" (RA2). I found frequent positive comments about the curriculum and an important emerging theme in the second cycle analysis of the research assistants' field notes.

The Chews Wisely classes' origin was identified in the second interim report provided by the primary researchers in January 2017. Chews Wisely was presented as a demonstration pilot project that focused on diabetes pathology and foods and fitness regiments that improve the hallmark of diabetes management performance measure, the laboratory values for hemoglobin A1c. According to the Mayo Foundation for Medical Education and Research (2020), hemoglobin A1c is a measurement of average blood glucose over a three-to-four-month period. Chews Wisely was initially designed to be a series of lectures and a cooking demonstration aimed at improving diabetes management for diabetic program adolescents. After the first few sessions, the external stakeholder and research assistants improved the curriculum by introducing the TRAQ survey, role-playing, and icebreaking activities.

A portion of the Chews Wisely curriculum was dedicated to individual goal setting for program adolescents. The research assistants paired up with Chews Wisely participants and set goals and assigned tasks (homework). The TRAQ survey, the adopted health care transition assessment tool by the primary researchers and by this time, incorporated program-wide by the county Title V program, was used to identify areas targeted for improvement by the research assistants: “her TRAQ survey showed the areas where she needed help” (RA3), “her (homework) for this week (was) based on her TRAQ survey scores, and included calling her doctor to check her next appointment” (RA9), and “I was able to view her TRAQ survey and noticed one of the issues she is having trouble with is filling a prescription on her own" (RA10). According to the reports provided to the primary research sponsor, the county Title V program recognized the TRAQ survey's value and established a policy to administer the TRAQ survey to all program adolescents 14 years of age and older whenever the opportunity to administer the survey presented.

Suggested by the public health nurse that was leading the instruction for the Chews Wisely classes: “As a (former) school nurse, I had noted (that)…for several of my diabetic students, embarrassment and secrecy about (their diabetes) was an issue. I believe if we can role model how to approach new and uncomfortable situations, we will achieve greater (management skills)" (RA11). Subsequently, "role-playing was introduced to help the (program adolescent) members practice real-life scenarios that they might experience at school or work." "The families really got into the role-playing" and "it seems like the parents use role-playing activities as a tool to teach their kids life skills" (RA11).

One research assistant suggested, "I think introducing an activity that would encourage friendly relationships between the families would be great" (RA1). Acting on the research assistant's suggestion, "We started off by breaking (the participants) into teams and assigning a marshmallow [*sic*] tower challenge. It's an icebreaker that uses teamwork to get them talking to each other" (RA11). According to the research assistants' field notes, the type of icebreaking activities varied, "Jeopardy was the featured icebreaker (for this session)" (RA9). The result of introducing icebreaking activities was summed up by, "families are connecting well, icebreaking activity was enjoyed by all" (RA11).

The primary researchers and research assistants did not recognize an emerging theme of collectivism in the diabetes cohort exhibited in the Chews Wisely classes. Although documented in the interim report for January 2017, early Chews Wisely field notes stated, "parents requested support group with other parents, and adolescents requested support group with other adolescents" (RA11). One research assistant field notes described an encounter between a program parent and their child's endocrinologist (sub-specialist directing the medical care) as "concern(ed) about the way some physicians made them feel when they first found out their children had diabetes…there was disapproval from all of the families on how the physicians broke the news" (RA1). This was their first impression of the sub-specialist that would care for their child until adulthood. Additionally, “the families must be getting this information (diabetes management education) from their (medical providers), but they are not registering it" (RA11). In other words, the sub-specialist (endocrinologist) for the program adolescent with diabetes is likely to provide diabetes management education but the individual session, typically at a regional children's hospital, is not effective. Chews Wisely offered an opportunity for program adolescents and their parents to meet other program adolescents and parents in the same disease cohort; there seems to be some benefit when delivering diabetes education management education in a collective venue, according to the research assistants’ field notes: “They noted how they enjoyed doing it (diabetes management education) as a group rather than individually” (RA8), “I was also surprised that they liked meeting (in) a group (setting). They did not want to meet as individual families” (RA10). Supporting the collective method was, “They seemed to be forming bonds with other families going through the same situations” (RA9), “They were giving each other advice and trying to console each other” (RA3), and “Allowing the families to share their stories helped them feel more comfortable and establish rapport” (RA9). In the end, there was no case study evidence of support group formation.

Code: Policies and Procedures

I had to rely on a segment of Simon's (2017) working definition of public policy, "what government does," to identify new policies and procedures pertinent to the primary research (p.3). The case study evidence did not include the county Title V program's official policies and procedures. Therefore, to identify an organizational change that traditionally requires new policies and procedures, I coded units from two final year-end reports describing the county Title V program's implementation of organizational changes to the research sponsor. I compared the organizational changes to the primary research’s budgets and determined that the organizational changes were funded solely by the county Title V program and the local Medi-Cal managed care organization, which further supported my assumption that these coded organizational changes caused new policies and procedures; government budgeting prioritizes the financing of public policy (Simon, 2017).

In the second cycle coding phase, I separated the new policies and procedures into two groups. The first group represents policies and procedures that were bureaucratically driven, aligning with the characteristics of the advocacy coalition framework model of public policy implementation. In this first group, the county Title V program was the agenda setter. The policy brokers included subject matter experts from advisory groups and academia; there was little internal stakeholder engagement in developing this first group of policies and procedures. The second group represents policies and procedures initiated and improved through direct internal and external stakeholder engagement, focus group and interview data, research assistant field notes, and empirical data.

The first group of policies and procedures included: the annual transition conference, the distribution of care notebooks, the diabetes management education named Chews Wisely, and establishing a health care transition registry.

Annual Transition Conference. The purpose of the annual transition conference was to create “a venue specifically focused on (health care) transition” and to “bring awareness, provide information, introduce adult services, and celebrate the graduation (a euphemism for aging-out) from (the county Title V program) to an adult model of care” (PI). The conference venue was designed to provide a space and time “where (program adolescents) interact with organizations that will likely be involved in their transition" (PI). "(The local Medi-Cal managed care organization) is an active participant and (contributes funds and staff)" (PI). The origins of the annual transition conference were documented in the county Title V program's strategic goals document (April 2015) and predate the primary research by one year. At the closing of the primary research, six annual transition conferences progressively outgrew the physical venues due to sizeable attendance by program adolescents and their families and external stakeholder participants. The physical venue started at a meeting room of an outpatient clinic for physical therapy and ended up at a conference center at the local convention center. I surmised that the annual transition conference policy and procedures were initiated and maintained by the county Title V program administrators with little to no internal stakeholder input; however, the policy gained acceptance by internal and external stakeholders every year—evident by the increasing level of participation that caused a venue change.

Care Notebook. The distribution of care notebooks to all program adolescents was conceptualized and implemented by the county Title V program administration. I did not find mention of its origin in the case study evidence. Additionally, I was perplexed as to why a binder and paper documents would suffice the program adolescents' needs in this day and age of electronic patient portals commonly used by commercial health plans. Nevertheless, the care notebooks were distributed at all meeting venues and home visits by the county Title V program staff.

Chews Wisely. Analysis of TRAQ survey data by the county Title V program showed that 32% of the survey sample was program adolescents with diabetes. This was the largest disease cohort in the primary research. Furthermore, the data showed a relatively static caseload over six years but with a steady increase of medical resource use by program diabetics. The institutional analysis caused the program administrators to pursue an intervention aimed at improving diabetes management of program diabetics. The diabetes management education initiative was named Chews Wisely by the county Title V program and consisted of five weekly sessions of 2-hour classes conveyed from 5:00 p.m. to 7:00 p.m. The curriculum promoted glycemic control with diet and exercise, diabetic replacement foods through a cooking demonstration, and building relationships among the program families with diabetic adolescents by ice breaker and role-play activities. The classes were led by a nutritionist, a public health nurse, and public health educators. The local Medi-Cal managed care organization participated by offering question and answer sessions and funding. The Chews Wisely classes rotated between the two most populous cities in the county on a quarterly basis to improve access and attendance for the classes. Although Chews Wisely did not directly address effective health care transition planning, the underlying theme of program adolescents with diabetes learning to self-manage and self-advocate indirectly addressed effective health care transition.

Health Care Transition Registry. The county Title V program decided to create a health care transition registry to “track and monitor the progress of (transition planning) for program adolescents” and “record and store TRAQ survey data" (PI). The registry information is shared with pediatric and adult medical providers, and the local Medi-Cal managed care organization to align health care transition efforts. Internally, the registry would develop individual health care transition plans, a strategic goal set before the primary research. The case study evidence did not reflect any internal or external stakeholders' involvement in establishing the health care transition registry.

The second group of policies and procedures developed with internal and external stakeholder participation included: The Family VIBE meetings, pharmacy class, a home visiting team, and a pilot project to assist with gaining conservatorship.

Family VIBE. Early in the primary research, the principal investigator and research assistants convene internal stakeholder engagement meetings to gain parental informed consent and adolescent assessment to participate in the primary research, conduct focus groups, and administer the TRAQ survey. "The outpouring of (program) family (questions) about routine program (issues) often usurped the meeting intended for the (primary) research" (PI). According to an entry in the final report by the primary researchers, "The (county Title V program) needed a community outreach function staffed by regular (program) workers to mitigate program issues before (the program) families were will to discuss (health care) transition planning" (PI). The county Title V program established a community outreach function called Family VIBE, or family voices, ideas, and building empowerment. "These outreach meetings were conducted in every community (of the county) by a (program) case manager, public health nurse, and frequently the (program) administrator" (PI). During the primary research period, the research assistant participated in Family VIBE to distribute care notebooks and administer TRAQ surveys. The outreach meetings oriented new members to the program and introduced the concept of health care transition. The local Medi-Cal managed care organization participates in the Family VIBE because most issues brought forth by the program families were related to their services.

Pharmacy Class. The focus group questions were based on the domains in the TRAQ survey. The initial TRAQ data analysis suggested that an intervention was needed to improve interactions by program adolescents at the pharmacy. The study of focus group data indicated that the internal stakeholders would participate in a pharmacy class to enhance their knowledge of medication labels, insurance authorizations, and interactions with the pharmacist. The pharmacy classes convened monthly and were led by a pharmacist with the local Medi-Cal managed care organization's participation. The pharmacy class was conceptualized by the primary researchers but driven by the internal stakeholder participation in its makeup.

Home Visiting Team. Analysis of TRAQ survey data by the county Title V program showed that 15% of the survey sample was program adolescents with cerebral palsy. This was the second-largest disease cohort in the primary research. A home visiting was comprised of "a public health nurse, a (program) case manager, and research assistant (during the time of the primary research)" (PI). The purpose of the home visiting team was to "accommodate families that are transportation challenged or face challenges when leaving their home" (PI). The home visiting team was formed after parents of adolescents with cerebral palsy told research assistants that they could not attend the initial primary research engagement meetings and focus groups and asked if they could come to their homes instead. "The home visits are designed to mitigate (program) issues, further (health care) transition planning efforts by collecting input and administering (TRAQ) surveys, (and) distribute care notebooks" (PI). The policy enables county Title V program staff to perform home visits due to some parents merely asking for it.

Assistance with Conservatorship. Analysis of qualitative interview data from program parents with cerebral palsy inflicted adolescents revealed a concern about parents obtaining legal conservatorship over their adolescent. Some program adolescents with cerebral palsy had cognitive challenges that required a parent or caregiver to supervise or manage normal daily activities. When adolescents with cognitive challenges reach 18 years of age, a legal tool (conservatorship) is required to allow the parent or caregiver to make financial and medical decisions on their behalf (Casuto et al., 2020). When a conservatorship is granted for a program adolescent with cerebral palsy, the responsibility to effect health care transition rests primarily with the conservator (Casuto et al., 2020). The county Title V program “investigated the process for obtaining conservatorship and found the use of attorneys and their associated fees to be a major barrier for low-income families in (the program)” (PI).

A pilot project was designed by the county Title V program where "staff assisted parents with filing the conservatorship documents, and fee waiver ... (the county's law library) committed staff to providing [*sic*] one-on-one culturally sensitive assistance to (program parents)" (PI). Although assisting program parents and caregivers with filing a conservatorship application is unrelated to effective health care transition policymaking, the policy and procedures were grounded in the primary research. They demonstrated the benefits of engaging internal and external stakeholders.

Category: Policy Evaluation Stage

The primary researchers provided two evaluation reports to the research sponsor covering the first year (January 11, 2016, to December 31, 2017) and second-year (January 18, 2018, to December 31, 2018). I analyzed the evaluation reports and found the primary researchers conducted an internal evaluation using a formal pre-posttest policy evaluation technique: "The assessment-intervention-reassessment cycle is a time-honored approach in the public health field of study…the TRAQ (survey) was used as the assessment and reassessment data collection tool" and "The (TRAQ) survey frequency was established annually, and 2 to 6 months directly following an intervention" (PI). Also, in the evaluation reports was "using pretest and posttest TRAQ survey scores, correlation studies were performed to determine if a significant positive change occurred, possibly due to the intervention that was deployed" (PI). The evaluation reports associated domains in the TRAQ survey with the intervention, or interventions designed and deployed to improve the readiness for health care transition, reflected by improved posttest scoring. A summary of the associations between TRAQ survey domains and the deployed interventions is provided in Table 7.

Table 7

Associating Domains in the TRAQ Survey With Deployed Interventions

TRAQ Survey Domain	Intervention
Managing medications	Pharmacy Class Chews Wisely
Appointment keeping	Care Notebook Participation by Medi-Cal managed care
Tracking health issues	Care Notebook Chews Wisely Participation by Medi-Cal managed care
Talking with providers	Care Notebook Chews Wisely

A single formal evaluation of policies created by deployed interventions in an internal evaluation environment is not the optimal test for objectivity and demonstrating the principle of cause and effect. Internal evaluations are susceptible to subjectivity in their methods when the pressure to show positive outcomes is present in the environment (Simon, 2017). The primary researchers could have arranged an external policy evaluation, which may have mitigated any bias caused by the reporting environment from them to the research funder.

The research assistants' field notes provided the starting point for an informal evaluation process. Informal evaluations constitute adjustments "made at various stages in the implementation process" and "relies on the experiences of policy administrators rather than solely in scientific objectivity" (Simon, 2017, p. 155). According to the interim report dated March 6, 2017, the research assistants were participant observers for the pharmacy class and Chews Wisely sessions. Their field notes “continued to the deployment of interventions, producing a large amount of textual material for coding and analysis” (PI). The field notes were used to improve the interventions in a formative fashion and were reliant on the county Title V program to approve and fund the adjustments.

The evaluation reports pointed to a single hypothesis test and mainly addressed the primary researchers' achievements. I found the single internal evaluation results in the correlation study document.

Code: Correlation Study

The draft correlation report, submitted by the primary researchers to the research grant sponsor, started with an explanation for their decision to identify the TRAQ survey data as interval level of measurement. The report continued by describing how the primary researchers used relative change (percent change) in the TRAQ survey data to engage the internal stakeholders in the correlation study in terms they may better understand. The draft correlation report concluded with a paired samples t-test of control and treatment groups of program adolescents.

Level of Measurement. The primary researchers explored scholarship to identify the level of measurement for the TRAQ survey data: "There is a scholarly debate about Likert-scale data, and whether it is a continuous measurement,” “On the one hand, researchers in the education field of study routinely consider pretest-posttest Like-scale [*sic*] data as an interval level of measurement," and "On the other hand, other disciplines claim that Like-scale [*sic*] data is ordinal and therefore not suited for parametric testing" (PI). The primary researchers' concern, or bias, for identifying the TRAQ survey data as a continuous measure may be attributed to the hypothesis test they wanted to perform: "The assessment-intervention-reassessment cycle has been analyzed for statistical significance using parametric testing; paired sample t-testing being the most common" (PI). The primary researchers justified the TRAQ survey data as an interval level of management in the draft correlation report:

> We make [*sic*] the assumption that TRAQ data has numerical properties and may be treated as an interval level of measurement because the numerical value intervals have properties that trigger events (e.g., a low numerical value represents the need for an intervention; a high numerical value represents an intervention is not necessary) (PI).

I returned to the final evaluation report because there was a reference to alternative hypothesis tests for the primary research, "a local peer-review by scholars from the economics discipline disputed the use of TRAQ scores in parametric testing and suggested repeated measures testing or a non-parametric test all together" (PI). I considered the effort that the primary researchers expended on exploring the scholarly debate about the level of measurement assigned to Likert scale data and the peer-reviewers' suggestion to consider non-parametric hypothesis testing. I suspected that bias towards their own discipline's position in the debate was the reason for not pursuing any other hypothesis testing method. The primary researchers were public administration practitioners first, where Likert scale data may be considered an interval level of measurement (Nishishiba et al., 2014).

Engaging Stakeholders. In the correlation report, the primary researchers recorded that internal and external stakeholders received “periodic updates of the project’s (primary research) progress” (PI). Additionally, “preliminary outcomes were presented at Family VIBE meetings, Chews Wisely (sessions), and the annual transition conference” (PI).

The primary researchers recognized that the results of the paired samples t-test would be challenging to communicate effectively to program adolescents and their families, so "the concept of percent change" was used "when presenting pretest and posttest TRAQ scores" (PI). The primary researchers reported to program adolescents and their families that a 23.5 % change between the pretest and post-test could be attributed to the county Title V program's interventions. Atypical in scholarly correlation studies, the relative change concept supported a primary research goal of using a stakeholder-centric approach in reciprocal communication. The draft correlation report describes an instance by the primary researchers to engage stakeholders in the process of evaluating new health care transition policies and procedures.

Correlation Study Results. The primary researchers performed an a priori power analysis using G-power calculation software to determine the sample size for the paired samples t-test (Heinrich-Heine-University of Düsseldorf, 2020). The correlation report provided the following information of the a priori power analysis: The G-power calculation determined a sample size of 34 ($ES = 0.5$, $\alpha = 0.05$, $1\text{-}\beta = 0.80$). According to the correlation report, “the treatment and control groups were (non-randomized) convenience samples” (PI).

The hypothesis, or null hypothesis, for the paired samples t-test, were not explicitly stated in the correlation report. I found passages in the interim report and the final report that implied a null hypothesis for the correlation study: "The purpose of the paired samples t-test is to determine if the mean difference between TRAQ scores measured twice per study subject is zero,” and “the null hypothesis assumes that the true mean difference is equal to zero” (PI).

The correlation report identified the study’s independent variable as a grouping of interventions:

> Posttest inclusion criteria (was program adolescents) that have an initial TRAQ survey in their medical record, and that have participated in the following interventions, attended a Family VIBE meeting, received a care notebook, attended a pharmacy class, and attended either Chews Wisely classes or (the) annual transition conference (PI).

The correlation report provided the following information for the results of the paired samples t-testing.

Control Group. The results from the pretest (*M* = 69.2, *SD* = 14.8) and posttest (*M* = 70.6, *SD* = 14.4) TRAQ scores indicated that program adolescents that did not complete interventions resulted in no significant improvement in their readiness for health care transition, $t(33) = -2.76$, $p = .009$ (2-tailed) (PI).

Based on the correlation study results, program adolescents who do not complete the prescribed interventions showed a strong correlation to no significant improvement in their readiness for health care transition, $r = .982$, $p < .05$ (PI).

Treatment Group. The results from the pretest ($M = 59.7$, $SD = 11.3$) and posttest ($M = 72.3$, $SD = 12.6$) TRAQ scores indicated that program adolescent that completed interventions resulted in a significant improvement in their readiness for health care transition, $t(33) = -4.51$, $p = < .001$ (2-tailed) (PI).

Based on the correlation study results, program adolescents who completed the prescribed interventions showed a small correlation with improvement in their readiness for health care transition, $r = .085$, $p < .05$ (PI).

I determined from the correlation study that the policy evaluation process was narrow and limited to how interventions may or may not have improved the readiness for health care transition of a sample of program adolescents with diabetes. Additionally, there were no established outcome measures, and no data from those program members transitioning to adult services. The policy evaluation stage, although engaged by the stakeholders, was incomplete.

Code: Identifying Best Practices

The purpose of the primary research was to develop best practices for effective health care transition of California's Title V program for children with medical complexity; this was explicitly stated by the primary researchers in the final reports. The primary researchers based their definition of best practices on "empirically developed processes" (PI) that were moved from the primary research project to practice at the county Title V program. The primary research concluded in a final report that the following were "components of a best practice model" (PI):

- Establish a health care transition organizational culture at (the county Title V program).
- Establish a Health Care Transition Registry.
- Use qualitative methods when engaging (program adolescents) and their families for input on intervention design and deployment.
- Use quantitative methods to identify (program adolescents) that need interventions (and) develop disease cohorts for focus groups/interviews, and outcome measures.
- Develop individualized health care transition plans.
- Assist the pediatric provider and (program adolescent) with the health care transition to the receiving clinician.
- Engage the transitioned (program member) to measure the effectiveness of health care transition from (the county Title V program) (PI).

The case study evidence lacked a description or criteria for the primary researchers' claim of developing a best practice model.

The primary researchers missed an opportunity to classify the results of their research formally. The Association of Maternal & Child Health Programs (AMCHP) developed criteria for cutting-edge practice, emerging practice, promising practice, and best practice (n.d., para. 2). The AMCHP represents state Title V program administrators, and the California members were not part of the county-level primary research project. At best, the AMCHP criteria for an emerging practice was met by the primary research. The criteria for an emerging practice are as follows:

- Describes any existing theories, research, standards/guidelines, models, programs, etc., that were used to develop and/or implement the practice.
- Describes how the practice addresses at least one social determinants of health.
- Describes how stakeholders were involved throughout all practice processes and activities.
- Describes an evaluation plan appropriate for the scope of practice.
- Describes a process for identifying lessons learned (AMCHP, n.d., para. 4).

According to the criteria established by the AMCHP (n.d.), the primary researchers' claim of developing a best practice model is negated because the research lacked external validation by peer-review, an external evaluation, and positive outcomes. In my review of evidence-based policymaking literature, I found that Horne (2017) strongly suggested the use of evidence-based program registries to support claims of developing best practices.

Summary

In Chapter 4, I explained that a primary research project was the focus of this explanatory case study. I received various products of the primary research from the research sponsor and created an inventory of case study evidence. I used a conceptual model to translate the processes from the primary research to stages in the policy process model of policymaking. Case study propositions that support effective health care transition policymaking and diffusing evidence from research to policy were based on a case study protocol that guided my inquiry. I found that the primary research processes were easily associated to three stages in the policy process model, which according to Dodd et al. (2019) and Doshmangir et al. (2019), are the initial framework for policymaking.

Initially, I coded data from the primary researcher's reports, focus groups, interviews, and field notes, using a deductive a priori method because the conceptual framework was made of pre-determined categories. I assigned coded units of data to the agenda setting, policy implementation, and policy evaluation categories. In the second cycle of coding, I coded data units for processes and events in the primary research that involved stakeholder engagement, intervention design and deployment, policies and procedures, and policy evaluation. Inductively, I coded units by frequency and pattern to identify emerging themes in the data. I found that a theme of “level of engagement,” defined by a headcount at events, was probably not a good measure of stakeholder engagement because confounding factors and the engagement quality are unknown. The second theme of “collectivism” was identified in the research assistants' field notes from the Chews Wisely sessions (diabetes management education). However, unsolicited and purely serendipitous, it was clear that program adolescents with diabetes and their parents wanted to learn, interact, and support each other in group venues. The two themes identified in the case study evidence did not influence the translation of the primary research's process to policymaking but warrant further investigation of how culture may impact stakeholder engagement in the policymaking process. I placed more emphasis on deductive coding because these codes directly address the purpose of my study.

Coded units in the agenda setting stage category reflected the county Title V program's agenda setting effort for improving health care transition policy with the participation of internal stakeholders. Triangulation of the data sources from which the coded units were identified showed that the primary research's initial processes involved empirical, scholarly, and effective stakeholder engagement components. This evidence easily translated to the policy process model and the conceptual model's agenda setting stage and was supported by the case study propositions.

Coded units in the policy implementation stage category were challenging to assign without developing sub-codes and sub-categories. The primary research, which was never intended as a policy instrument, used jargon that did not translate well to the policymaking process. However, labels for the coded units and sub-units reflected the translations of designing and deploying interventions by the primary researchers to policy formation and implementation by the county Title V program; interventions in the primary research were eventually adopted as practice by the county Title V program.

Through a triangulation process, I found strong evidence that policy formation and implementation had participatory involvement by internal and external stakeholders except for a blanket policy to issue care notebooks to all program adolescents. The pharmacy class, the Chews Wisely diabetes education management project, and the local Medi-Cal managed care organization's inclusion in all interventions were extensively designed, improved, and deployed with internal and external stakeholder engagement. The care notebook intervention and subsequent policy were initiated by the primary researchers without local stakeholder engagement but was aligned with a national best practice according to most advocates for children with special health care needs; stakeholders were likely engaged at some point in developing the care notebook intervention, the primary researchers simply adopted and implemented a well-known best practice.

Coding the case study evidence found other adopted interventions into practice by the county Title V program but were not intended by the primary research design. An annual transition conference was established before starting the primary research by the county Title V program to provide a venue dedicated to the topic of health care transition planning. However, internal stakeholder engagement during the primary research caused two community outreach policies. Internal stakeholders wanted more engagement with the county Title V program for program orientation of new members and case management issues of existing members; the county Title V program started an outreach project called Family VIBE, which deployed county Title V program staff to communities and addressed their concerns. The second outreach program was based on internal stakeholder feedback from the parents of program adolescents with cerebral palsy and their mobility challenges; a home visiting policy was established to address the mobility challenges of program adolescents. Lastly, through the intervention design focus groups, some parents asked about assistance with obtaining a conservatorship for adolescents with the decreased cognitive capacity to manage for themselves. The county Title V program responded by assisting parents in filing court documents for obtaining conservatorships. These policies initiated through stakeholder engagement processes of the primary research exhibit how the county Title V program valued participatory policymaking.

The policy evaluation stage category was comprised of an informal evaluation process that was performed by research assistants on two interventions in a formative fashion and a single internal pretest-posttest evaluation comparing paired samples from a control and treatment group. Research assistants were participant observers in the pharmacy classes and Chew Wisely session. Their informal evaluation consisted of reflexive journaling that suggested improvements for the interventions, which I coded from their field notes. I triangulated data sources and found evidence that the informal evaluation process included stakeholders and produced qualitative data for analysis and, therefore, an empirical basis to improve pharmacy and diabetes education policies.

The pretest-posttest internal evaluation consisted of one correlation study. The correlation study represents an effort to identify evidence through hypothesis testing. Coded units revealed weaknesses in the correlation study, including a non-probability convenience sampling technique and a debatable choice by the primary researchers to consider the survey data analyzed in paired samples t-testing, as interval level of data; the primary researchers considered no other inferential statistical test. On point with the conceptual model and case study propositions, I found evidence that the stakeholders were engaged in the policy evaluation stage.

The case study evidence lacked an explanation or criteria for identifying best practices that the primary researchers claimed to develop. The primary researchers missed an opportunity to engage external stakeholder organizations that establish criteria for a best practice or qualify claims of developing best practices. According to the criteria set by the Association of Maternal & Child Health Programs (n.d.), the primary research's findings represent an "emerging practice" model, which I still consider as evidence to inform new health care transition policy. In Chapter 5, I interpreted the findings, discussed this study's limitations, provided recommendations, and identified the implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this explanatory case study was to explore the products of a primary research project aimed at improving the transition planning of adolescents with medical complexity for evidence that could inform new health care transition policy. I framed the inquiry with a conceptual model that mapped the primary research components to stages in the classical policy process model. I used concept-driven qualitative coding to translate evidence from the primary research to the policymaking process. I found that the primary researcher's processes, which included the use of scholarship, empirical methods, and stakeholder engagement, translated to stages in the policy process model of policymaking. I found that the translation of primary research evidence into a policymaking framework revealed similarities in temporal precedence used in the flow of the primary research design and in the stages in the policy process model; research and policy making share structural characteristics.

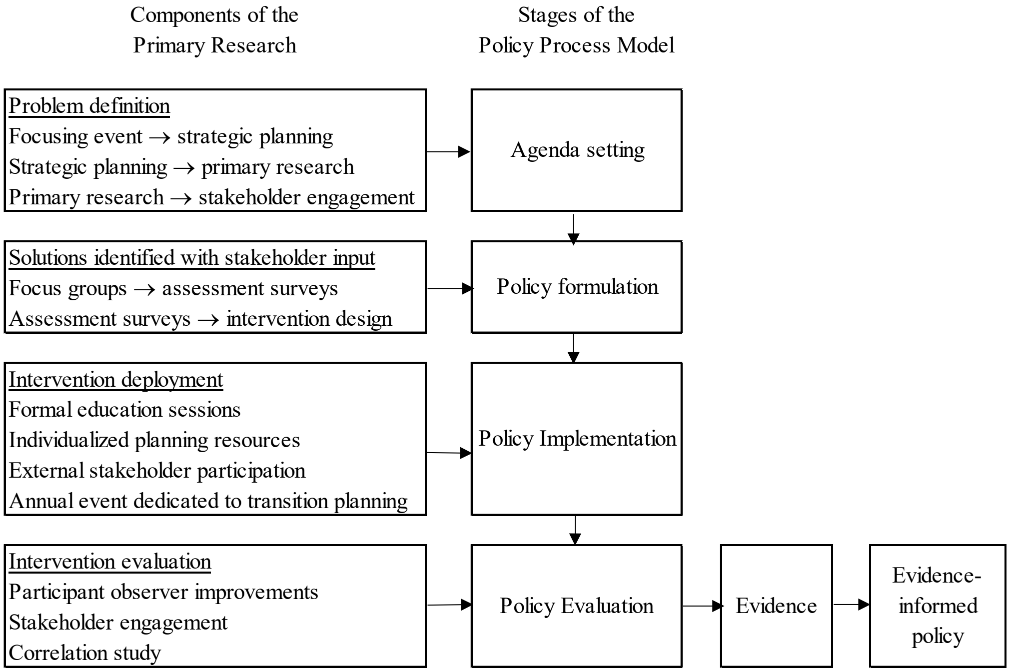
Interpretation of the Findings

This study's findings are illustrated using a post hoc conceptual model as a framework (see Figure 2) and with explanations of how evidence was identified in the primary research products to inform new health care transition policy. I used a concept-driven coding method to translate evidence into predetermined categories that represented the policy process model stages. Additionally, two themes emerged inductively and are prime for future research because they exceed the scope of this study: How should the level of stakeholder engagement be measured, and how does collectivism improve diabetes management education?

I identified evidence in the primary research products based on the study's propositions and current literature. When linked with empirical research, the linear properties of the policy process model are more likely to produce and implement evidence-informed policy (Dodd et al., 2019; Hillman et al., 2015). Moreover, based on the facilitational model of diffusing research evidence into the policymaking process, participatory development by stakeholders in the primary research processes strengthens the opportunities for policymakers to create evidence-informed policies (Cairney & Oliver, 2017; Ferris et al., 2015; Ogbe et al., 2018; Schlucter et al., 2015; Shlonsky & Mildon, 2014).

Figure 2

Post Hoc Conceptual Model



Agenda Setting Stage

I found evidence in the primary research products that the county Title V program initiated a strategic planning evolution. The strategic planning evolution identified ineffective health care transition planning for its program adolescents. The strategic plan documented events in their day-to-day operations that are considered focusing events because they described negative outcomes of ineffective health care transition planning. The strategic planning evolution incorporated a literature review and new policies aimed at improving health care transition planning. The county Title V program was awarded a research grant by a foundation affiliated with a regional pediatric hospital and adopted the concept of stakeholder engagement as a necessary component in their research. After the county Title V program defined the problems with ineffective health care transitions, personnel engaged the internal stakeholders to further define the problems from the program adolescents and their families' perspective. The policy agenda was initiated by the county Title V program administrator and enhanced by stakeholder engagement through the participation of the program's adolescents and their families.

Policy Formulation Stage

Through multiple data sources, a convergence of coded content pointed to a participatory environment for developing interventions to improve the readiness for health care transition. I used an assessment tool, which was validated in scholarship (Sawicki et al., 2017; Wood et al., 2014), to assess the readiness for health care transition of the program adolescents and frame topics for focus groups and interviews. The assessment tool and focus group and interview data underpinned the development of interventions in the primary research that diffused to policies in the county Title V program.

Policy Implementation Stage

The primary researchers designed interventions with stakeholder input. A plan for informal evaluations by participant observer research assistants was used whenever interventions were deployed. The research assistants' field notes were a rich source of data that formatively improved the interventions and documented the stakeholders' engagement in the processes. The primary researchers selected a formative process over a summative process to improve deployed interventions. Implementation of new policies for the county Title V program had an element of policy evaluation with stakeholder input.

Policy Evaluation Stage

The primary researchers performed a single internal formal evaluation to test the relationship between deployed interventions and improved healthcare transition readiness. The primary researchers used a pretest-posttest model and survey data, paired samples of program adolescents who experienced interventions were compared to a control group of program adolescents who did not experience interventions. I interpreted the results of the paired samples t-test. I determined a strong correlation that healthcare readiness did not improve in the control group that did not experience interventions. A small positive correlation indicated that the interventions may have increased the readiness for health care transition in the treatment group. The convenience sampling method and small sample size were weaknesses of the paired samples t-testing. I did not find evidence that confounding variables or other hypothesis testing were considered, strengthening the correlation study. However, according to Head (2015), it is not unusual for a quasi-experimental research project to produce evidence-informed policymaking results due to constraints that prevent the evidence-based policymaking method. Additionally, the case study evidence showed a commitment by the primary researchers to use process-based instead of outcome-based evidence to support their claim of developing best practices. According to La Brooy and Kelaher (2017), process-based evidence is associated with evidence-informed policymaking, while outcome-based evidence is associated evidence-based policymaking.

The primary researchers concluded their study with a claim of developing best practices for health care transition planning. Although the primary research processes were translated to the stages in the policy process model of policymaking, I did not find evidence of criteria to support their claim. However, based on the case study evidence, the primary research processes and products had a strong potential to inform new healthcare transition policymaking processes.

Limitations of the Study

This study was limited by the availability of data associated with the primary research project. Although the primary research products were rich in data, the county Title V program's policies and procedures, which resulted from the primary research, were not accessible. When the county Title V program adopted interventions as practice, I had to imply that policies and procedures ensued based on operational and budgetary changes mentioned in the case study evidence.

The absence of outcome measures and data further limited this study. An evaluation of outcomes related to the implementation of new policies was narrowly addressed in this study. However, data associated with the successful or effective transition of program adolescents to the adult model of care were not available. Young adults who aged out of the county Title V program were not included in the primary research.

Ultimately, case study research has inherent limitations for the generalizability of findings (Yin, 2018). However, the homogenous properties of county programs within California's Title V programs for children with medical complexity potentially offset the generalizability limitations of the case study method and contribute to the purpose of this study.

Recommendations

The purpose of this study was to address a knowledge gap in health care transition research by exploring a potential method to identify research evidence that informs effective health care transition policy.

I suggest that conducting empirical research to inform effective policymaking be adopted by county Title V programs because it facilitates stakeholders' engagement and increases the possibility that the new health care transition policies are effective. Additionally, I encourage that empirical research includes outcome measures and the involvement of an organization that can confirm the development of best practices. In this study, the primary researchers did not include outcome measures or validate their claim of developing best practices with criteria from an organization that defines and appraises evidence-based claims, which could have been an external stakeholder (evidence-based program registry) in their processes.

Further research is warranted to address two themes that emerged inductively from the case study evidence analysis. However, the data analysis revealed internal stakeholder engagement in the stages of the policy process model. The level of engagement was a concern for the primary researchers. The primary researchers gauged the level of stakeholder engagement by attendance rates to focus group meetings and educational interventions. However, the quality of the stakeholder engagement was not explored; how do we measure stakeholder engagement? And, should stakeholder engagement be a representative sample of the population?

The second theme that warrants additional research emerged from the research assistant's field notes when documenting feedback from families that attended the diabetes management education intervention. Although unsolicited, the families of program adolescents with diabetes supported the group meetings provided by the primary research over individual meetings typically provided by their medical provider. The collectivist nature of their comments points to factors that may influence the framing of disease management education or the need for disease-specific support groups in the Title V program environment.

Implications

The findings of this study have policymaking and social implications. First, research and policymaking should not be thought of as two different concepts but components that could be considered together for effective policymaking. Second, according to a consensus by world leaders on societal measures, addressing our most vulnerable population's needs is a moral imperative.

Policymaking Implications

I found similar characteristics in the flow of the primary research design and the stages of the policy process model that suggested research intended to inform policy could be initially framed in a policymaking framework. I found it reasonable to deduce that recognition of similar characteristics between research and policymaking could increase the likelihood that evidence-informed policy results from research with a policy process in its design. Perhaps the practitioner should be well trained to be a researcher?

The primary research project was unique to one county within California’s Title V programs for children with medical complexity. Documented in the primary research’s first interim report to the research sponsor was their adoption of the academic public health model, an "evidence-based model" for establishing a relationship between the county Title V program and the local university's expertise and resources. Evidence-informed policymaking needs an empirically-based approach where resources are readily available at most academic institutions and challenging for most government agencies. This study explored a unique instance when academia and local government partnered to conduct empirical research to improve inadequate policy. This study's policymaking implications were how to overcome local government constraints for conducting empirical research by partnering with academic resources.

Social Implications

Improvements are needed for transitioning adolescents with medical complexity from the pediatric to an adult model of medical care. For adolescents with medical complexity, the usual transition from adolescence to adulthood is complicated by a medical condition that requires a new medical provider, new health plan, and life-skills for self-management and self-advocacy in an already convoluted health care system. This study provides insight for medical providers, health plans, and policymakers on creating effective health care transition policy for a vulnerable population.

Conclusion

This study explored the potentiality of translating research evidence to inform effective health care transition policy. The case study evidence, guided by propositions gleaned from health care transition and policymaking literature, affirmed that the products from a primary research project could inform effective health care transition policy. Moreover, research designed and conducted using a policymaking framework may increase the possibility of implementing evidence-informed policy because of similar characteristics shared by research and policymaking processes. Social change that addresses effective health care transition for adolescents aging-out of pediatric programs should be created with their input, the input from their parents, and the participation of external stakeholders.

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Appendix A: Case Study Protocol

Section A. Overview of the Case Study

- Goal: Contribute to the health care transition research knowledge gap and provide insight to inform new health care transition policy for California's Title V programs for children with medical complexity.
- Central research question: How can examining and translating health care transition research contribute to the knowledge gap and provide insight to inform new health care transition policy for California's Title V programs for children with medical complexity?
  - Sub-question 1: What are the perceived factors for effective health care transition policy?
  - Sub-question 2: What is the relationship, if any, between health care transition research and health care transition policymaking?
- Theoretical framework: Agenda setting, policy formulation, policy implementation, and policy evaluation stages of the policy process model.
- Propositions:
  - Health care transition planning for children with medical complexity is more effective with participatory development from the stakeholders (Ferris et al., 2015; Schlucter et al., 2015).
  - Stakeholder engagement is important for the diffusing of research evidence to inform policymaking (Cairney & Oliver, 2017; Shlonsky & Mildon, 2014).

  - The agenda setting and policy formation stages of the policy process model provide the initial framework for policymaking and analysis (Dodd et al., 2019; Doshmangir et al., 2019; Hillman et al., 2015; Simon, 2017).
- Role of the protocol: This protocol guides the inquiry and serves as a reminder for the researcher to identify evidence in the primary research components, prompted by the propositions, and crosswalk the evidence to stages in the policy process model. Synthesis includes explaining how the primary research process could be used to inform new health care transition policy.

Section B. Data Collection Procedures

1. Request the publicly available primary research reports and documents, and anonymized datasets, from the primary research sponsor. Secure an executed agreement from the primary research sponsor to use the reports, datasets, and data logs as case study evidence for this study.
2. Catalog, type, and describe the primary research reports, documents, and datasets into a Case Study Database.
3. Enter or upload raw data into NVivo™ software platform for analysis.

Section C. Protocol Questions

Agenda setting stage

- Problem definition:
    - How was the problem or issue identified?
    - At this stage, who were the stakeholders?
    - How were the stakeholders engaged?
    - How is the problem or issue a policy issue?
    - How was the problem or issue assessed?
- Research proposal:
    - How was the primary research conceptualized?
    - How were the stakeholders engaged?
    - Were there any competing interests or power struggles?

Policy implementation stage

- Interventions:
    - How were the interventions designed and deployed?
    - How were the stakeholders engaged, and at what level?
    - How were the interventions assessed?
- Policies and procedures:
    - What new procedure was implemented?
    - How were new procedures implemented?
    - What new policy was implemented?
    - How were new policies implemented?

Policy evaluation stage

- Policies and procedures:
    - How were the new policies and procedures evaluated?
    - What was the level of stakeholder engagement and agreement?
    - How did the primary research's conclusions translate to new policies or procedures?
- Synthesis:
    - How do the components of the primary research translate to the policy process model?
    - How does the primary research evidence inform new policy?

Appendix B: Case Study Database

Inventory Number--File Name	File Type	Description	Date (Range)
100--FG-Adolescent	Excel	Adolescent focus group data	8/10/16-11/16/16
101--FG-Parent	Excel	Parent focus group data	8/10/16-11/16/16
102--FG-Mixed	Excel	Mixed focus group data	8/17/16-12/15/16
129--RA1	PDF	Field notes	6/22/17-7/13/17
130--RA3	PDF	Field notes	6/22/17-7/13/17
131--RA7	PDF	Field notes	6/22/17-7/13/17
132--RA8	PDF	Field notes	6/22/17-7/13/17
133--RA9	PDF	Field notes	6/22/17-7/13/17
134--RA1-DM	PDF	Field notes-diabetes	2/14/2017-3/7/17
135--RA2-DM	PDF	Field notes-diabetes	2/14/2017-3/7/17
136--RA3-DM	PDF	Field notes-diabetes	2/14/2017-3/7/17
142--RA9-DM	PDF	Field notes-diabetes	6/22/17-7/19/17
143--RA10-DM	PDF	Field notes-diabetes	6/22/17-7/19/17
144--RA6-DM	PDF	Field notes-diabetes	4/17/18-5/15/18
145--RA11-DM	PDF	Field notes diabetes	4/17/18-5/15/18
147--TRAQ Database	Excel	TRAQ survey database ($N = 493$)	n.d.
148--Contact Detail Log	Excel	Stakeholder contact and attendance	5/24/16-3/21/18
150--TRAQ Survey	PDF	Transition Readiness Assessment Questionnaire (TRAQ), version 5.0	n.d.
151--Strategic Goals	PDF	Organizational strategic goals	5/13/15
152--Interim Report 1	PDF	Progress report for the grant sponsor	1/11/16-6/20/16
153--Interim Report 2	PDF	Progress report for the grant sponsor	6/21/16-12/31/16

Inventory Number--File Name	File Type	Description	Date (Range)
154--Interim Report 3	PDF	Progress report for the grant sponsor	1/2/17-6/26/17
155--Draft Evaluation Report	PDF	Progress report for the grant sponsor	1/11/16-12/31/17
156--Draft Correlation Report	PDF	Progress report for the grant sponsor	1/11/16-12/31/17
158--Interim Report 4	PDF	Progress report for the grant sponsor	12/9/17-6/15/18
159--Final Evaluation Report	PDF	Final report at the conclusion of the study for the grant sponsor	1/1/18-12/31/18
160--Final Report	PDF	Final report at the conclusion of the study for the grant sponsor	1/1/18-12/31/18