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# Advance care planning among African Americans: A review and synthesis of theory application

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#### Abstract

**Objectives.** Theoretical and conceptual frameworks are often underutilized in research, which may diminish understanding of the phenomena and contribute to the under-development of interventions. The topic of low/disparate rates of Advance Care Planning (ACP) among African Americans has been researched extensively; however, the use of theoretical and/or conceptual frameworks has not been reported. The purpose of this review is to describe theoretical and/or conceptual frameworks utilized in studies that investigated factors affecting perceptions of ACP or ACP rates among African Americans.

**Methods.** Utilizing a narrative, literature review process, themes were generated, applied, and described with frequencies across broad categories of study characteristics, framework categories and key constructs, mode of framework application, and quality of framework reporting. **Results.** Four main types of frameworks were found with behavioral frameworks dominating the collection of studies. Complex, systems theoretical frameworks were less common. Framework use and reporting quality findings are described.

Significance of results. The problem of disparate rates of ACP among African Americans is nuanced and varied, stemming from both internal (e.g., personal, behavioral) and external factors (e.g., living conditions). While important and necessary to focus on internal, psychological factors, it is also vital to incorporate systems' theories such as the Cumulative Disadvantage Theory to better understand and demonstrate inherent complexities. Recommendations for framework use are discussed for research and clinical application. Incorporating complexity science approaches and multi-systems theories may support multi-level modeling needed to understand this problem and reduce ACP disparities in this population.

Advance Care Planning (ACP) is an ongoing process of health behavior change in which patients and their loved ones establish their end-of-life care preferences and values prior to losing decision-making capacity (Fried et al., 2009). Successful ACP is associated with increased use of hospice and palliative services at end-of-life, fewer in-hospital deaths, reduced suffering, and improved quality of life (Brinkman-Stoppelenburg et al., 2014). African Americans (15–47%) have historically had lower rates of ACP than whites (20–80%), and determinants of these disparities reflect conflicting findings (Sanders et al., 2016; Hong et al., 2018). Patterns of theory use in ACP studies may elucidate the variability of findings and enhance understanding of ACP disparities among African Americans.

Theory, as an integral part of science, describes, explains, and predicts phenomena (Dickoff et al., 1968). Theories provide a conceptual basis for understanding and investigating relationships within social systems. A goal of hypothesis-testing is to form well-substantiated theory by demonstrating statistical evidence that supports assumed relationships. Despite this emphasis, the theory is rarely used or reported as underpinning research (Im, 2015), yet could strengthen studies in several ways. Theory provides structure and conceptual clarity to a research problem or *a priori* assumptions. Theory may also be challenged and refined through research by operationalizing constructs and testing propositions. To our knowledge, the use of theory in research of ACP disparities among African Americans is unexplored or synthesized.

The overarching intent of this review is to explore the use of theory related to ACP uptake in this research area (Mays et al., 2005). The specific aim of this integrative review is to describe and synthesize the use of theoretical and conceptual models or frameworks used to investigate perceptions of ACP among African Americans and factors that influence ACP behaviors.



#### **Methods**

## Search strategy

In collaboration with a biomedical librarian (RLW), a search strategy was implemented in CINAHL, PubMed, and Web of Science in July 2019, and updated in April 2021. Samples of the search strategy are available upon request. The first search yielded 493 non-duplicate studies, and the second search yielded 109; all studies were published between 2000 and 2021.

## Inclusion criteria and study selection/review process

A PRISMA diagram (Figure 1) depicts the selection process and combined results for both searches (N = 602). Studies were included if they (1) used a theoretical or conceptual model/framework for any component of the study; (2) were written and published in English, (3) included at least a 10% partial sample of

community-dwelling African Americans, (4) and investigated factors related to racial differences in ACP. Studies were excluded if the theoretical or conceptual model/framework was exclusively a methodological model, e.g., qualitative methods approach. Of note, the authors hereafter refer to theories as frameworks since often only a few concepts were used within studies. Titles and abstracts of all 602 studies were independently reviewed by two authors (CK, CAM) for relevance. Conflicts were resolved using Rayyan, a web-based application for systematic reviews (Ouzzani et al., 2016). A total of 534 articles were excluded for reasons including (1) wrong population (e.g., nursing home residents, HIV, homeless, hospitalized patients, surrogate decision-makers), (2) wrong outcome (e.g., life-sustaining treatment, place of death), (3) wrong publication type (e.g., editorials, informational only, systematic review), and, (4) lack of relevance to the research question.

After a review of titles and abstracts, 84 studies met eligibility for full-text review (C.K.). During data abstraction, studies were

## PRISMA Flow Diagram<sup>a</sup>

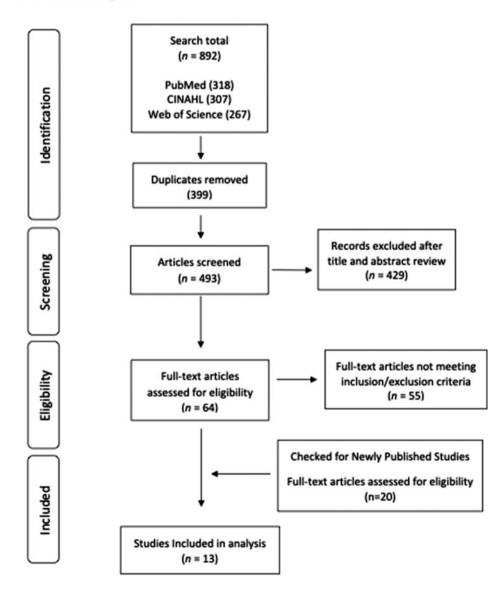


Fig. 1. PRISMA flow diagram<sup>a</sup>.

<sup>a</sup>Adapted from Moher, Liberati, Tetzlaff, & Altman (2009)

closely reviewed for theory use, and 71 were eliminated because the use of theory was absent or reference to theory did not support the research process or dissemination of the study. Thirteen studies were included in the final review.

#### Data abstraction

Data abstraction was performed to extract data about study characteristics, conceptual framework categories and key constructs, mode or type of framework application, and quality of reporting. Information was collected from each study including authors, year of publication, duration, setting, sample, aims, design, variables/outcomes, analysis, results, and name (terminology) of theory. Regarding specific use of theory, data were abstracted for (a) inclusion of a figure, (b) relationship with ACP, (b) key concepts and propositions, (c) provision of and level of definition completeness, (d) rationale or justification for theory use, (e) modes or ways theory was applied. Abstracted data were entered into a table for comparison and synthesis. A publication table and figure were created from the data abstraction spreadsheet depicting study characteristics (Table 1) and framework characteristics (Figure 2), respectively.

## **Analysis**

A unique process of the thematic organization was used to aggregate abstracted data, determine category definitions, and consistently apply the definitions to all data. For instance, the process of identifying *modes of theory application* began with abstracting text from different article sections into an Excel spreadsheet for side-by-side comparison. Similar to the process of qualitative, thematic analysis, the text was first inductively analyzed for types of theory use until themes were generated. Themes varied in complexity in terms of theory usage within individual studies. For instance, the theme of *modes of theory application* generated 10 unique ways in which theory was applied across studies, e.g., aims construction, variable selection. A detailed (print) version of this undertaking, including all theme definitions and process explanations is available upon request. For brevity, this report includes our most salient findings.

### **Results**

Five sections were identified, from which we synthesized our findings, including: (1) study characteristics, (2) methodological approaches to the study aims, (3) theoretical frameworks and construct categories, (4) modes (study components) in which frameworks were applied, and (5) reporting quality. Figure 2 provides a summary of categories and components from which we discuss our synthesis.

## Study characteristics

Thirteen studies were analyzed and synthesized (Waters, 2000; Bullock, 2006; Allen et al., 2009; West and Hollis, 2012; Huang et al., 2016; Inoue, 2016; Koss and Baker, 2018; McAfee et al., 2019; Sanders et al., 2019; Collins et al., 2020; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). Years of publication ranged from 2000 to 2021 (Table 1). Sample sizes ranged from 21 to 6,946 with 6 of the studies having a sample of 102 participants or less. Eight studies reported an age

range (minimum = 25 to maximum = 110) (Waters, 2000; Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; Inoue, 2016; McAfee et al., 2019; Sanders et al., 2019; Collins et al., 2020). Six study samples were composed of 100% African Americans (Waters, 2000; Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; Sanders et al., 2019; Collins et al., 2020) and seven study samples consisted of 13.4% to 73.7% African Americans (Allen et al., 2009; Inoue, 2016; Koss and Baker, 2018; McAfee et al., 2019; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). Of the ten studies with complete gender data, 4,868 were female (56.1%) and 3,652 male (42.1%) (Waters, 2000; Bullock, 2006; Huang et al., 2016; Inoue, 2016; Koss and Baker, 2018; McAfee et al., 2019; Collins et al., 2020; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). Five studies were conducted in the Southeast United States (Bullock, 2006; Allen et al., 2009; West and Hollis, 2012; Huang et al., 2016; Sanders et al., 2019).

## Methodological approaches

Methodological approaches to scientific aims within the studies included descriptive (N=4 studies) (Bullock, 2006; West and Hollis, 2012; Sanders et al., 2019; Collins et al., 2020), associative (N=6) (Inoue, 2016; Koss and Baker, 2018; McAfee et al., 2019; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021), and explanatory (N=3) (Waters, 2000; Allen et al., 2009; Huang et al., 2016). Descriptive studies explored racial disparities in ACP using qualitative methods to generate themes of contributing factors. Associative studies investigated associations with surveys to examine events that co-occur with ACP behaviors. Explanatory studies investigated the causal influence of independent variables on ACP outcomes (e.g., ACP engagement) used a randomized controlled trial (Huang et al., 2016) or a quasiexperimental, one group, pre-posttest design (Waters, 2000; Allen et al., 2009)

Independent variables differed across studies such that synthesis was difficult. Across the quantitative studies, including one mixed-methods study, independent variables included cognitive (e.g., sense of control), socioeconomic (e.g., financial assets), demographic (e.g., age, living arrangement), and ACP knowledge and behavior variables (Waters, 2000; Allen et al., 2009; Huang et al., 2016; Inoue, 2016; Koss and Baker, 2018; McAfee et al., 2019; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). Among qualitative studies, including the mixed-methods study, interview guides were used to generate themes or analyze the content (Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; Sanders et al., 2019; Collins et al., 2020). Themes are identified in Table 1.

Heterogeneity of individual studies precluded in-depth synthesis of statistical significance or effect size. Table 1 provides a summary of individual study results. ACP perceptions and rates of ACP completion were influenced by sociodemographic variables (Inoue, 2016; Koss and Baker, 2018; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021); the importance of family and social support in the ACP process (Waters, 2000; Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; McAfee et al., 2019; Sanders et al., 2019; Collins et al., 2020), religion and faith (Sanders et al., 2019; Collins et al., 2020); lack of awareness and the role of education (Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; Hong and Kim, 2020), and mistrust of the

 Table 1. Study characteristics

Authors, pub. year (ref. no.)	Theory/Aim	Study design and methods	Study sample and state	Key findings (theory terms bolded as applicable)
Waters (2000)	Ethic of Care Framework (Moral)     Freire's empowerment education theory (Moral)     African American's knowledge, attitudes, and utilization of ADs before a health crisis	Explanatory Quasiexperimental Pre, post test One group Survey, Community-based discussion	27 African Americans Oregon	82% of participants indicated willingness to consider in completing an Advance Directive after the community-based discussion intervention
Bullock (2006)	Faith-Based Promotion Model (Moral)     Explore what factors influence African Americans to complete an AD or not	Descriptive Qualitative Focus Groups	102 older African Americans North Carolina	Spirituality     Death and dying     Social support network     Barriers to utilization     Mistrust of health care
Allen et al. (2009)	<ul> <li>Protection Motivation Theory (Process, Behavioral)</li> <li>Examine racial differences in intent to complete a Living Will with rational decision-making and maladaptive coping responses to a health crisis</li> </ul>	Explanatory Quasiexperimental Pre, post test One group Surveys, Vignettes	60 older adults (51.7% African Americans) Alabama	Compared to African Americans:  • Whites more likely to seek ACP information in response to <b>perceived threat</b> $[F_{(1, 47)} = 4.30, p = 0.044]$ • Whites were more variable in <b>maladaptive responses</b> $[F_{(1, 49)} = 5.98, p = 0.018]$
West and Hollis, (2012)	Erikson's Developmental Stages (Process)     Transtheoretical Model (Behavioral, Process)     Identify barriers to AD completion in African Americans ages 25–84 years old	Descriptive Qualitative Focus Groups	40 African Americans North Carolina	<ol> <li>Surrogate-decision-making (younger prefer medical personnel, older prefer family)</li> <li>Lack of ACP education</li> <li>Fear and denial</li> <li>Spirituality</li> <li>Ages 25-44: fatalism</li> <li>Ages ≤64: Mistrust in Medical System</li> <li>Ages 45-64: Economics</li> </ol>
Huang et al. (2016)	<ul> <li>Health Literacy and Health Actions framework (Behavioral)</li> <li>Self-determination Theory (Moral)</li> <li>Test feasibility of framework-informed intervention and explore barriers to completing ACP in the deep South</li> </ul>	Explanatory Pilot Feasibility RCT Mixed Methods	30 African Americans Alabama	Increase in ACP knowledge in the intervention group from T1 to T2 ( $t_{(14)}$ = $-3.06$ , $p$ = $0.01$ , $d$ = $1.67$ ), No change in the control group Qualitative Themes:  1. Lack of education and information 2. Lack of family/social support 3. Sense of hopelessness, mistrust of doctors 4. Get caught up in life 5. Reticence to talk about death/future care decisions
Inoue (2016)	Expectancy Theory     (Behavioral)     Examined which     sociodemographic and     psychological factors affecting     ACP completion	Associational Secondary Analysis of Health and Retirement Study Data	1,056 Cases (13.4% African American) Nationally Representative Dataset	Compared to whites, interaction of African Americans with <b>perceived constraints</b> (lower sense of control) were less likely to have informal ACP plans only (OR = $0.62$ , 95CI: $0.39$ , $0.98$ , $p < 0.05$ )
Koss and Baker (2018)	Cumulative Disadvantage Theory (Systems) Test if variation in estate planning (i.e., will or trust) accounted for black-white disparities in ACP	Associational Secondary Analysis of Health and Retirement Study Data	6,946 cases (17.2% African American) Nationally Representative Dataset	After adding <b>financial and estate planning variables</b> (i.e., having a will or trust), there was no difference between blacks and whites in odds of Advance Directive completion (OR = 0.96, 95%Cl: $0.82-1.12$ , $p > 0.05$ ), but the difference remained for ACP discussion (OR = 1.75, 95%Cl: $1.50-2.03$ , $p > 0.05$ )
McAfee et al. (2019)	Integrated Behavioral Model (Behavioral)     Precaution Adoption Process (Process)     Explain and predict racial or ethnic disparities in ACP using these frameworks	Associational Observational, nonexperimental, cross-sectional study design • Survey	386 participants (16.6% African American) Northeast (18%), Midwest (22%), South (37%), and West (23%) United States	Integrated Behavioral Model: <b>Direct attitude</b> toward ADs, ( $\beta$ : 0.30, 95% CI: 0.09–0.77, $p$ = 0.014), <b>indirect attitudes</b> ( $\beta$ : 0.24, 95% CI: 0.03–0.24, $p$ = 0.010), and <b>indirect perceived norms</b> ( $\beta$ : 0.18, 95% CI: 0.04–0.68, $p$ = 0.028) were positively associated with behavioral intention to complete an AD Precaution Adoption Process:

(Continued)

Table 1. (Continued.)

Authors, pub. year (ref. no.)	Theory/Aim	Study design and methods	Study sample and state	Key findings (theory terms bolded as applicable)
				Participants with higher scores in precaution adoption process variables (e.g., self-efficacy, most positive direct attitudes toward ADs) were more likely to report a decision to engage with ACP than those with lower scores
Sanders et al. (2019)	<ul> <li>Social Ecological Model (Systems, Behavioral)</li> <li>Aimed to use the model to compare perspectives (experts, community church members, and caregivers and patients with serious illness) on factors influencing ACP</li> </ul>	Descriptive Qualitative interviews	25 participants (88% African Americans) Massachusetts and South Carolina	<ol> <li>Religion and spirituality</li> <li>Trust and mistrust</li> <li>Family relationships and experiences</li> <li>Patient-clinician relationships</li> <li>Prognostic communication</li> <li>Care preferences</li> <li>Preparation and controlExperts reinforced literature findings regarding trust and religion</li> <li>Participants with serious illness exhibited more trust in clinicians and wanted prognostic communication</li> </ol>
Collins et al. (2020)	<ul> <li>Leininger's Culture Care Diversity and Universality Theory (Moral)Aimed to identify cultural patterns around ACP with African Americans to inform culturally congruent nursing care</li> </ul>	Descriptive Qualitative Interviews	21 African Americans Michigan	<ol> <li>Faith in God and belief in life after death</li> <li>A strong matriarchal family structure</li> <li>Fear of talking about death and mistrust of the US health care system.</li> </ol>
Hong and Kim (2020) and (Hong and Kim, 2020)	Anderson's Health Model (Behavioral)     Aimed to use the framework to identify contributing factors to three ACP behaviors	Associational Secondary analysis of the 2012 wave of the National Health Aging and Trends Survey	543 Medicare beneficiaries (73.7% African Americans) Nationally Representative Dataset	Anderson's Health Model Education ( <b>enabling factor</b> ) was the only theory variable that consistently increased the odds of each ACP behavior (discussion, picking a durable power of attorney, and completing a living will) OR: 1.19, 95%CI: 1.07–1.32, <i>p</i> = 0.002; OR: 1.14, 95%CI: 1.02–1.26, <i>p</i> = 0.02; OR = 1.14, 95%CI: 1.02–1.28, <i>p</i> = 0.02, respectively
Suntai (2021) and Suntai et al. (2021)	Anderson's Health Model (Behavioral)     Hypothesized that racial and ethnic disparities in ACP behaviors will remain after adding framework variables	Associational Secondary analysis of the 2018 wave of the National Health Aging and Trends Survey	1,326 Medicare beneficiaries (21.1% African American) Nationally Representative Dataset	Anderson's Health Model and picking a Power of Attorney: Racial and ethnic disparities remained after adding theory variables (non-Hispanic black, ref: white, OR: 0.53, 95%CI: 0.52–0.53, $p < 0.05$ ) Anderson's Health Model and completing a living will: Racial and ethnic disparities remained after adding theory variables (non-Hispanic black, ref: white, OR: 0.33, 95%CI: 0.33–0.33, $p < 0.05$ )

health care system (Bullock, 2006; Huang et al., 2016; Sanders et al., 2019; Collins et al., 2020).

Framework categories and key constructs

In this section, we synthesize frameworks into categories (i.e., type of theory, e.g., behavioral) and discuss key constructs (i.e., core theory concepts). Frameworks were grouped according to construct similarities with definitions and categories assigned. Among 13 studies, 15 distinct models, theories, and/or frameworks were used with duplication of one theory only (i.e., Anderson's Health Model) (Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). The frameworks were categorized as behavioral (explaining behavior change), systems (social ecological, environmental), moral (community-based participatory, patient-provider interaction), and/or process frameworks (how

ACP happens). Each category, as well as overlap among categories are presented below.

## Behavioral frameworks

Behavioral frameworks (*N* = 7) were the most frequently used category, including the following frameworks: the Integrated Behavior Model (McAfee et al., 2019), Protection Motivation Theory (Allen et al., 2009), Expectancy Theory (Inoue, 2016), Transtheoretical Model of Change (West and Hollis, 2012), Social Ecological Theory (Sanders et al., 2019), the Health Literacy and Actions Framework (Huang et al., 2016), and Anderson's Health Model (Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021). Within these studies, ACP is characterized as a health behavior that is malleable to change (Fried et al., 2009). The products of this change entail specific behaviors or actions such as family discussions or documentation of end-of-life

## **Study Characteristics**

- -African Americans
- -Sample Size
- -Age
- -Gender
- -U.S. Region

## Methodological Approaches to Study Aims

- Level of analysis
- Descriptive (4)
- Associative (6)
- Explanatory (3)
- -Independent variables -Effect sizes

## Theoretical Framework **Construct Categories**

- -Behavioral (7)
- Internal psychological (6)
- Social (1)
- Systems (2)
- -Moral (5)
- Community-based, participatory (2)
- Patient-provider interactions (3)
- -Process (4)

## Modes (study components) of Application

- -Aims construction (9)
- -Instrument development (8)
- -Results explanation (8)
- -Intervention creation (4)
- -Variable selection (3)
- -Recruitment methods (2)
- -Setting selection (2)
- -Eligibility criteria (2)
- -Data analysis (2)
- -Focus group organization (1)

# Reporting Quality

- -Framework definition & completeness (15)
- Highest (4)
- High (3)
- Moderate (2)
- Lowest (6)
- -Justification of framework (7)
- -Inclusion of figure (4)
- -Fit of constructs with Advance Care Planning among African Americans
- (Relevance of constructs to study aims)

Fig. 2. Summary of synthesis of theoretical approaches to ACP among African Americans.

care preferences (Fried et al., 2009). Behavior refers to the observable human response to a situation ("Behavior,"). Health behavior refers to an interaction of knowledge, attitudes, and patterns of practice with health-related actions (e.g., physical activity) (Health Behavior, 1989). Behavior theory typically draws on a continuum of factors, ranging from individual, psychological factors to larger social forces (Kwon and Silva, 2020). Frameworks were designated as behavioral if constructs included either psychological (e.g., motivation) or social influences (e.g., family structure) and a behavioral component (e.g., completion of an advance directive). Six behavioral frameworks focused on psychological factors (e.g., beliefs) (Allen et al., 2009; West and Hollis, 2012; Huang et al., 2016; Inoue, 2016; McAfee et al., 2019; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021) while only one framework embedded ACP behavior within a social context (Sanders et al., 2019).

#### Systems frameworks

Two frameworks focused on systemic influences (e.g., financial, or social system) including Cumulative Disadvantage Theory (CDT) and Social Ecological Theory (Koss and Baker, 2018; Sanders et al., 2019). Systems Theory asserts that complicated interrelationships and interdependencies among parts form a functioning, cohesive whole that influences the action(s) of individuals (Systems Theory, 1980). Such theory posits that behavior emerges from the sum of these parts and those individual factors cannot be easily isolated from the larger system with which they interact. Constructs include structural forces (e.g., social/economic advantages and disadvantages within institutional procedures and customs), individual life trajectories, resource and health inequities, moral decision-making, and social systems.

## Moral frameworks

The moral category of frameworks entails how to approach a problem based on ethical standards that delineate right from wrong ("Morals,"). Frameworks were categorized as moral if constructs aligned with an ethical principle such as justice, autonomy, or beneficence (Beauchamp and Childress, 2001). This category was applied broadly to five of the frameworks and sub-divided into two subcategories of key constructs: community-based participatory approaches and patient-provider interactions (Waters, 2000; Bullock, 2006; Huang et al., 2016; Collins et al., 2020).

Community-based participatory approaches are often used for effective and lasting resolution of social and economic inequities through sharing power and ownership within communities (Wallerstein and Duran, 2010; Jull et al., 2017). One study used such an approach to boost ACP rates with the Faith-Based Promotion Model by delivering ACP education and recruitment within a faith community (Bullock, 2006). The Empowerment Education Theory doubles as an empowerment framework at both the patient and community level. This theory emphasized the capabilities within the community and the need for community input (Waters, 2000)

Additionally, moral frameworks focused on patient-provider interactions incorporated patient empowerment and a professional orientation. Patient empowerment in health care decisionmaking refers to actively involving patients through education and communication (Guanais and Soares, 2017). Self-Determination Theory supported the motivational interviewing component of a multi-faceted ACP intervention (Huang et al., 2016). Motivational interviewing empowers individuals through a cooperative process of expanding participant self-awareness of possibilities through coaching (Huang et al., 2016). The Ethic of Care Framework and Leininger's Culture Care Theory argue for a professional orientation to provider–patient decision-making as opposed to an authoritarian approach to clinical decision-making (Waters, 2000; Collins et al., 2020).

#### Process frameworks

A process refers to a natural occurrence characterized by gradual changes that lead to a specific end-product (Merriam-Webster). We categorized frameworks as a process if they consisted of stages or phases of change. Four theories incorporated process elements: Precaution Adoption Framework, Protection Motivation Theory, Transtheoretical Model (TTM), and Erikson's Stages of Development (Allen et al., 2009; West and Hollis, 2012; McAfee et al., 2019). The Precaution Adoption Framework represented stages of engagement with precautionary measures for health purposes (McAfee et al., 2019). The Protection Motivation Theory was used to test hypotheses of how an individual's first reaction to ACP may be influenced by processes of coping and threat appraisal (Waters, 2000). The TTM and Erikson's Stages of Development were used to create an interview guide and organize focus groups by age group, respectively (Allen et al., 2009).

Examples of process constructs included temporal stages, such as complete lack of awareness of issue and maintenance (TTM, Precaution Adoption Theory); coping and threat appraisal processes of evaluating severity, vulnerability, and self-efficacy response costs (Protection Motivation Theory); and developmental stages of intimacy versus isolation and ego integrity versus despair (Erikson) (Allen et al., 2009; West and Hollis, 2012; McAfee et al., 2019).

## Mode of application

We identified 10 unique modes of framework application across studies, i.e., ways in which the theory was used in the research or dissemination process. Modes of application included aims construction (n = 9 frameworks), instrument development (n = 8), and result explanations (n = 8) were the most common modes of applications. These were followed by: intervention creation (n = 4), variable selection (n = 3), recruitment methods (n = 2), setting selection (n = 2), eligibility criteria (n = 2), data analysis (n = 2), and focus group organization (n = 1).

## Reporting quality

We assessed reporting quality of each framework within studies by the following criteria: framework definition inclusion and completeness, rationale for framework use, inclusion of a figure to display the framework, framework citation or reference, reference to theory throughout the report, and fit of theory with study content. Of the nine frameworks that were *defined*, four definitions were deemed the highest level of completeness (Allen et al., 2009; Inoue, 2016; Collins et al., 2020; Hong and Kim, 2020; Suntai, 2021; Suntai et al., 2021), three were considered high (Waters, 2000; McAfee et al., 2019), and two were moderate (Koss and Baker, 2018; Sanders et al., 2019). Completeness of the definition was determined by the inclusion of key constructs, relationships among constructs, and explanation of the overall phenomenon. The remaining six frameworks were not defined, i.e.,

lowest level of completeness (Bullock, 2006; West and Hollis, 2012; Huang et al., 2016; McAfee et al., 2019).

Rationale for framework use refers to the presence or absence of a rationale for why the framework was applied to the study. Within studies, five frameworks were accompanied by an explanation for why the framework was used. Five frameworks included a description of other applications of the theory within previous health studies (Allen et al., 2009; Huang et al., 2016; McAfee et al., 2019; Hong and Kim, 2020). The Ethic of Care framework was justified as part of a professional nursing organization's position statement (Waters, 2000). Anderson's Health Model was justified in another study as having predictive and explanatory power (Suntai, 2021).

Four of the 15 frameworks within studies were displayed via conceptual *figures* in the studies (Allen et al., 2009; Huang et al., 2016; Collins et al., 2020; Suntai et al., 2021). For instance, Huang et al. (2016) used figures to represent how two frameworks worked in tandem: the Health Literacy and Health Actions Framework and the Self-Determination Theory (Huang et al., 2016). One figure was depicted in the methods section to show how the intervention and outcome measures corresponded to the frameworks (Huang et al., 2016). The second figure appeared in the discussion section as an enhanced version of the first figure based on the qualitative data (Huang et al., 2016).

As a final area of synthesis, we examined the fit of the framework constructs to the specific purpose or aims of each study related to ACP among African Americans. Overall, several of the theories aligned with each research purpose and exploratory factors that influence ACP and perceptions among African Americans. Behavioral theories that focused on psychological factors with ACP provided helpful explanations of relationships among factors with ACP. For instance, Allen et al. (2009) used the Precaution Adoption Framework by adapting constructs (seven stages: lack of awareness through behavior maintenance) into a questionnaire and simulating threatening scenarios with vignettes of persistent vegetative states (Allen et al., 2009). ACP has traditionally been conceptualized as a process most useful before crises occurs. The use of this framework demonstrated that the ACP process is useful for all populations of all ages, even those that are either less likely to adopt preventative screening such as younger patients or those that may avoid health care due to historic exploitation and discrimination (Allen et al., 2009).

CDT aligned with the issues of the disparate, low uptake of ACP among African Americans. This framework addressed the general problem of social inequities, which is congruent with ACP inequities. Additionally, this framework incorporated a nuanced account of the financial and social factors that are a source of many types of inequities among African Americans (Koss and Baker, 2018). CDT addressed the complex social determinants of health beyond the individual and psychological forces that contribute to decision-making.

Other frameworks aligned with important factors such as faith or health literacy. For instance, the Faith-Based Promotion Model was used as an action-oriented, community-based participatory framework which was consistent with African Americans who culturally and historically have relied on their faith community as a source of guidance and strength, and a way to take action to promote social change (Bullock, 2006). Lastly, the Self-Determination Theory and the Health Literacy and Health Actions Framework applied to decision-making, the need for complex interventions, and the essential component of health literacy to disparate rates of ACP engagement among African Americans (Huang et al., 2016).

#### **Discussion**

This review and synthesis underscore the application of theories that target individual vs. higher-level factors. While useful for stimulating change in individuals or small groups, such application may not be sufficient to sustain change at local and national levels. Health disparities research has evolved to address multi-faceted indicators within systems and communities, and similar approaches should be considered to address inequities in ACP uptake among African Americans (Myers, 2009). This review contributes to the scientific literature by identifying how theory use in this area is varied and encompasses behavioral, social/systems, elements of process, and moral/ethical perspectives. Among the four perspectives, most frameworks focused on behavior factors from the individual, psychological perspective. Despite this prevalence, a more systems-based perspective may be warranted, given the structural and social determinants of ACP inequities among African Americans (Hong et al., 2018; Sanders et al., 2019).

## **Implications**

These findings have implications for research and clinical practice. Theory-guided research is lacking, but its use to comprehensively address factors of ACP inequities among African Americans is promising (Im, 2015). The study of the problem of ACP inequities among African Americans has exploded over the last 30 years since the passing of the Patient Self-Determination Act of 1990 (Sanders et al., 2019; Teoli and Ghassemzadeh, 2019), and the use of theory may help to overcome challenges and move the field forward. Several of the studies (n = 11) included in this review were published within the last 10 years, suggesting that theory use has become more important to investigators. These studies provided a means to evaluate different theories by testing propositions, validating concepts, and identifying the boundaries of application across settings and populations. Likewise, each theory acted as an organizing framework to identify aims, isolate relevant variables, select participants, and construct instruments. This review of theoretical approaches to complex problems may spark new directions of research toward effective and sustainable solutions for marginalized communities.

This review detailed prominent and useful theories for the problem of inequitable ACP uptake among African Americans but also identified underused theoretical approaches to address the complex nature of this problem. Health and social inequity theories such as the Cumulative Disadvantage Theory (CDT) posit that life-course trends, intersectionality of marginalized identities, and systemic factors contribute to deepening inequities (O'Rand, 1996). The CDT use in one study demonstrated how a theory may be used to address the complexity and how it might be used to its fullest extent (Koss and Baker, 2018). Life-course theories such as CDT posit that early childhood factors and ongoing socioeconomic and health status have a cumulative effect on future health and socioeconomic status (O'Rand, 1996). Koss and Baker (2018) applied this temporal component in their study of ACP inequities by averaging longitudinal data from the Health and Retirement Study (i.e., household income from four waves of data collection). Additionally, while studies often dilute socioeconomic status to one variable (e.g., annual individual income), this study applied CDT by including multiple financial indicators (e.g., home ownership) to address the full picture (Koss and Baker, 2018).

CDT, the Social Ecological Framework, and the Ethic of Care Framework (Waters, 2000; Koss and Baker, 2018; Sanders et al., 2019) address the complex nature of ACP inequities in a way that individual-level theories cannot. These systems frameworks were consistent with Complexity-Informed Approaches to Science (Greenhalgh and Papoutsi, 2018). Such approaches acknowledge the intricacy of interactions among systems, call for a strong theoretical foundation with flexible methodology, and advocate for the representation of a multitude of perspectives (Greenhalgh and Papoutsi, 2018). The individual-level theoretical approaches to ACP inequities may not address complexity by providing a one-size-fits-all match with subject matter. Additionally, these approaches may account for variations in effect sizes across ACP studies. Systems frameworks align well with the goal of understanding a problem that originates from multiple overlapping systems and structures, the necessity of gleaning wisdom and experience from multiple perspectives (e.g., patients, caregivers, community health workers), and grounding research in a strong theoretical background.

Clinical practice may benefit from the findings of this review. First, understanding the influence of overlapping perspectives highlights the complexity of the problem of ACP among African Americans. Sanders et al. (2019) applied the Social Ecological Framework to structure participant perspectives and qualitatively analyze data according to social role (Sanders et al., 2019). African American health care providers were more likely to discuss factors such as medical mistrust and discrimination. However, seriously ill, African American patients, their caregivers, and healthy community members were more willing to learn about ACP than suggested by participants that worked in health care (Sanders et al., 2019). Health care providers must not assume that African Americans are not willing to engage in ACP.

Second, some of the frameworks discussed in this review provide practical applications for the clinical practice setting. For instance, the Ethic of Care framework, applied by Waters (2000), acknowledged the complex nature of decision-making and the ethical duty of health care providers to celebrate patient decision-making and create opportunities to collaborate with patients (Waters, 2000). This framework underpins a philosophy of care as well as an attitude. ACP involves rational preferences that originate from unconscious biases, health literacy levels, personal experiences, and fears. Providers and other health care professionals may develop ways to understand these deeper reasons, as well as create an environment where discussing these topics is easier. The myriad of frameworks may be useful to provide ideas as to how this problem may be approached.

#### Limitations and strengths

This review could reflect publication bias and was limited to published articles that could be found on CINAHL, PubMed, and Web of Science. However, the systematic search strategy was conducted with the guidance of a trained and experienced biomedical librarian (RLW), which improved the return of results. Gray literature was not considered in this review, so conclusions are limited to those that have been published and are available in the relevant databases. The review also reflects author(s) subjectivity in assessment and grading within particular synthesis areas (e.g., reporting quality); however, the assessment provides the reader with a metric to consider differences among studies. In terms of strengths, a rigorous and systematic review process was used and a systematic inductive approach was used to synthesize results into an

organized final product. Our intent was not to directly evaluate the frameworks applied to this sample of articles, rather we identified frameworks and describe how frameworks were applied and reported. Future reviews and research may consider the criteria for theory evaluation prior to utilization within studies.

## **Conclusion**

To our best knowledge, this literature review provides the first examination of theory use to describe and explain factors influencing ACP perceptions and rates among African Americans. Findings from this review may facilitate future research on this topic and guide use of theory in future research. Research and clinical practice rely on clear reporting to adopt and use theory at all levels.

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