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Disaggregated Data and Beyond: Future Queries in Cancer Control Research

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Abstract

The goal of health equity requires the collection and reporting of disaggregated data in underrepresented populations such as Asian American (AA) and Native Hawaiian and Other Pacific Islander (NHOPI) communities. A recent Department of Health and Human Services report outlines the necessity for disaggregated data which would offer communities, providers and planners better tools to address health problems. In a recent collaboration, the National Cancer Institute (NCI) and several registries published a series of papers tracking cancer incidence data on AA and NHOPI communities using data from the NCI's Surveillance and Epidemiology and End Results (SEER) program. The findings indicate a need for concentrated focus and planning for the next stages of cancer prevention and control for AA and NHOPI subpopulations. In this article, we provide (a) the context for the perpetuation of the model minority myth as well as historical and socio-cultural factors that have shaped health and disease for AA and NHOPI subgroups; (b) potential strategies for research and public health policy for AA and NHOPI groups using subpopulation-based approaches while addressing challenges and limitations; and (c) a portfolio analysis of currently funded projects within the NCI/DCCPS to identify gaps and areas of potential research.

Keywords

Asian American; Native Hawaiian and Other Pacific Islander; Health Equity; Health Disparities; Disaggregated Data; Cancer Prevention and Control; Transdisciplinary Research

INTRODUCTION

Despite overall longevity and improved quality of life, racial and ethnic minorities still experience significant differences in health outcomes (1-5). The commitment to health equity within the context of cancer prevention and control still requires greater efforts across the cancer continuum. One important way to gauge health equity is to establish quality monitoring and surveillance systems. In keeping with this objective, efforts must be made to

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strengthen existing information systems or to devise new ones to accurately track and monitor outcomes for racial/ethnic populations/subpopulations.

In the past ten years, the Department of Health and Human Services (HHS) has been steadily refining standards for the collection of data on race and ethnicity. A recent HHS report laid out an action plan specifying multi-faceted data collection strategies for health disparities (6). These standards have afforded granularity in the area of race and ethnicity for Asian Americans (seven categories – Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asians), Native Hawaiian and Other Pacific Islanders (four categories - Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islanders), and Hispanics (four categories – Cuban, Mexican, Puerto Rican, and Other South or Central American or other Spanish culture or origin) (7).

Outside of the realm of public policy, there are increased efforts to report disaggregated racial/ethnic subpopulation data in health research studies. Recently, the NCI's Surveillance and Epidemiology and End Results (SEER) program's collaborative published a series of papers by Gomez et al. (8) and Liu et al. (9) on disaggregated Asian American (AA) and Native Hawaiian and Other Pacific Islander (NHOPI) communities tracking cancer incidence. These publications allow for the identification of racial/ethnic subpopulations that are at higher risk for cancers and offer insights to lessen the burden of cancer over time for such historically underserved groups. These reports place into context the importance of unique historical and political narratives of the subgroups found within the AA and NHOPI populations.

Disaggregated approaches may also reveal subpopulation-specific attributes that can inform cancer prevention and control strategies by highlighting protective mechanisms. Just as we should avoid stereotypes associated with the "model minority myth," we must also exercise caution in overgeneralizing risk factors as AA and NHOPI subgroups represent both extremes of socioeconomic and health indices (10;11). A report released by the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS) examined national estimates for selected health status indicators among AA adult subgroups (11). There were some notable discrepancies in access to care indicators and health care utilization among AA subgroups in health insurance status (e.g., 9% of Japanese adults were uninsured vs. 36% of Korean adults), having a usual source of care (12% of Japanese adults reported not having a usual source of care vs. 25% of Korean adults), delaying medical care due to cost (e.g., 3% of Filipino adults delayed medical care vs. 7% of Korean adults). Discrepancies in health behaviors among AA subgroups were also observed smoking (e.g., 7% of American Indian adults were current smokers vs. 22% of Korean adults), alcohol use (e.g., 6% of Vietnamese adults were current moderate or heavier drinkers vs. 14% of Japanese adults), and obesity (e.g., 4% of Chinese adults were obese vs. 14% Filipino adults). These findings (11) confirm that heterogeneity exists in AA subgroups and suggest it is equally important to attend to both risk factors *and* protective factors that are found within different cultural groups when devising intervention strategies in cancer prevention and control. Much more work is needed to understand the biological, behavioral, and cultural mechanisms that shape cancer risk factors and outcomes for these communities.

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In this paper, we discuss topics surrounding AA and NHOPI subpopulation research, focusing on: (a) the model minority myth and its intersection with social determinants of health; (b) potential strategies for research and public health policy for these subpopulations; (c) a portfolio analysis of currently funded subpopulation projects within the Division of Cancer Control and Population Sciences (DCCPS) at the NCI to identify gaps and areas for potential research. Finally, we conclude with future steps to guide cancer prevention and control efforts.

HISTORICAL HEALTH NARRATIVES

The Model Minority Myth

A prevailing approach in the study of the health of racial/ethnic minorities is the use of aggregate data in which AA and NHOPI subgroups are collapsed and studied as a monolith. The view that these subgroups comprise one homogenous population is a misconception fraught with problems as AA and NHOPI subgroups have very distinct historical narratives with different immigration and settlement experiences in the U.S. For example, Chinese and Japanese immigrant laborers in the 19th century seeking economic opportunities differed from the Vietnamese and Cambodians escaping political persecution in the late 1970s (12). Similarly, social status of the immigrants and their ethnic subgroup in the country of origin played an important part in the ease of transition to the destination country. Consider the immigration experience of the Filipinos with that of the Hmong. Filipinos that arrived to the U.S. in the early 20th century were Roman Catholic, equipped with English-speaking skills, and considered ‘Nationals’ due to the annexation of the Philippines by the U.S. following the 1898 Spanish-American War. On the other hand, the Hmong comprise a culturally distinct group that is fragmented and found within regions of southern China and northern Southeast Asia, including Laos and Vietnam; historically, they have been isolated and marginalized in their homelands and continue to experience extremely low social status even after immigrating to the U.S. (13).

A large concern with the use of aggregate data is that it masks important distinctions within AA and NHOPI subpopulations. Broad generalizations have led to the endorsement of the ‘model minority myth,’ which is the belief that, as a collective group, Asian Americans have achieved success on indicators of health and well-being (14-16). There are cultural and corresponding health differences between Pakistani/Indian peoples and Guamanian/Kampuchean peoples, yet they are all captured under a single category ‘Asian.’ Perpetuation of the ‘model minority myth’ runs the risk of blurring the very real health issues found within specific communities. A study by Miller and colleagues (17), one of the first to examine cancer incidence and mortality rates among AA and NHOPI subgroups, revealed that as an aggregate group, the AA and NHOPI population experienced lower overall cancer incidence rates in comparison to non-Hispanic Whites. However, closer examination of disaggregated rates revealed distinct patterns. Specific AA and NHOPI subgroups experience different incidence rates for site-specific cancers in comparison to non-Hispanic Whites. For example, colorectal cancer incidence rates for Japanese men and women and nasopharyngeal cancer incidence rates for Chinese and Vietnamese men and women exceeded rates found for non-Hispanic White men and women(17). In addition, there were

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varying rates of site-specific cancers as experienced among AA and NHOPI subgroups. Native Hawaiian and Samoan men experienced the highest rates of prostate and lung cancer while Native Hawaiian and Samoan women experienced the highest rates of breast and lung cancer compared to other AA/NHOPI subgroups. In addition, the reports by Gomez et al (2013) and Lui et al. (2013) further dispel the model minority myth by revealing differences in cancer incidence rates and trends among AA and NHOPI subgroups.

As the HHS pursues its effort to reduce health disparities, improved monitoring and reporting of disaggregated data will elucidate important structural and social mechanisms that lead to poor health outcomes among the underserved.

The Conflation of Cultural Differences and Social Inequalities

In the current literature, there is strong evidence for the association between poor health outcomes with low levels of educational attainment, occupational status, wealth, housing, and income (18-21), factors commonly referred to as *social determinants* of health. These differences among disaggregated AA and NHOPI subgroups are a product of historical factors and social inequalities and should not be dismissed as mere manifestations of different expressions of culture.

Reflecting on how culture is poorly understood and measured, Kagawa-Singer (22) discusses the misuse of *culture* as the underlying cause of the burdens of disease in underserved communities. While race/ethnicity and social class are highly interrelated constructs (23-25), there is a tendency to conflate the two. Examples from ethnic enclaves and neighborhoods illustrate this. For many immigrant communities, ethnic enclaves arise in response to a need for social, economic, and psychological support as refugees and immigrants adjust to a larger host society (26;27). However, these enclaves are often located in poor neighborhoods associated with a host of upstream determinants that include racial segregation, unacceptable built environments, increased exposure to environmental hazards, inadequate educational institutions, and decreased employment opportunities – all of which lead to downstream consequences in poor health outcomes (25;28-30). Hence, poor health outcomes due to social determinants of health are often misattributed to ethnic or cultural enclaves. At its very worst, misuse of ‘culture’ blames marginalized members for their poor health outcomes (31).

SUBPOPULATION-BASED APPROACHES TO HEALTH

More than a quarter of a century ago, Geoffrey Rose described two sets of prevention strategies: those that targeted high-risk individuals versus those that were population-based approaches (32;33). Applying a high-risk prevention strategy is challenging, costly, requires screening for all individuals to determine individual risk, and creates barriers for access to care for some. Further, this strategy does not address underlying mechanisms and behaviors that are related to chronic disease. On the other hand, while population-based approaches do not suffer from these limitations, they assume best practices that are created for the ‘average’ individual while ignoring sociocultural and demographic factors that may result in increasing one’s individual risk. We believe optimal prevention strategies developed for specific AA and NHOPI subgroups will be placed between these two spectrums of Rose’s

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prevention strategies. We refer to this middle approach as a *subpopulation-based approach*. The paper will now explore potential strategies for this middle approach in two important areas in cancer prevention and control for AA and NHOPI subpopulations. These two areas include: (a) methodologies and sources for examining subpopulation data; and (b) transdisciplinary research and training.

Methodologies and Sources for Examining Subpopulation Data

Disaggregated Data—While disaggregated data is crucial for cancer research in AA and NHOPI subpopulations, there are limitations associated with such data. First, few data sources have large enough samples to disaggregate information on AA and NHOPI populations. Second, data sources that enable disaggregation often do not have comprehensive measures that allow researchers to address the myriad factors driving cancer incidence or mortality trends. For example, several population-based surveys include information on cancer prevention (e.g. cancer screening) or health behaviors (e.g. diet and physical activity) but have limited clinical information (e.g. cancer incidence stage, treatment) that would allow for analyses across the cancer continuum. By contrast, other data sources, such as registry data, provide thorough information on clinical cancer variables enabling estimation of population-based cancer incidence rates and trends but lack items that measure preventive behaviors and health cognition. Linkages to registry data provide additional information such as socio-economic variables at the county and census tract level, types of services used during treatment and costs of care but have limited data on screening, health behaviors, or immigration experience.

No comprehensive and large data sources include variables related to immigration (e.g., country of origin, age at immigration, length of time spent in the US, citizenship status, reasons for immigration), which would provide the sociocultural context to understand a specific population's health behaviors. Furthermore, very few population-based data resources include any information on health beliefs or attitudes towards use of preventive services in AA and NHOPI communities. These gaps in data pose problems for researchers in testing hypotheses on theoretical frameworks as necessary measures are not fully captured in any single dataset.

In order to address these data gaps, we offer strategies to address limitations with disaggregated data. These include: (1) optimizing existing resources by pooling or layering data sets across years to increase the sample size of AA and NHOPI subgroups and to enable disaggregating information within the pooled data; (2) supporting the development of data linkages. For example, data sources linked by geographic indicators such as census tract, metropolitan service area, or county, enable a single data resource to include variables at multiple points of the cancer continuum at an ecological level; (3) improving methodologies, including statistical approaches, to examine small population groups and promote mixed methods research; (4) triangulating data sources to foster comparisons between different types of data; and (5) developing transdisciplinary research teams to address the complex nature of studying a heterogeneous immigrant population with varied social histories, health status, cancer risk, preventive behaviors, and differing health beliefs.

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The paper will now discuss two methodological approaches, mixed methods research and multilevel modeling, both of which can inform and elevate the quality of research on these communities by shedding light on underlying mechanisms that drive health disparities behaviors and outcomes.

Mixed methods research—Mixed methods research has become increasingly common, particularly among small population groups that typically have inadequate sample sizes in quantitative surveys. While there does not exist one consensual definition of mixed methods research, it is now widely considered as a major research approach or paradigm alongside qualitative and quantitative research (34). Mixed methods research integrates both quantitative and qualitative methods in a single study in order to more fully under the phenomenon of interest. Mixed methods focuses on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences. It employs rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs; and in utilizing multiple methods (e.g., intervention trials and in-depth interviews), it draws on the strengths of each while frames scientific inquiry within philosophical and theoretical frameworks (35). In 2011, the Office of Behavioral and Social Science Research at the NIH published the *Best Practices for Mixed Methods Research* to foster the appropriate use of mixed methods study designs, describing health disparities as an area of relevant application (36).

To date, descriptive studies have used mixed methods designs to examine a number of research topics among AA and NHOPI populations, including: cultural and health beliefs associated with health behaviors among breast cancer survivors; the impact of acculturation on lifestyle factors; attitudes, beliefs, and practices surrounding mental health; end-of-life care; intimate partner violence; adolescent health; and the development of culturally tailored interventions targeting health behaviors (37-44). Studies such as these shed light on mechanisms underlying health behaviors, such as cultural beliefs, norms, and practices, and provide information on contextual factors that shape health disparities within these communities. However, the application of mixed methods for intervention research is still limited in AA and NHOPI subpopulations and may be bolstered by a multi-level modeling/ intervention conceptual framework.

Multilevel Modeling and Intervention—The reliance on multilevel conceptual frameworks can reveal the different levels from which determinants of health inequities operate (35;37). Socioecological models provide a comprehensive framework (38;39;45) and illustrate how health disparities may arise from levels that include micro determinants (pathophysiologic pathways, genetic and individual risk factors), interpersonal processes (social relationships, living conditions, neighborhoods and communities), and macro factors (institutions and social/economic policies). These determinants are also considered within an environmental context and across a history or life course with the understanding that interactions occur among multiple levels and may move along non-linear pathways, demonstrating the challenges and complexities in studying health disparities.

The multidimensionality of health disparities may be addressed through intervention study design. Study designs that address factors on multiple levels have the potential to make

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sustainable changes by improving community conditions. As summarized by Trickett and Beehler (40) multilevel interventions should endorse an ecological perspective on behavior, foster collaborative partnerships with the community, involve both community and individual-level goals, provide long-term commitment to local projects, be theory-based and empirically driven, and build and train transdisciplinary teams. Multi-level estimation of effects can contribute to knowledge of multi-level interactions and guide interventions that can be tailored to subpopulations. To better study these complex relationships, statistical techniques such as randomization and matching may be considered (41). More complex study designs, such as nested designs, may also be needed (41). Thus, multilevel interventions, because they demonstrate how structural and community factors work in combination with individual level factors are immensely necessary to understand the complexities of health disparities.

Through analysis, multi-level modeling can simultaneously examine the contributions of individual-level and group-level variables on health while controlling for confounding factors especially when randomization is not possible or feasible (41;42). Propensity scores, which are the probabilities of being in the treatment/experimental group (accounting for covariate values), can be used to control for potential confounders. The propensity score can also be used to conduct matching, stratify subjects, or be used directly in regression models to simulate treatment and control groups that are balanced on a set of confounders. Another modeling technique is instrumental variable analysis where the instrumental variable is predictive of the intervention but not associated with the outcome.

Transdisciplinary Research and Training

The adoption of mixed methods and multilevel modeling presupposes a transdisciplinary or team science approach to studies of AA and NHOPI communities. The transdisciplinary approach gathers scientists representing diverse disciplines to capture the complex causes and consequences of health disparities (43) while developing models to address them. Though researchers are initially guided by their respective disciplines, the approach encourages collaborators to mutually inform each other while transcending the borders of their disciplines. This cross-fertilization leads to formation of a new intellectual space, stimulating innovative modes of thinking and knowledge (44). In particular, transdisciplinary research can serve as a viable strategy in understanding AA and NHOPI subpopulation health by overcoming three silos: (i) information silos; (ii) population silos; and (iii) training silos, discussed below.

Information silos—Current biomedical and academic models condone ‘information silos’ which refer to organizations and/or data systems that do not exchange data with other similar systems (46). Since very few data sources have large enough samples to study disaggregated AA and NHOPI subgroups, the use of data linkages permit researchers to address previously unexplored relationships. Under transdisciplinary efforts, health disparities research benefits as new questions will integrate behavioral, social, medical, and biologic components while also affording increased statistical power with large samples to study between- and within-effects (47) resulting in a holistic and cumulative knowledge base.

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Population silos—Often, ethnic minority researchers pursue ethnic minority health research. The advantage is that these researchers, belonging to the respective communities that they study, are intimately aware of culturally appropriate strategies and perspectives needed for scientific inquiry. However, the disadvantage is that they operate within ‘population silos,’ (e.g., Vietnamese health disparities research being conducted by Vietnamese researchers). Since health inequities arise from social determinants, many of which are common across subpopulations, transdisciplinary research can encourage experts across subpopulations to collaborate thereby suggesting effective interventions for underlying social inequalities (43). The pooling of research effort across AA and NHOPI communities will also serve to garner enough voices to lead to necessary paradigm shifts that will enact policies for healthier AA and NHOPI communities to address upstream determinants of health such as quality health care access, fair housing, safer neighborhoods, and higher standards of education (44).

Training silos—Transdisciplinary efforts will also defy current models of training and encourage universities and institutions to attract mentors and mentees from various disciplines to form diverse teams (43). There is increasing emphasis for transdisciplinary work at the NCI and NIH where it is increasingly recognized that today’s health problems “demand that scientists move beyond the confines of their individual disciplines and explore new organizational models for team science (47).” However, because these projects are time-intensive and require extensive networks, there is lack of recognition for their importance, and they may not be amenable to the current university incentive and reward systems (48). In addition, ongoing efforts must commit to identifying and training members from AA and NHOPI populations to become the next generation of cancer prevention and control scientists as these researchers will be more inclined to study and address health issues relevant to their communities.

PORTFOLIO ANALYSIS

So far, the paper has presented some promising subpopulation-based approaches with potential implications for research and public health policy among AA and NHOPI subgroups. Against this backdrop, an analysis of currently funded projects within DCCPS was conducted to identify whether there are applications being submitted that account for these gaps in research. The aim of this section is not to evaluate the currently funded projects against the suggestions in the foregoing part of the paper but to present them as they are with the hope that they can provide areas for future research.

The following is a report on currently funded grants through the R01 (NIH Research Project Grant Program), R21 (NIH Exploratory/Developmental Research Grant Award) and R03 (NIH Small Grant Program) mechanisms in DCCPS that are focused on AA and NHOPI populations in the US. Definitions of these mechanisms can be found at http://grants.nih.gov/grants/funding/funding_program.htm#RSeries. The analysis is restricted to these three funding mechanisms because they provide the basis for hypotheses-driven research.

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Focus of the Grants

At the end of the 2013 fiscal year, there were no grants focused on NHOPI communities, while nine actively funded grants focused on AA communities only. Of these nine, six are R01s, two are R21s, and one is an R03 grant.

Of the six R01s, two studies do not specify the AA subpopulations while four disaggregate the AA subpopulations. Of the two that did not specify the AA subpopulation, one study focuses on HPV vaccination barriers and uptake and the other focus is on implementing evidence-based approaches and programs among community lay health workers. The four R01s that specify the AA subpopulations focus on Chinese, Korean, Vietnamese and Japanese communities.

Regarding the content of the six R01s, four are intervention studies that describe interventions for health promotion and secondary prevention. Three of these four intervention studies are conducting randomized clinical trials. The remaining two R01s are descriptive, with one focusing on cancer survivors' quality of life and well-being

Of the two R21s, one is an intervention study for health promotion among breast cancer survivors in the Korean community and the other is a descriptive study in the South Asian community about the use of tobacco practices.

The R03 focuses on Chinese survivors of Hepatocellular carcinoma and their attitudes to liver transplantation.

Success Rates

Data from 2013 were used to estimate the success rate of AA and NHOPI applications submitted to DCCPS. The overall success rate was 8%.

An analysis of the unfunded R01s that were "largely focused" on these subpopulations was conducted to understand the critiques made by the peer review groups. "Largely focused" applications are those that had at least 50% AA or NHOPI recruitment or when studies compared equal percentages of all racial and ethnic groups enrolled.

There were 26 R01s that were received by DCCPS of which four received a score at review while the rest were not discussed at review. The study section noted major flaws in the applications of the four that received scores at review. All the four studies were focused on developing and implementing interventions for health promotion and improving secondary prevention strategies. Common critiques across these applications were methodological - the overall design of the interventions in the applications was not well developed and specified; the intervention effect and outcomes were not clearly specified; often, there was a lack of comparison groups; statistical models for the sample size were proposed but not clearly laid out. Another area of critique involved concern with the leadership of the research team (e.g., lack of experience of the investigator(s) in the area of study as indicated by the lack of appropriate publications; no track record to prove that the principal investigator could conduct such a large project). It is important to demonstrate a track record of previous successful collaboration among members of the transdisciplinary team, and many of the

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studies failed to demonstrate this as indicated by the lack of co-authored publications among team members.

Our portfolio analysis indicates that there are very few robust applications received by DCCPS that address the important issues concerning AA and NHOPI communities. This should not be construed as a criticism but as an impetus to renew our efforts to improve methodology and design in the submission of research on subpopulations.

CONCLUSION AND FUTURE QUERIES

Adoption of innovative prevention/intervention strategies in research is imperative to improving the health of AA and NHOPI subpopulations. In order to improve methodologies and increase generalizations that can be made to subpopulations across the U.S., we pose unanswered inquiries: (1) What statistical tools are needed to analyze subpopulation data? (2) What aspects of the subpopulation research in one community allow for generalizations to other AA and NHOPI subpopulations? (3) Can evidence-based interventions from other large populations be adapted to smaller diverse populations? What are the factors that need to be considered when testing and implementing multilevel interventions? Would the methodological considerations of pragmatic trials assist in answering the question, “does the intervention work under usual conditions, for whom, and under what circumstances?” Could these pragmatic trials can also offer some guidance for design features that researchers and partners can study among interventions implemented “across specific types of settings or across a wide range of settings (49) (4)?” Given the diverse locations of the subpopulations, how can the concept of *place* (i.e., social, environmental, and ecological factors) be incorporated in these studies? How can we account for these factors in interventions? These questions and the responses to them will not only strengthen the methodology and design but will allow for the results of the research to be extended to other subpopulations.

The current problems found in small population research are not restricted to AA and NHOPI subgroups but can be extended to Native American, lesbian/gay/bisexual/transgender, African American, Hispanic, and other small subpopulations. These communities continue to face severe health problems with multiple chronic conditions and are limited in their inclusion in research projects currently funded by NIH. Promoting prevention strategies requires the development of methodologies and strategies that can be relevant to all these subpopulations to improve overall health. Factors such as immigration and settlement experiences, language, geography, environment, sample size, and varied health systems found among subgroups pose difficulties and challenges in studying population-based health. However, they do provide opportunities to develop meaningful methodologies and strategies for subpopulation-based research.

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