Community-based culturally tailored education programmes for black adults with cardiovascular disease, diabetes, hypertension and stroke: a systematic review protocol of primary empirical studies

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ABSTRACT

Introduction Chronic conditions and stroke disproportionately affect black adults in communities all around the world partly due to patterns of systemic racism, disparities in care, and lack of resources. Culturally tailored programmes can potentially meet the needs of the communities they serve, including black adults who may experience reduced access to postacute services. To address unequal care received by black communities, a shift to community-based programmes that deliver culturally tailored programmes may give an alternative to a healthcare model which reinforces health inequities. The objectives of this review are to: (1) synthesise key programme characteristics and outcomes of culturally tailored community-based (CBCT) programmes that are designed to improve health outcomes in black adults with cardiovascular disease, hypertension, diabetes, or stroke and (2) identify which of the five categories of culturally appropriate programmes from Kreuter and colleagues have been used to implement CBCT programmes.

Methods and analysis This is a protocol for a systematic review that will search Medline, Embase and Cumulative Index to Nursing and Allied Health Literature databases to identify studies of CBCT programmes for black adults with cardiovascular disease, hypertension, diabetes, or stroke between 2000 and 2021. Two reviewers will assess each study based on the inclusion criteria and any disagreements will be resolved by a third reviewer. Data will be extracted using a customised data extraction form to identify programme characteristics and the strategies used to develop culturally appropriate programmes. AMSTAR will be used to evaluate the articles included in the study. The aggregated data will be presented through textual descriptions of programme characteristics and outcomes.

Ethics and dissemination This systematic review protocol does not require ethics approval without the inclusion of human participants and will use studies that have previously obtained informed consent. The systematic review findings will be disseminated in a peer-reviewed journal and used to inform future research led by JF and HS.

STRENGTHS AND LIMITATIONS OF THIS STUDY

► This systematic review contributes to the current literature by including multiple conditions that greatly impact the lives of black adults and will allow researchers to identify key characteristics of culturally tailored community-based (CBCT) programmes across conditions rather than targeting a single condition.

► Two independent reviewers will complete abstract and full-text screening with a third reviewer to address any disagreements and reduce the risk of bias.

► Due to varying terminology used to describe CBCT programmes, relevant articles may be missed during the literature search.

BACKGROUND

The ageing population combined with medical advances have enabled people to live longer, but the proportion of people living with chronic diseases and/or with the effects of a stroke has been increasing.1 This is particularly so for black adults (defined in this review as individuals of African descent) who experience a higher incidence and severity of stroke and their odds of cardiovascular disease, hypertension, and diabetes is greater than white individuals.2-5 Chronic conditions, including cardiovascular disease, hypertension and diabetes not only increase the risk of additional health events, such as a stroke, but also reduce functional status, health-related quality of life, social and psychological functioning, and productivity of those living with these chronic conditions.6 Sharing a greater
Numerous studies have demonstrated that black adults receive poorer disease prevention and management care from health care systems. For example, medical advances in the identification and treatment of cardiovascular diseases have resulted in decreased incidence of and mortality from cardiovascular disease at a population-wide level. However, cardiovascular disease rates among black adults remain high as a result of poor disease management among black communities. Furthermore, Bonow et al have found that racialised communities experience a higher frequency of undiagnosed risk factors that stem from disparities in access to care and health literacy. Black adults experience poorer health outcomes from chronic health conditions than white adults. Moreover, Odonkor et al noted that ‘Black individuals were less likely to receive care that was concordant with clinical guidelines per the reported literature’.

Health disparities among black communities have been recognised for decades, but specific programmes meant to address them have yet to become a priority within the medical field. Although it is not a predominant intervention strategy, a growing body of literature have called for culturally tailored community-based (CBCT) programmes to reduce health disparities and improve health outcomes for racialised communities. They do so by taking into account specific factors, including social–cultural (eg, ethnic–cultural values, racially discriminatory social policies), community (eg, institutional racism), and familial factors (eg, differential acculturation) that can cause health disparities among specific communities. CBCT programmes can be used to provide services to marginalised communities who may not receive the same levels of support from the healthcare system. In particular, they can be used to improve the health outcomes of black adults who have been diagnosed with hypertension and diabetes.

For this review, a ‘community-based’ refers to an intervention delivered within a community setting (eg, an individual’s home, healthcare clinic) that brings people together with the intention of empowering members of the community to share their own knowledge and experience to develop a common understanding to address common problems faced by communities. Multiple terms have been used, sometimes interchangeably, to describe interventions that take culture (eg, ‘culturally appropriate,’ ‘culturally targeted,’ and ‘culturally relevant’); in this review culturally tailored is used to refer to ‘recognition of a group’s cultural values, beliefs and behaviours’ as indispensable context to addressing specific health problems impacting a specific ethnic community. The combination of community-based and culturally tailored allows for the empowerment of individuals living within communities to use their cultural values, beliefs and behaviours to inform programmes and interventions to address health issues in their community.

Multiple frameworks exist to evaluate and develop interventions based on the cultural characteristics of the communities the interventions are meant to serve. While many of these frameworks outline similar approaches, concepts and ideas, the culturally appropriate framework developed by Kreuter et al provides evaluation tools for surface level cultural characteristics (eg, materials), deep structure cultural characteristics (eg, language) and sociocultural issues facing target communities. Kreuter et al have outlined five strategies for designing and implementing culturally tailored programmes, which can serve as a valuable framework for understanding and comparing CBCT programmes. The five strategies include: (1) peripheral strategies, (2) evidential strategies, (3) linguistic strategies, (4) constituent-involving strategies and (5) sociocultural strategies. Peripheral strategies entail creating programme materials featuring images and text meant for the target cultural group. Evidential strategies employ data to highlight the impacts of specific conditions on participants who are from a specific group. Linguistic strategies develop the programme around the linguistic capabilities of participants using their native language or basic everyday vernacular. Constituent-involving strategies involve members of a target community to develop insights and cultural awareness in programme development. Sociocultural strategies recognise the impact of social and cultural characteristics in community health practices and leverage them to provide context into the issues facing these communities.

A common practice in CBCT programmes is to involve community members in programme design. Designing CBCT programmes with input and developmental insights from cultural groups that they intend to serve allows the programmes to target relevant barriers and challenges, and resources to be applied where most needed. CBCT programmes have shown promising impacts on chronic disease awareness, condition management, medication adherence, programme satisfaction, condition-specific knowledge, psychosocial factors, and health intervention strategies among black communities. However, the design, structure and operational definition of CBCT programmes varies considerably from programme to programme, making them difficult to compare. Thus, the purpose of this systematic review is to understand the design, structure and definition of CBCT programmes that have been used to improve health outcomes in black adults with cardiovascular disease, hypertension, diabetes, or stroke using Kreuter and colleagues’ framework.

**Review questions**

We will address the following questions in this review:

1. What are key programme characteristics and outcomes of CBCT programmes that are designed to improve health outcomes in black adults with cardiovascular disease, hypertension, diabetes or stroke?
2. Which of the five categories of culturally appropriate programmes, as identified by Kreuter and colleagues, have been used in CBCT programmes for black adults with cardiovascular disease, hypertension, diabetes or stroke, and how have they been implemented in these programmes?

METHODS
This review will follow the procedures outlined in the Preferred Reporting Items of Systematic Review of Interventions and Meta-Analyses 2020 statement and has been registered with the International Prospective Register of Systematic Reviews (CRD42021245772).

Search strategy
To access published materials, a comprehensive search strategy will be conducted within the following electronic databases: Medline, Embase (OvidSP), and Cumulative Index to Nursing and Allied Health Literature (EBSCO-host). These particular databases were selected as they focus on health-related literature and include community-based interventions, which will allow us to locate the most relevant articles. Concepts relating to (1) community-based or culturally tailored education, (2) cardiovascular disease, hypertension, diabetes, or stroke, and (3) black adults (eg, ‘African continental ancestral group’) will be searched for within the selected databases. The use of the search term ‘African continental ancestral group’ was meant to broaden the search outside of just the American context while also recognising black adults as a heterogeneous population connected by shared ancestry. A comprehensive search strategy will be created with assistance from EMU, an Information Scientist (see Appendix A for the full search strategy for Medline). No language restrictions will be applied to the search strategy. The preliminary search, which was conducted on 30 September 2021 in Medline, generated 627 articles.

Inclusion criteria
Detailed inclusion criteria can be found in table 1.

Study design
We will include published empirical studies of any study design that gather evidence from a CBCT programme for black adults with cardiovascular disease, hypertension, diabetes or stroke. Empirical studies are any study ‘obtaining direct, observable information from the world, rather than, for example, by theorising, or by reasoning, or by arguing from first principles’.

The key concept from this definition is the ‘observable information from the world’ that is found from empirical studies (eg, pilot studies, randomised control trials, cohort studies, qualitative interviews, surveys) and not from opinion letters, commentaries protocols, or intervention descriptions.

The use of primary source studies will provide an opportunity for reviewers to extract data from the original source and ensure data specific to our topic of interest will be recorded. The inclusion of quantitative and qualitative data will allow us to generate an understanding of the effects of CBCT programmes on health outcomes using quantitative data as well as patient-reported outcomes by the target community through qualitative inquiry. Our research team decided to limit to empirical published studies to effectively address our research aims. We have excluded grey literature due to lack of peer review and the variable quality and inconsistent reporting of programme outcomes.

Setting
No restrictions will be placed on the country in which the programme occurred. However, this review will limit to programmes that take place in the community setting (ie, outside of a hospital setting).

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**Table 1** Inclusion criteria

| Inclusion criteria | Other terms for title abstract | Screened and included | Study type and designs |
|--------------------|-------------------------------|-----------------------|-----------------------|
| Black adults (≥18 years of age) possible terms: | | | |
| African American | | | |
| Black Canadian | | | |
| Black British | | | |
| Afro-Caribbean | | | |
| Afro-Brazilians | | | |
| Afro (other countries of Central or South America) | | | |
| Other terms for title abstract Screening | | | |
| Minorities | | | |
| Visible minority | | | |
| People of colour | | | |
| Racialised | | | |
| Ethnic minority | | | |

| Community based (CB) | Culturally tailored | At least one education component Examples: |
|----------------------|--------------------|---------------------------------------------|
| CB approach brings people together with the intention of sharing knowledge, experiences and to develop a common understanding | | Diet/nutrition |
| Members of the community have roles in the intervention | | Medication adherence |

| Programme includes at least one of the five strategies of culturally appropriate programmes | Existing programme |
|------------------------------------------|-------------------|
| Peripheral strategies | Published 2000–2021 |
| Evidential strategies | |
| Linguistic strategies | |
| Constituent-involving strategies | |
| Sociocultural strategies | |

| Participant has cardiovascular disease/hypertension/ diabetes/stroke | Published 2000–2021 |
|--------------------------|-------------------|

| Patient focused | Study type and designs |
|------------------|-----------------------|
| Programme developed for patients rather than clinicians | Primary source |
| Published 2000–2021 | Any empirical study design |
Participants
The participants in this review will be black adults (≥18 years of age) with hypertension, cardiovascular disease, diabetes or stroke.

Intervention
This review will include programmes which deliver culturally tailored education to black adults with cardiovascular disease, hypertension, diabetes or stroke. Thus, studies focused on prevention will not be included in this systematic review. The education should relate to the management of one of these conditions (ie, hypertension, cardiovascular disease, diabetes, or stroke). To be considered culturally tailored, the intervention must include at least one of the following culturally appropriate strategies outlined by Kreuter and colleagues: (1) peripheral strategies, (2) evidential strategies, (3) linguistic strategies, (4) constituent-involving strategies and (5) sociocultural strategies.

Type of outcome measure
As the intent of this review is to inform the design and structure of future programmes, all outcome measurements will be reported in this systematic review, including participant-level (eg, health-related outcomes, health literacy, medication adherence, psychosocial measurements) as well as program-level outcome measures (eg, programme adherence, satisfaction).

Patient and public involvement
While the researchers recognise the importance of patient and public involvement in the research process, we will not engage with patients or the public in completing this systematic review.

STUDY RECORDS
Search methods
The search will be conducted by the lead author (JF) and Information Specialist (EMU) on the relevant databases. To ensure we maximise our results, we will hand search the reference lists of included studies.

Selection process
All articles identified from the search will be uploaded into Covidence, a reference management software. Duplicates will be removed in Covidence. The titles and abstracts of the identified articles will be independently screened by two reviewers based on the inclusion criteria (see table 1). However, prior to beginning title and abstract screening, inter-rater reliability with title and abstract screening among the researchers will be tested using a random sample of 50 articles. A Kappa score of ≥0.80 will be deemed acceptable as it indicates almost perfect agreement among the research team.36

Once studies are identified for the full-text screening, a similar process will be followed with two reviewers deciding if inclusion or exclusion criteria. All articles excluded in the full-text review will be categorised based on predefined terms to document the reasoning behind the exclusion. To resolve any discrepancies between reviewers during title/abstract and full-text review, meetings will be held at regular intervals to discuss disagreements and reach a team consensus.

Data items and collection process
For each article, one researcher will complete a data extraction form to record: programme names, study participants, setting, study design, duration, evaluation measure, intervention, outcome, outcome measurements and study results to summarise the existing data.15 37 38 A customised data extraction form will be created based on the Joanna Briggs Institute Manual for Evidence Synthesis,37 TIDIER guidelines to identify essential programme characteristics (Tidier guidelines),38 and Kreuter’s five strategies of culturally appropriate interventions to determine the number and type of strategies used for each programme included in the review.16

Quality appraisal
Quality assessment and risk of bias will be evaluated independently by two researchers using AMSTAR: A Measurement Tool to Assess Systematic Reviews40 for all articles included in the systematic review to note the quality and detect any bias present in the study. This tool is appropriate for this review as it demonstrates substantial inter-rater agreement and has acceptable reliability, construct validity and feasibility.41

Data synthesis
This systematic review of the literature will aggregate data from all studies that have used CBCT programmes to improve health outcomes of black adults with diabetes, hypertension, cardiovascular disease, or stroke using a thematic analysis.42 A textual description of key programme characteristics (eg, populations served, type of intervention) and outcomes of each programme will be provided. Following this, an inductive thematic analysis will be used to identify similarities and differences among and within programmes.42 A deductive thematic analysis using Kreuter and colleagues’ five categories of cultural appropriateness (ie, peripheral, evidential, linguistic, constituent involving, and sociocultural) will be used to determine how many, which and how these components have been used within the design and delivery of culturally tailored education programmes.16 These insights will inform the creation of recommendations that can guide the design and implementation of future CBCT programmes for black communities.

DISCUSSION
This systematic review will generate comprehensive insights into CBCT programmes for black adults with cardiovascular disease, hypertension, diabetes or stroke. The recognition of significant health inequities within racialised communities presents a major gap in the
current healthcare system where new possibilities must be explored to reduce this gap. The current healthcare system has done little to incorporate cultural values, beliefs, practices, customs, diets and religious views in the development of programmes for racialised communities, instead programmes are built with an one-size-fits-all approach that do not address the specific issues impacting the target community. CBCT programmes differ from a one-size-fits-all approach by acknowledging cultural differences in health experiences and intend to address the barriers facing culturally diverse communities to improve overall health with the assistance of the community members. As CBCT programmes are becoming more popular, more attention must be directed to the valuable lessons that can be learnt from existing CBCT programmes and applied to future CBCT programmes.

This review will not be without limitations. First, given variability within the literature of terminology that has been used to describe CBCT programmes, there is a potential we may miss relevant articles. Second, based on the heterogeneity within study designs and outcomes included in this review, we will be unable to perform a meta-analysis and therefore unable to determine the effectiveness of these programmes. Third, to ensure contextual relevance of programmes, we have restricted articles published within the last twenty years; however, we recognise that limiting the study date may exclude relevant articles published before this date. Fourth, for feasibility and resource constraints, we decided to limit inclusion of articles to those available in English (ie, articles will be excluded during title/abstract screening); however, we may miss potentially relevant literature. Fifth, the focus of this review will be on interventions designed and developed for people living with the target condition rather than prevention. Future research should explore studies that focus specifically on culturally tailored prevention programmes and interventions. Lastly, to ensure we generate recommendations based on high-quality evidence, we have limited this review to published articles, and as a result we will be unable to capture programmes introduced within grey literature sources. While grey literature is not deemed necessary to answer our questions, omitting grey literature may introduce publication bias, and it could be a valuable resource for future research (eg, informing intervention development). Nonetheless, this review will highlight valuable insights into CBCT programmes.

Conclusion
Health inequities experienced by black communities stem from a long history of systemic racism, differential treatment, and neglect from medical institutions. While health disparities are recognised as an issue within medicine, little has been done to shift the focus of medical research to solutions that are tailored to meet the specific needs of racialised communities. New models of care must be prioritised and researched to identify possible solutions to health inequities facing black communities.

CBCT programmes do present a possible path forward to improve the health of racialised communities with messaging that is tailored to their specific cultural needs and encourages a deeper level of ownership over the type of care they receive. CBCT interventions must be assessed to determine the effectiveness of addressing health disparities in the interest.

Ethics and dissemination
This systematic review protocol does not require ethics approval without human participants. The review will be an aggregate of published studies that focus on CBCT rather than developing a CBCT programme. The systematic review findings will be disseminated in a peer-reviewed journal with an interest addressing health inequities faced in the black community. The intention of the authors is to use the review findings to disseminate potential strategies to develop culturally tailored programming within community-based organisations.
