

Cancer Care Experiences and the Use of Complimentary and Alternative Medicine (CAM) and Home Remedies in Nova Scotia's Black Community: A Pilot Study

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Research Questions

- What is the experience of African Canadians with cancer at end-of-life?
- What role, if any, do complementary and alternative medicine and home remedies play during terminal illness from cancer and end-of-life in the Black community?

Nova Scotia's Black Population Demographics

- African Canadians account for more than half (52%) of Nova Scotia's Visible Minorities (pop. 19,670);
- 66% live in metropolitan Halifax (13,100);
- Nova Scotia's Black Population is diverse and is comprised of indigenous Blacks (Canadian born), and immigrants from African and Caribbean countries.
– (Statistics Canada, 2003).

Rationale

- There is limited research available that examines the meaning that African Canadians ascribe to health and their cancer experiences;
- There is no research available that examines understandings of pain and suffering, death, palliative care and end-of-life care in the African Canadian community;
- There is no research available that examines the use of home remedies and complementary and alternative healing practices at end-of-life in the African Canadian community.

Previous Research

- Long history of racism in Nova Scotia's social institutions (BLAC, 1994; Head & Clairmont 1989);
- Extensive research in the United States has shown that African Americans have reduced access to health services and poorer health status than the general population and there are institutional and cultural barriers to accessing palliative care and pain management;
- Available data in Canada suggest similar patterns of poor health and reduced access to services;
- Increasing use of CAM in general population in treating cancer.

Study Design

- Study was designed in collaboration with Health Association of African Canadians;
- Qualitative research design (Case Study);
- Four Case Studies (1 Rural family, 1 Urban family (both Indigenous African Nova Scotians), 1 Caribbean Immigrant Family and 1 African immigrant Family);
- Three families were identified using purposeful sampling. (We were unable to identify a family from the African immigrant community that met inclusion criteria);
- Case Studies consisted of qualitative interviews with Primary Caregivers of decedents who died from Cancer (no sooner than 6 months and no longer than 3 years) and secondary caregivers (family, friends, etc.);
- Interviewing secondary caregivers permitted triangulation of results;
- Racial and cultural matching was done with the interviewers for each case study.

Data Analysis

- The overarching mode of analysis for the interview data included a critical analysis of the discourse surrounding the decedent's – and their caregiver's – experiences with their cancer experiences, end-of-life care issues and use of CAM and home remedies.

Principal Findings: Primary Caregivers

- There is an expectation among African Canadians that family members will assume the primary caregiving role during chronic illness and at end of life in the home setting;
- Most caregivers experience multiple caregiving demands;
- Most caregivers had a limited understanding of how to access necessary supports from the health and social service systems;
- Most caregivers had a limited understanding of their loved one's disease;
- There was a lack of culturally competent support systems to facilitate caregiving in the home setting;
- There is a lack of follow-up care available for caregivers following death of loved ones;
- CAM and home remedies were utilized during end-of-life care.

Principal Findings: Cancer Decedents

- Differences exist among people of African descent living in NS in terms of cultural beliefs regarding pain, suffering, death and dying, ways of coping, and gender roles in caregiving;
- Decedents were often in the role of caregiver up to the point of (and sometimes during) their own illness;
- Rural-urban differences exist in experiences related to end-of-life;
- Spirituality is an important dimension of end-of-life care for decedent and caregivers;
- "Fatalism" i.e. resignation to fate, "...its my time", "...its God's will" are important aspects of end-of-life in the Black community;
- There is a reluctance to discuss the diagnosis of "cancer" and terminality of disease.

Implications for Policy and Practice

- There is a need to develop policies and practices to support culturally competent end-of-life and palliative care in the Black community;
- There is a need to develop support systems to facilitate end-of-life care in the home setting.

Future Research

- Findings from this study suggest there are several areas worthy of further exploration regarding end-of-life care in the Black community including;
- Understanding the role of spirituality in terminal illness;
- Family knowledge of the health and social service systems to support end of life care;
- Cultural understandings of pain and suffering;
- Rural-urban differences in cancer experiences.

References

- Black Learners Advisory Committee (BLAC) (1994). Black Report on Education: Redressing Inequality – Empowering Black Learners. Halifax.
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