

Stigma and On-line Health Information Seeking of U.S. South Asian Cancer Survivors

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Abstract

The internet has replaced physicians as primary health information source for cancer-survivors. It is important to uncover barriers/facilitators to cancer information seeking, particularly on-line. Asian Americans are the fastest growing U.S. racial/ethnic minority, 2) cancer is the leading cause of death and 3) cancer knowledge is low among them and little research is done on their cancer information seeking strategies. This study aims to examine qualitatively cancer information-seeking patterns of the Asian American group, South Asians, using in-depth interview methods. Family members and social networks are highly engaged in providing informational support to South Asian cancer survivors. Such collaborative information seeking is limited by stigma related to cancer and must be taken into consideration when developing culturally appropriate cancer health information seeking interventions in such communities.

Keywords:

Health information seeking; cancer survivors; Asian American

Introduction

As cancer survivorship has become acknowledged as an important stage in the cancer continuum of care, health information seeking by cancer survivors is a major under-addressed area of need. The widespread access to readily available on-line health information has been characterized as having the potential to level the playing field for all patients, particularly for underserved racial and ethnic minority populations experiencing health disparities. Yet, Asian American survivors and families receive limited guidance on health information seeking.¹

Materials and Methods

A 90-minutes to 2 hours in- in-depth interviews were conducted with a sample of 40 participants, including 20 dyads of 20 cancer survivors, varying by level of education and 20 information-support providing family members/friends. South Asians included those having ethnic origins in the Indian subcontinent, including India, Pakistan, Bangladesh and Sri Lanka. Questions addressed a range of domains including expectations, experiences and needs that shape cancer health information seeking.

Results

Family members and social networks are highly engaged in providing informational support to South Asian cancer survivors, as is the case for other ethnic and minority

populations.² In South Asian communities, differences in norms about patient autonomy and cultural/family values, linguistic challenges and health literacy may result in greater reliance of cancer patients on family members and social networks, such that they function as a unit, and in some cases, family members may conduct all information seeking for the cancer survivors. Such family-based information seeking behavior and patterns of communication go against assumptions about patient autonomy in the U.S. health care.

We found that their collaborative information seeking was limited by stigma or negative reactions to cancer in the community, which led to selective sharing of cancer with family and community. Participants characterized cancer stigma as: 1) judgment from God; 2) a marker of hereditary genetic failing and 3) a marker of lost social status, such as mastectomies, where women can be seen as not fully women.

Conclusions

To better understand health information seeking of Asian Americans, particularly recent immigrants, models of culturally collaborative or surrogate information seeking are needed compared to existing models assuming autonomous individual information seeking. For many South Asian cancer survivors, the fabric of life is intertwined with that of family/friends due to cultural, logistical, and linguistic dependency. Such a conceptualization would allow interventions to adapt health information resources/channels to relevantly meet the needs of these sub-populations. The explicit stigma against cancer points to the value of understanding the sources of such stigma, its impact on cancer health information seeking and developing appropriate strategies to deliver cancer information resources to such populations, particularly those with language/health literacy deficits.

Acknowledgments

This work was supported by the National Cancer Institute, NIH (grant 3U54CA153499-04S1)

References

- [1] Chen Jr MS. Cancer health disparities among Asian Americans. *Cancer*. 2005;104(S12):2895-2902.
- [2] Watts T., Merrell J., Murphy F. & Williams A. (2004) *Journal of Advanced Nursing* 47(5), 526-535 Breast health information needs of women from minority ethnic groups

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