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Review

Sexual minority experiences of cancer care: A systematic review



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ABSTRACT

There is a lack of published evidence from within the UK examining the needs of LGB cancer patients. A full systematic review of the worldwide literature was carried out with the aim to ascertain the experiences of sexual minority cancer patients and identify specific needs required.

Key databases were searched with a variety of terms relating to the sexual minority cancer experience. Suitable literature was reviewed and references within all articles were search to ensure as inclusive a review as possible. Articles were subject to critical appraisal and scoring using The Support Unit for Research Evidence (SURE 2013) critical appraisal tools to assess eligibility for inclusion within the review. Twenty-five articles were selected for inclusion and were analysed. The papers were categorised into the emerging themes from the literature: Experiences of care (n = 6), Coping and Wellbeing (n = 6), Emotional Support (n = 4), Body Image (n = 3), and Sexual Function (n = 6). The data extraction revealed contrasting views and experiences of LGB individuals' experience of cancer care. Lesbian and gay individuals have different perspectives of cancer care and needs from heterosexuals. Discriminatory attitudes were found to be present in many studies as well as inequalities and gaps within care and support.

There is evidence that supports the development of sexual minority specific cancer support groups. Further research of sexual minorities affected by cancer in the UK should be carried out to increase the evidence base and better identify the needs in this cultural group.

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1. Introduction

Her Majesties Treasury Department estimates that 5-7% of the population in the UK are lesbian, gay or bisexual, which equates to approximately 3.6 million people [1]. Based on Cancer Research UK (2014) figures approximately one third of these individuals will develop cancer at some point in their lives [2]. Reports released by Macmillan (2013) and Cancer Research UK (2008) discuss the increased need of Lesbian Gay and Bisexual (LGB) individuals affected by cancer to have specialised support services [3,4]. Progress has started to be made with the recent introduction of gay cancer support groups in the UK and the formation of organisations such as the LGB cancer alliance [5,6]. There is however a lack of published evidence from within the UK examining the needs of LGB cancer patients and as such the full extent of their needs has yet to be fully determined. Therefore, the aim of this paper is to carry out a full systematic review of the worldwide literature to ascertain the experiences of sexual minority cancer patients and identify any specific needs required.

2. Objectives

This project sought to carry out a thematic analysis encompassing the worldwide literature base to evaluate and assess if the development of specialised sexual minority cancer support services is required, and to obtain a perspective of sexual minority experiences of cancer care.

For the purpose of this article the term sexual minority will be used as it encompasses all those that identify as having a sexual orientation whereby they engage in sexual activity with those that are of the same sex.

The following objectives were established for this review.

- 1. To determine the psychological and emotional needs of sexual minority individuals affected by cancer.
- To determine the factors that could influence the quality of life of sexual minority individuals affected by cancer.
- To determine if there is an evidence base behind developing sexual minority specific cancer support services.
- 4. To critically evaluate the evidence uncovered in the review and assess its merit to influence services.

3. Methodology

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology to increase the rigour of the work. PRISMA is a widely recognised evidence-based set of items for reporting in systematic reviews and meta-analyses for academic journals and as such was deemed an appropriate methodology for this study, ensuring the transparent and complete reporting of the results [7].

The search strategy included the initial identification of peer review articles following a broad-ranging literature search carried out on several health and social science databases. These included The Cochrane Library, Medline, Embase, CINAHL, AMED, Science Direct and ASSIA databases. Key terms were identified that related to LGB health and oncology, then Boolean operators were applied (Table 1). Articles were reviewed and selected on the basis of complying with inclusion and exclusion criteria:-

- English language only sources of literature were selected as there was no means of translating other languages.
- Peer reviewed only publications were included to ensure the academic rigour required of this review.

Table 1 List of search terms used.

Gay OR Lesbian OR Bisexual OR Bisexuality OR Homosexual OR Homosexuality OR LGB OR LGBT OR GLBT OR BLAG OR LGBTQ OR Sexual Minorities OR Sexual Minority Men OR SMM OR Sexual Minority Women OR SMW OR Sexual Orientation OR sex orientation OR Men-who-have-sex-with-men OR women-who-have-sex-with-women AND

Cancer OR Neoplasm OR Malignancy OR Malignant cells OR Oncology OR
Tumour OR Radiotherapy OR Chemotherapy

Survivorship OR Experiences OR Quality of Life OR QOL OR Outcomes OR anxiety OR depression OR Support OR Social Support OR Discrimination OR psychological inhibition OR psychological OR psychosexual OR Psychosocial OR psycho-sexual OR Psycho-social OR distress OR perceived stress OR Stress OR health-services accessibility OR needs assessment OR psychosocial adjustment OR physician-patient relations OR Doctor-Patient relations OR sexual Function OR body Image OR stigma

- Articles had to be published within the last ten years to ensure that only current or recent experiences of sexual minority care were taken into account.
- Papers related to targeting screening programmes, HPV vaccination and health awareness in the LGB community were excluded as were not the primary focus of this review.
- Other Meta-Analysis or systematic Cochrane reviews were excluded from this study, but hand searching of reference within these articles was carried out to identify other potential primary studies for inclusion.

Articles were then subject to critical appraisal and scoring to assess their eligibility to be included within the study. The Support Unit for Research Evidence (SURE 2013) critical appraisal tool was determined to be the most appropriate tool to use in the evaluation of the articles given that the studies for review were qualitative in nature [8]. Once suitable articles were appraised they were then analysed and coded by subject matter to classify emergent themes within the literature, these themes are then appraised in this paper.

4. Results

Two-hundred-and-Thirty articles from a variety of publications were uncovered as part of this review. Fig. 1 indicates the number of included articles in the review from the hits identified from the database searches. One-Hundred-and-Thirty were deemed worthy of analysis and were screened using eligibility criteria leaving Forty-seven research articles to analyse. The articles were then reviewed and fifteen were rejected because they related to targeting health promotional programmes and cancer screening programs focused on LGB individuals. Thirty-two studies remained and were then analysed for this paper using the SURE critical appraisal tool. Twenty-five articles were selected for inclusion (Table 2). No minimum score for the SURE tool was established, but seven articles were rejected as they were replicated studies and such demonstrated duplicate results.

The data extraction was carried out and revealed contrasting views and experiences of LGB individuals' experience of cancer care and this formed the body of the discussion of this paper. The papers were categorised into the emerging themes from the literature: Experiences of care (n=6), Coping and Wellbeing (n=6), Emotional Support (n=4), Body Image (n=3), and Sexual Function (n=6), the groupings then formulated a structure to the discussion of LGB experiences of cancer care for this review.

Studies methodologies were a combination of online and postal surveys (n=8), face-to-face or telephone based semi structured interviews (n-15), or focus groups (n=2). Of the articles uncovered, all were found to be qualitative in nature and provided an

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