Risk factors for loneliness in patients with cancer: A systematic literature review and meta-analysis

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ABSTRACT

Objective: To systematically review the literature on the severity and risk factors for loneliness in adult cancer patients.
Methods: We systematically reviewed quantitative studies addressing loneliness in cancer patients. Exclusion criteria were absence of a validated loneliness questionnaire, and studies that focused on loneliness determined by specific circumstances, and not cancer in general (e.g. appearance concerns, cultural and language barriers, requiring palliative care). We searched PsycINFO, CINAHL, Embase, Cochrane Library, and Pubmed in compliance with the predefined in- and exclusion criteria. The search, quality appraisal, and data extraction were performed by two independent reviewers. Weighted mean scores were calculated by using random effects adjusted inverse variance weighting.
Results: We included 15 studies. In 13 studies the UCLA loneliness scale was used (range 20—80; higher scores indicate higher loneliness). The weighted mean loneliness score was 38.26 (95% CI: 35.51—41.00), which corresponds to moderate loneliness. Time since diagnosis was positively associated with degree of loneliness. Other cancer-related factors, such as cancer site, treatment type, or stage of disease were not associated with loneliness. The non-cancer related determinants of loneliness in cancer patients that emerged from our review were being unmarried (people who have never been married, are widowed or divorced), and lack of psychological or social support.
Conclusion: Our findings suggest that the level of loneliness rises with increasing time after cancer diagnosis. Furthermore, social functioning emerged as a consistent theme, for which it was shown that lack of social support was associated with increasing levels of loneliness.

Introduction

With advances in early detection and cancer treatments, numbers of cancer survivors are rising (Maddams et al., 2009). Whereas cancer used to be a fatal disease, it is now developing towards a chronic or even curable disease (Hewitt et al., 2006; Pavlic et al., 2009). The growing group of cancer survivors mandates attention to quality of life and psychosocial consequences of cancer and its treatment (Stanton, 2012). Traditionally, the consequence of cancer and cancer treatment that is evaluated most often is survival. The consequences on quality of life, however, are less

clear. An important aspect of quality of life is loneliness. Loneliness is defined as "an unpleasant experience that occurs when a person's network of relationships is felt to be deficient in some important way" (Peplau and Perlman, 1982). Central to loneliness is that it is a subjective and negative experience (De Jong Gierveld et al., 2006).

It has been shown that loneliness, social isolation, and social support reflect related but distinct concepts (Tomaka et al., 2006). Whereas loneliness is a subjective and negative experience, social isolation is an objective situation and refers to the absence of relationships with other people (Dykstra, 2009). Hence, socially isolated persons are not necessarily lonely, and lonely persons are not necessarily socially isolated (De Jong Gierveld et al., 2006). Similarly, persons with adequate social support might still be lonely and vice versa. Whereas loneliness refers to the subjective experience of deficits in social relations, social support refers to the availability of interpersonal resources (Perlman and Peplau, 1984). Furthermore, social support includes several types of support ranging from

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emotional, to informational and instrumental support (Tomaka et al., 2006).

The consequences of loneliness are not to be taken lightly. As aptly put by Masi et al., "loneliness influences virtually every aspect of life" (Masi et al., 2011). Loneliness is a risk factor for numerous health disorders, ranging from elevated blood pressure and poorer sleep quality (Cacioppo et al., 2002) to diminished immunity (Pressman et al., 2005), abnormal ratios of circulating white blood cells (Cole, 2008), anxiety (Russell et al., 1980), and depression (Cacioppo et al., 2006). Furthermore, Penninx et al. found that during a 29-month follow-up and after controlling for age, gender, chronic diseases, alcohol use, smoking, self-rated health, and functional limitations, loneliness predicted all-cause mortality (Penninx et al., 1997). This finding was also supported by two studies that are more recent (Luo et al., 2012; Newall et al., 2012). The other way around is also true; health disorders are also risk factors for the onset of and continuation of loneliness (Penninx et al., 1999; Savikko et al., 2005).

From this point of view, it has been shown that loneliness is an important concern for patients with cancer (Wells and Kelly, 2008). Qualitative studies have shown that especially the period after the initial treatment is characterized by feelings of loneliness (Ekwall et al., 2007; Rosedale, 2009). Furthermore, two studies in cancer patients that aimed to refine the Distress Thermometer problem list included loneliness as an additional item because patients identified it as an important source of distress (Brennan et al., 2011; Tuinman et al., 2008).

Previous studies have shown that life stressors significantly predict loneliness (Cacioppo et al., 2010; Hensley et al., 2011). Hence, patients with cancer might be particularly vulnerable to becoming lonely.

Because loneliness is a negative experience, and it is associated with a large spectrum of negative consequences, it is important to gain insight in the occurrence of loneliness in patients with cancer. As a first step, we decided to systematically review the existing literature. To our knowledge, a systematic literature review on the severity and risk factors for loneliness in patients with cancer has not yet been published. The aim of this review is to gain insight in the severity and factors associated with loneliness in patients with cancer.

Methods

Information sources and search strategy

Pubmed, Embase, PsycINFO, Cochrane Library and CINAHL databases were searched for articles published before 24 September 2013. The search was based on combinations of database-specific subject headings. For Pubmed, Cochrane Library and CINAHL, these were 'social isolation' in combination with 'neoplasms'. The term social isolation was used because social isolation and loneliness have often been used interchangeably (Dickens et al., 2011) and in MeSH terms loneliness is a subheading of social isolation. For Embase and PsycINFO we used 'social isolation' in combination with 'neoplasms', and 'loneliness' in combination with 'neoplasms' as separate search strategies because in these two databases loneliness was not a subheading of social isolation. Reference lists of included studies were hand searched and experts in the field were contacted to identify additional studies.

Eligibility criteria and study selection

The review included all original quantitative studies that considered loneliness reported by adult cancer patients (≥18 years), with or without a non-cancer control group. Studies were only included if loneliness was measured with a validated scale. Studies using a single-item question, or directly enquiring about one's perceived level of loneliness, were excluded since the answers are likely to be biased as loneliness may be seen as a stigmatizing concept and provoke socially desirable answers (Victor et al., 2005). Studies in which loneliness might have been determined by specific circumstances and not cancer in general were excluded. These included studies that especially focused on loneliness related to appearance concerns (e.g. facial disfigurement, malodorous fungating wounds), cultural and language barriers (e.g. being an immigrant), and requiring palliative care. We excluded these studies because we believe that these circumstances might influence the severity of loneliness, and therefore, loneliness scores in these subgroups might not be representative of loneliness in cancer patients in general. Furthermore, we excluded studies that measured loneliness before cancer diagnosis as the causal pathway between loneliness and the development of cancer was beyond the scope of this review.

Appraisal

All abstracts were screened by two independent reviewers who were blind to each other's decisions. Citations were categorized into three groups: relevant, not relevant, and undetermined. Based on full texts of all relevant and undetermined citations, the quality of the remaining records was independently appraised by the same reviewers; this included compliance with the in- and exclusion criteria, and whether the quality of the text was comprehensible and coherent. In cases of disagreement, open discussion took place between the two reviewers and a decision was reached by consensus. Reasons for exclusion were recorded.

Data collection and analysis

Data from the articles included in the review were extracted into a standardized template by the two reviewers separately. Extracted data considered four domains; 1) study design and patient characteristics, 2) the scale used to assess loneliness, 3) the severity of loneliness and 4) risk factors for loneliness.

Patient characteristics included number of participants, mean age, age range, types of cancer, and time since diagnosis. Extracted data on the loneliness scale included the name and version of the scale that was used, number of items, scale on which the items were answered, range of the total score, direction of the scores, and Cronbach's alpha. For the severity of loneliness, mean scores with their standard deviations, and distribution were extracted. For randomized controlled trials, the baseline loneliness scores were extracted, as the intent of our review was observational. For observational longitudinal studies, all available loneliness scores were extracted. Risk factors for loneliness included subgroup mean loneliness scores, standard deviations, regression coefficients between loneliness and possible risk factors, statistical tests and corresponding P values. As possible risk factors, we considered cancer-related factors (time since cancer diagnosis, cancer type, treatment, and stage), demographic characteristics as described by Perlman and Peplau (age, marital status, gender, socioeconomic status) (Perlman and Peplau, 1984), and risk factors as described by de Jong Gierveld et al. (gender, marital and partner status, kin and nonkin relationships, size and composition of the network, relationships standards, personality characteristics, objective and subjective health) (De Jong Gierveld et al., 2006). For marital status we considered married versus unmarried persons. Some studies did not differentiate between persons who have never been married, who are widowed, or are divorced. Therefore, we defined the group of unmarried persons as persons who have never been

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