Review

Patient and health professional's perceived barriers to the delivery of psychosocial care to adults with cancer: a systematic review

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Abstract

Objective: To explore the barriers experienced and perceived by health professionals and patients in the delivery of psychosocial care to adults with cancer.

Methods: Systematic searches were undertaken using the PsychInfo, Medline and CINAHL electronic databases, up to October 2013. Research reporting health professional or patient experiences and perceptions of barriers to psychosocial care are included in the review. The systematic review includes studies that have non-experimental, exploratory and observational designs, as is appropriate to answer the review question. Included studies were critically appraised. The results of individual quantitative studies were aggregated. Qualitative content analysis was used to analyse the qualitative results.

Results: Twenty-five papers met the pre-specified inclusion criteria for the final review. The most commonly perceived barrier for patients relates to receiving adequate support from elsewhere and a lack of perceived need for psychosocial care. Health professionals report barriers at an organisational level most frequently followed by cultural and then individual clinician-related barriers.

Conclusions: Barriers exist on a variety of levels. People with cancer need clear appropriate information and communication about psychosocial services, including information about the role of psychosocial care in addition to existing supports. Interventions that target the complex interplay of individual, organisational and cultural factors need to be developed. Strategies that improve health professional communication skills, identify clear referral pathways, improve acceptability of interventions and clearly identify the need for services could address many of the barriers identified in this review. Copyright © 2014 John Wiley & Sons, Ltd.

Introduction

Rationale

A need for improved psychosocial care for people living with cancer is well established [1–3]. Evidence-based clinical practice guidelines have been available internationally for many years [2–5]. Despite the availability of these guidelines, their implementation into routine care is limited [6]. Research continues to identify the unmet psychosocial needs of patients [7–10], along with limited service availability, service accessibility and poor uptake of psychosocial interventions [11–14].

Within the extant literature, there are reviews, meta-analyses and meta-reviews that examine the role of screening for psychological symptoms among people with cancer [15,16], the efficacy of psychosocial interventions [17–20] and the evidence regarding communication needs with this population [21]. Less readily available is work that details the problems associated with the delivery of psychosocial care in routine clinical practice.

Objective

This systematic review examines the question: What are the barriers to providing psychosocial components of clinical care to adults with cancer?

Empirical qualitative and quantitative research was reviewed to examine the perceptions of health professionals and patients. The aim of the review is to generate knowledge about the nature of the barriers to such care and how they may be addressed, not to evaluate the effectiveness of a specific intervention or interventions. For this reason, observational and exploratory research was analysed using methods that allowed the synthesis of both qualitative and quantitative evidence [22–24].

Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines [25] were used to develop the review. In recognition of the PRISMA focus on the evaluation of intervention studies, the analysis and interpretation of results for this review differ from PRISMA guidelines [22]. Where possible, quantitative data were aggregated to allow descriptive exploration but not synthesised in any comparative or differential meta-analysis. The review also includes analysis of qualitative research through the use of qualitative content analysis [26].

Eligibility criteria

Inclusion criteria included the following: qualitative or quantitative primary, empirical research that investigated the experiences and perceptions of staff delivering psychosocial care to adults with a cancer diagnosis and patients receiving psychosocial care. Papers that only evaluated the efficacy of psychosocial/psychological interventions were not included. The patient participants were adults (over 18 years) with any cancer diagnosis. Where papers focused specifically on the terminal phase of palliative care, for example, specific psychiatric symptom management in terminal care, family involvement and other concerns very specific to terminal palliation, the papers were excluded, as these were considered to be outside of the scope of the aims [27]. The staff participants were not limited to particular discipline, context or setting. The search was limited to papers published in English because of resource availability. To ensure that rigour could be established, only primary research with clear detail of method was included. In accordance with the study's objectives, the search was restricted to peer-reviewed published studies rather than grey literature, for example, policy document and reports. As an exploration of staff and patient perception and experience, the value of grey literature including policy documents was limited. Systematic reviews and other review papers are not included in the results of this review, but their reference lists were examined to identify relevant research.

Search

A list of key words was developed by the research team. The list included the following: Cancer, Neoplasm, Oncology, 'Cancer care', 'Cancer nursing', Psycho-oncology; psychosocial care, psychosocial support, psychosocial treatment, supportive care, psychological treatment, psychological support, psychological care; and barrier*, obstacle*, problem, stigma*. See Appendix 1 for the full list of key words and Appendix 2 for the full search strategy in Medline. Systematic key word searches were conducted in PsychInfo, Medline and CINAHL. Databases were searched from inception up to March 2011, with an update in October 2013. Scopus was used to identify additional papers from the reference lists of relevant articles.

Study selection

Study selection involved screening of titles and abstracts to determine if the study met the eligibility criteria and to ensure study relevance. Once relevance was established, the whole article was retrieved. If eligibility or relevance was unclear, the whole article was retrieved.

Data collection process

Data items for both qualitative and quantitative research included the following: citation details, study aim, study design, methods and instruments used, sample and setting details, methods of analysis, results, risk of bias and limitations.

Risk of bias

Critical appraisal was conducted using a tool developed from the resources available on the Centre for Evidence Based Medicine website [28,29]. Appropriate tools were used to assess the quality of each paper [30]. The Strengthening the Reporting of Observational Studies in Epidemiology initiative (STOBE) checklist was used to assess the quality of reporting in the included observational studies ($n = 10$) [31,32]. For qualitative research papers, consideration was given to the appropriateness of methods of data collection and analysis, participant and setting selection, consideration of researchers' perspective, credibility, reflexivity and fittingness [29]. A series of critical appraisal questions were asked of each paper (see Appendixes 3, 4 and 5).

Synthesis of results

Analysis and synthesis of results included simple descriptive statistics and a qualitative content analysis [26] of the barriers described within the research. The combination of analytic methods allowed the development of a meta-narrative review of both qualitative and quantitative data [23,24].

Demographic details of participants were tabulated. This allowed calculation of the numbers of patients and health professionals in the sample and comparison between settings. Appendix 6 provides the demographic characteristics of the sample population. Basic descriptive statistics were used to aggregate the results of the individual quantitative studies where possible. This involved grouping the survey responses from the original papers together under similar headings. The broader categories were used to explore and describe the perceived barriers to care, as per Appendix 7.

Qualitative findings were synthesised using qualitative content analysis [26]. This is an inductive approach that

facilitates the description and representation of the qualitative data [26]. The aim of content analysis is to represent the data descriptively, with little interpretation [26]. The use of methods likened to that of primary qualitative research is recommended when conducting a review of qualitative research [33,34]. The individual findings of the qualitative studies, or themes, were extracted. Common topics, meanings and experiences were coded, sorted and grouped into similar related categories. The synthesised categories were used to describe the perceived barriers thematically. Appendix 8 details the individual findings and categories of the qualitative papers.

Results

Study selection

The search strategy identified 1192 papers in total. This included 32 duplicates. Of the remaining 1160 papers, 1066 were excluded based on title and abstract. Ninety-four full-text articles were assessed for eligibility. The final sample includes 25 papers (Figure 1).

Where the search identified related systematic, critical or descriptive review papers, the reference lists were utilised to identify relevant papers [35–38]. Papers that included description of barriers as well as the experience of receiving/providing psychosocial care are included with a focus on the barriers [39].

Study characteristics

Of the 25 articles included in the review, 11 were qualitative, 10 quantitative and 4 mixed method papers. Thirteen reported staff perspective, eight reported the patient perspective and four reported the views of staff and patients. Six of the papers had nurse only samples, three had medical practitioners (doctor/physicians) only, eight were patients only, four combined health professions, four included patients and health professionals, two included allied health staff and one included family or carers within their samples.

Details of the included studies, including citation, stated aims, design, methods and/or instruments, samples and setting details, and methods of analysis, are included in Table 1.

The literature represents health professionals practicing in developed countries. More nurses than doctors/physicians have been included within the studies. The nurses are predominantly female and work within the hospital setting. The doctors/physicians in the review population are more often male; a variety of specialties
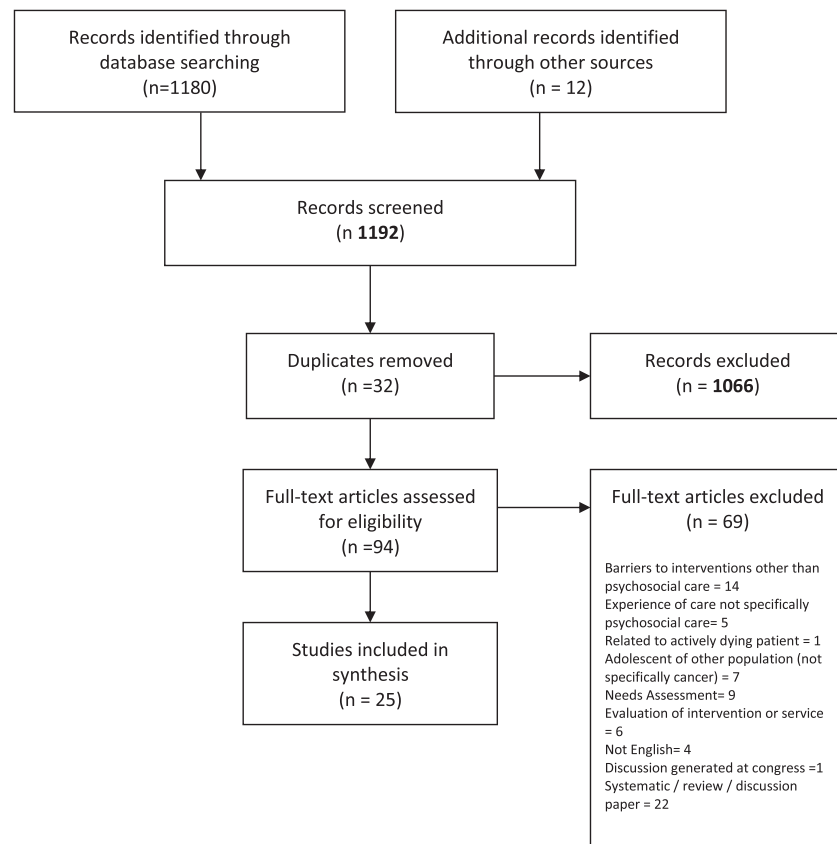

Figure 1. Study selection flow diagram

Table I. Study characteristics

Citation	Stated aim	Design	Method/instrument	Sample and setting	Analysis
Qualitative					
(Absolom et al., 2011) [82]	Explore health professional views related to emotional distress screening	Qualitative descriptive	23 individual interviews	6 Clinical Nurse Specialist, 8 oncologists, 4 surgeons and 5 ward sisters. Hospital in Yorkshire, UK	Framework analysis
(Botti et al., 2006) [52]	Capture experience of psychosocial care	Qualitative exploratory	2 focus groups	15 experienced registered nurses. Melbourne, Australia	Content analysis
(Chibnall, Bennett, Videen et al., 2004) [53]	Explore doctors' perceived barriers to psychosocial care at the end of life	Qualitative exploratory	Focus groups (20 sessions)	17 physicians. USA	Software package (NUD*IST). Unit of text paragraph.
(Griffiths, Ewing, & Rogers, 2010) [39]	Explore how UK district nurses describe and conduct early support visits with palliative care patients	Qualitative descriptive	Interviews, observations and focus groups with district nurses, patient and carers	58 National Health Service district nurses in 4 primary care trusts in northwest and southeast England. 10 palliative care patients and carers	ATLAS.ti used for thematic content analysis of focus groups and observations. Negative cases and rival explanations explored and discussed.
(Kenny et al., 2007) [51]	Explore rural nurses' perceptions of psychosocial care	Qualitative descriptive	3 focus groups	19 registered nurses from 3 rural hospitals. Victoria, Australia	Work of Attride-Stirling (2001) to develop a coding framework. Text dissected line by line.
(Neumann et al., 2010) [48]	Explore health professionals and patients' perceptions of barriers to psycho-oncology service utilisation	Qualitative exploratory	Focus groups (7) with 27 participants and individual interviews (5)	Patients, nurses and doctors (N=34). Germany	Thematic analysis to develop framework, then data interpreted using documentary method
(Ristevski et al., 2011) [57]	Explore clinicians' experiences with supportive care screening and referral, and identify perceived barriers and benefits	Qualitative exploratory	Semi-structured interviews	5 chemotherapy nurses and 1 radiation therapist. Large regional hospital in Victoria, Australia	Thematic analysis
(Schulman-Green, 2003) [56]	Explore perceived role of physicians related to psychosocial aspects of palliative care	Qualitative exploratory	Semi-structured, in-depth and individual interviews	20 physicians (haematology/oncology 6, geriatrics 5, internal medicine 4, surgery 3 and palliative care 2. 11 fellows, 3 residents, 3 interns and 3 attending physicians). Massachusetts, USA	ATLAS.ti to explore significant and recurring themes based on a grounded theory approach
(Steele and Fitch, 2008) [47]	Explore reasons lung cancer patients reject care despite identifying an unmet need	Exploratory qualitative (mixed method—reports only qualitative data in this paper)	Needs screening using standardised survey tool with 61 items plus demographics, followed by semi-structured telephone interviews	34 people with lung cancer. Urban, outpatient regional cancer centre, Canada	Coded for content separately, then categories reviewed across all participants to identify common themes and relational patterns
(Turner et al., 2007) [54]	Explore barriers and needs of nurses in delivering psychosocial care to parents	Qualitative exploratory (scoping project)	Focus groups (4) and individual interviews with nurses (5)	24 nurses in rural and metropolitan Australia	Content analysis
(Watts et al., 2010) [59]	Explore cancer nurses' perceptions ability to provide psychosocial care	Qualitative exploratory	One focus group interview. Demographic data and Job Satisfaction Survey (not reported here)	10 registered nurses (oncology/haematology). Melbourne, Australia	Content analysis
Mixed methods					
(Lee, 2007) [55]		Mixed methods	Focus group and survey		Thematic analysis

Study	Aim	Design	Details	Sample/Setting	Analysis
(Luxford et al., 2006) [50]	Describe approaches to psychosocial care Explore if current practice concur with best practice. If not, why not?	Mixed methods	Matrix explores (a) compatibility with current practice, (b) relative advantage over current practice, (c) observability of outcomes, (d) trialability, (e) simplicity of use and (f) perceived barriers	Multidisciplinary, mostly nurses, in rural Victoria, Australia 48 members of Colorectal Group of the Victorian Cooperative Oncology Group, Australia	Frequency analysis for quantitative responses; thematic analysis on qualitative responses
(Napoles-Springer et al., 2009) [42]	Identify the barriers + benefits, needs and component interventions of Spanish-language cancer psychosocial support services among Spanish-speaking Latinos with cancer	Mixed method	Survey details demographics, preferred language, clinical details and barriers to service use. Semi-structured interviews —open-ended questions about diagnosis; support; unmet support or informational needs; and potential barriers to support services	Telephone surveys of Spanish-speaking Latinos referred to the Community partner (n = 89); semi-structured interviews (group and individual) with Spanish-speaking Latinas living with breast cancer (n = 29); and semi-structured interviews with community advocates (n = 17). California, USA	Descriptive statistics and simple logistic regressions used to identify any differences in the group. Semi-structured interviews were content analysed using a constant comparative method.
(Zhang et al., 2008) [46]	Examine reasons for refusing a psychosocial intervention and differences between those who consent	Mixed methods	Demographic details. Reasons for refusal (n = 29)	Men with urinary incontinence after a prostatectomy. 21 (50% consent rate). Cleveland, Ohio, USA	Simple statistical analysis (t-test and chi-square test). Thematic analysis of qualitative data
Quantitative					
(Carlson et al., 2004) [44]	Assess cancer patients' distress, psychosocial problems, awareness and use of psychosocial services	Survey	Demographic detail, brief symptom inventory, problem checklist and psychosocial questionnaire	Patients with cancer; 90% response rate = 2776/3095. Canada	Descriptive statistics; continuous General Severity Index scores compared between the categorical groups using ANOVA. Multivariate analysis using multiple linear regression analyses
(Del Giudice et al., 1997) [41]	Assess attitudes of Canadian oncology practitioners toward psychosocial interventions	Retrospective cohort survey	Ad hoc survey—dealing with psychosocial support in metastatic breast cancer. Plus demographics. Study also included a second survey not included in review.	351 medical, radiation and surgical oncologists, and 375 oncology nurses across Canada	Descriptive statistics. Comparison chi-square test. Reports subgroup differences with a p-value² 0.05
(Devitt et al., 2010) [45]	Determine the models of support preferred by people with lung cancer and the barriers to the uptake	Cross-sectional survey	Self-administered questionnaire developed for this study	Patients with lung cancer: 101/172 (59% response rate); support group facilitators: 74/145 (51%). Victoria, Australia	Descriptive statistics and chi-square test for differences
(Eakin and Strycker, 2001) [14]	Investigates patient, and provider awareness and barriers to the use of cancer support and information resources by Health maintenance organization patients with breast, prostate and colon cancer	Retrospective survey	Ad hoc survey and Medical Outcomes Study plus Short-form and 13-item Illness Intrusiveness Scale (IIS)	N = 368 (76% for prostate, 73% for breast and 71% for colon)	Descriptive statistics for possible violations of normality assumptions. t-Tests and chi-square tests for differences between respondents and non-respondents. Plus multiple logistic regression to evaluate

(Continues)

Table 1. (*Continued*)

Citation	Stated aim	Design	Method/instrument	Sample and setting	Analysis
(Endo *et al.*, 2008) [40]	Investigate the type and frequency of barriers to psychological care perceived by the patient	Survey	Self-administered survey: developed for the study plus Hospital Anxiety and Depression Scale (HADS), assessment for minor or major depression after cancer diagnoses	100 outpatients with lung cancer (119 approached, 5 too ill, 5 cognitive problem, 5 other reason—not stated and 4 refused). Japan	Unpaired *t*-test and Pearson correlation to investigate association between bio-medical and psychosocial factors and patient perceived barriers. Univariate analysis entered into multiple regression and all *p*-values two-tailed predictors of use of services
(Frost *et al.*, 1997) [48]	Examine (a) the importance staff nurses place on intervening with patient and family members' psychosocial needs, and (b) nurses' perceived skill level in meeting those psychosocial needs	Survey	Ad hoc survey includes open-ended questions and Likert rating to rate the importance of psychosocial interventions	310 nurses. Large inpatient centre, USA	Descriptive statistics, independent *t*-tests and analysis of variance
(Gosselin *et al.*, 2011) [49]	Develop and implement a survey of Oncology Nursing Society (ONS) members focused on current practices and needs for providing psychosocial care	Descriptive, cross-sectional	Self-report survey developed for this study	401 ONS members (4% response rate; 64% cooperation rate). Web-based survey of Oncology Nurses Society members	Standard descriptive statistics, subgroups compared using Pearson's chi-square tests. All stats were two-tailed, using an alpha of 0.05.
(Kumar *et al.*, 2012) [13]	(a) Measure rate of service utilisation of supportive and palliative care services (SPCS) at an urban, academic medical outpatient cancer centre; (b) identify factors related to use of SPCS; and (c) identify and describe patient reported barriers to access to SPCS	Cross-sectional survey	Self-report survey developed for this study	313 (81.9% response rate). Three outpatient oncology clinics, primary diagnosis of cancer; Karnofsky score of 60 or greater	Descriptive statistics to examine distribution of the outcomes and covariates. X^2 tests to identify factors that are associated with SPCS use. Multivariate logistic regression to identify independent predictors of SPCS use, using variables that were significant at the *p* = 0.10 in X^2 analyses
(Okuyama *et al.*, 2008) [43]	Explore cancer patients' concerns about emotional disclosure emotional distress to their physicians, and investigate the factors associated with them	Self-administered survey	Reluctance for emotional disclosure questionnaire (developed for this study) and HADS	104/123 people with lung cancer, ambulatory, outpatients. Japan	Factor analysis and varimax rotation used to extract the underlying factors of this study questionnaire
(Voerman *et al.*, 2007) [60]	Understand why people express a desire for support but do not seek help or accept offered support	Quantitative	Measured those men who were not interested in attending 136 (57%), were interested but did not attend 55 (23%) and were interested and did attend 47 (19.7%)	Final sample 238/784. Netherlands, inpatient, outpatient community	Two logistic regression analyses: (a) intention to participate and (b) actual participation as dependent variables

are represented within the sample. The patients represent a variety of cancer diagnoses. Other clinically relevant subgroups would be inpatient/outpatient and early versus advanced disease. These details are not discernible in this sample.

Risk of bias within studies

Quality assessment of observational studies based on the STOBE checklist was undertaken (see Appendixes 3 and 4 for tabulated data). None of the included papers addressed all of the STOBE criteria. The scores ranged between 25/32 [40] and 8/32 [41]. Areas that were poorly or inconsistently reported are discussed: None of the papers utilised a CONSORT flow diagram to present participation rates and reasons for non-participation or withdrawal. The reasons for non-participation were not consistently reported with only half of the papers including this information, hence limiting the confidence regarding the representativeness of the sample and generalizability of the conclusions for the target population [31]. The potential for bias and attempts to address bias was poorly reported. The settings, including recruitment periods, time intervals and follow-up, were only reported by four of the papers.

Qualitative papers were assessed for methodological validity prior to inclusion in the review using a critical appraisal tool as detailed in the Methods section and available in Appendix 5.

Synthesis of results

Patient perceived barriers

Quantitative data: Patient perspectives are most strongly represented by data gathered in surveys. This allowed for aggregation of some of the results. Figure 2 represents the patient-reported barriers from the included studies.

The most frequently reported barrier is 'no need for psychosocial services and support', with 38.77% of patients surveyed reporting this as a barrier to the use of psychosocial services [14,40,42–44]. This is followed by lack of information about services that included not knowing that services existed [14] and wanting more information [14,42]. Transport and parking are practical barriers encountered (17.01%) and included inconvenience and difficulty of travel and inconvenient service locations [13,42,44–46]. Lack of confidence in services included feeling 'emotional burden cannot be relieved by medication' [40], concerns about dependence and addiction, and the side effects of counselling [40]. Negative perceptions and stigma about psychosocial care included 'feeling uncomfortable seeking counselling' [14], 'negative attitude' [43], not wanting to use 'medications that act on the mind' [40] and 'not wanting to participate in a group' [45]. Health provider/communication barriers included 'lack of referral' [13], not being asked about or recommended psychosocial services [14,40,42] and 'hesitation to disturb the physician' [43]. Being too busy or too unwell are minor barriers [13,14,42,45,46], being too expensive was reported by one American study [13].

Qualitative data: Qualitative patient data are limited. Steele and Fitch [47] represented the only all-patient sample. In line with the quantitative data, they reported current ability to manage, assumptions about symptoms and issues, existence of support networks, busyness of clinic, and lack of awareness of resources [47]. Neumann et al. [48] included nurses, doctors/physicians and patients in their sample. They reported the barriers as patient and physicians' information deficits about psycho-oncology
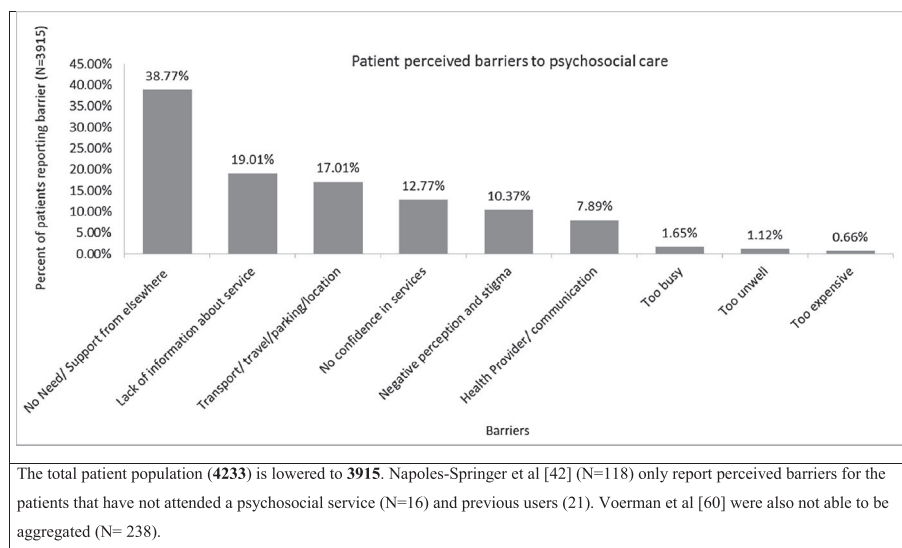

The total patient population (**4233**) is lowered to **3915**. Napoles-Springer et al [42] (N=118) only report perceived barriers for the patients that have not attended a psychosocial service (N=16) and previous users (21). Voerman et al [60] were also not able to be aggregated (N= 238).

Figure 2. Patient perceived barriers to psychosocial care

services, patient and physicians' subjective norms, psychosocial care not being seen as integral to routine care/only for terminal illness and patients with specific characteristics. Griffiths et al. [39] included nurses and patients; however, they did not specifically include patient perceived barriers in their discussion.

Health professionals

Quantitative data: Health professional perspectives about the barriers to psychosocial care are not as strongly represented in the quantitative data. Where possible, the data have been aggregated. However, with much smaller numbers and fewer studies, the results of one study greatly influence the aggregate data. As such, results are more meaningful when considered as part of the whole data set. Nurses reported a lack of time and resources as the most prevalent barrier. Doctors/physicians reported negative perceptions as the most common barrier. This category includes perceived lack of scientific validity of psychosocial interventions, potential to cause psychological damage, preference for symptom control drug treatment over psychosocial care and unwillingness to refer before problems were identified [41]. As noted earlier, all of the findings in this category are from a single study [41].

Two studies could not be included in the aggregate because they used Likert scales to rate the barriers [14,49]. Eakin and Stryker [14] reported not knowing enough about the services (2.3/5), not enough time (2.2/5). Gosselin et al. [49] measured the barriers in oncology nurses practice. Lack of time, followed by lack of insurance coverage and cost, closely followed by 'lack of value and support for the provision of psychosocial care in the culture of the practice setting' were the most commonly reported as very much a barrier [49].

Luxford et al. [50] reported on a small sample of health professionals ($N = 48$), predominantly doctors/physicians. They reported that all respondents felt that the current practice was not in accord with psychosocial guideline recommendations. The barriers that were reported (without quantification) were limited resources, lack of time, not being recognised as a patient need, lack of knowledge regarding the benefits and lack of referral systems. These findings are in line with much of the qualitative findings as detailed later.

Qualitative data: Qualitative data that report health professional perceptions are described by a framework developed from the research findings. The framework includes three themes: cultural, organisational and clinician. The framework allows some comparison and recognition of commonality. Appendix 8 presents the individual results of the qualitative studies and the synthesised categories.

The most common barriers relate to the organisational theme (40/81). Organisational themes relate to lack of formal support [51–54], the nature of the workforce (part time), the model of care (primary nurse) and inexperience [52,54], lack of referral or late referral to appropriate services, haphazard continuity of care for support needs, and disputed responsibility for assessment [48,55,56,82] including concerns about scope of practice [57]. A lack of time and the burden of a heavy workload are the most frequently cited barriers to the provision of psychosocial care [50–53,56–59].

The cultural theme accounts for 22 of the 81 reported barriers. The cultural theme includes barriers related to the multi-skilled nature of work, a lack of team cohesion and working in isolation [51,52], including a lack of professional dialogue among nurses [52,59]; training that marginalises psychosocial aspects of care [53,56]; and a medical practice environment where it is suggested there may be self-imposed 'busyness' [56] and a milieu marked by lack of support around emotional concerns [53]. The culture of nursing practice in some settings was identified specifically the tension that arises for nurses between physical and emotional needs, 'task' versus 'care' [52]. Ristevski et al. [57] specifically described clinician hesitance related to stigma of psychosocial interventions.

Finally, barriers that related to the clinician or individual theme (19/81) include the emotional burden of caring, a lack of self-care and issues around personal resonance [52,54,59]; the duality of relationships, for example, being a community member versus professional [51]; and communication difficulties. The communication difficulties here refer to problems on an individual level, for example, health professionals' fear of 'making things worse' [54]. This is differentiated from aspects of team cohesion and lack of communication or referral pathway between services as outlined earlier [53].

Risk of bias across studies

In terms of assessing the limitations in the cumulative results, consideration was given to the design of the studies. All quantitative studies are cross-sectional; that is, the sample is assessed at the same point in time. Cross-sectional surveys are often employed to examine the prevalence of exposures, risk factors or disease [31]. In this case, they are examining the prevalence of a perceived barrier or attitude, and in some cases, trying to establish reasons or risk factors or establish a relationship between the barriers and patient or staff attributes. However, by using this design, it cannot be established if the barriers described are causally related to the risk factors or patient attributes described.

Much of the quantitative work is generated in small studies [42,46,49,50,58]. All of the quantitative studies utilise ad hoc surveys developed for the study being

presented. The use of tools that have not previously been validated may reduce the validity and reliability of the results. Retrospective cohort or convenience samples were utilised. Low response rates are a common feature [42,49,58,60].

Much of the qualitative data were collected using group interviews [51–54,59]. The limitations of focus groups include censoring and conformity, public versus private accounts, themes may not necessarily represent consensus, cannot measure strength of opinion, accounts presented are linked specifically to this social situation and one cannot assume that a person will express the same opinion in any other setting [61]. The strengths include the ability to gain rich experiential data using group interaction and addition of social context for consideration in analysis [61]. Three of the focus group studies include samples from a single setting [48,52,59], which may increase the likelihood of censoring and conformity in the participant's responses. Alternatively, it may create familiarity and promote open discussion. Incomplete description of the methods used to collect and analyse data limits the confirmability/dependability of these studies.

Discussion

Summary of evidence

This review reveals a set of important barriers impeding the provision of psychosocial care to adults with a cancer diagnosis. The review found 25 papers that explored the experiences and perceptions of staff and patients in relation to psychosocial care. The quality of reporting and research is not high within this sample as determined by quality appraisal tools. However, as a whole, a set of consistent findings emerged.

The main barrier reported by patients is the perception that psychosocial care is not needed [14,40,42–44,46,47,60]. There is a need to better understand what underpins patient and carer perceived need for psychosocial care in this context. Steele and Fitch [47] found that despite patients identifying unmet needs, there were barriers to asking for help with these. Similarly, Carlson et al. [44] reported that almost half of those reporting significant distress had not and did not intend to use psychosocial services. Okuyama et al. [43] found that patients with higher distress levels were significantly more likely to endorse a fear of negative impact from psychosocial intervention, whereas those patients with low distress were significantly more likely to endorse no need for support. Eakin and Strycker [14] reported large differences in reported referral rate (70%) and actual service use (8%). Distress screening alone is limited in its ability to identify need for service. Recent criticisms of the cost benefits of screening [62] have highlighted the detection of distress as being only one component of an overall service model.

Subsequent and more detailed assessments of distress and treatment needs need to be tailored to levels of distress and the patients specific situation [63,64]. Strategies for more targeted assessment of patients' need for services that move beyond distress levels alone are needed. Attention to known psychosocial risk factors may be useful in identifying those with greatest unmet needs such as low social support and cumulative adversity [65].

Lack of knowledge about services, lack of confidence in the help services can offer and negative perceptions of psychosocial services highlight the need to inform patients with cancer about what is available, what these services/interventions may be able to offer and how these might complement the supports that they already have in place. Stigma is a known barrier to mental health care in population studies [66–68], but there is little study of its impact in the perception of need for psychosocial assistance in the setting of cancer diagnosis [69]. How services are promoted needs to address patient perceptions of psychosocial care, stigma reduction campaigns are an example [69,70]. Negative patient (and clinician) attitude to psychosocial care is important and needs to be addressed if those who might benefit from them most are going to be comfortable accessing them when needed.

Practicalities of delivering/receiving support are important and potentially addressable. It appears that recent interventions have taken into account some of the issues relating to accessibility with interventions being delivered over the telephone or in alternate settings dependant on patient need/preference [65,71,72].

The barriers perceived by health professionals are perhaps more complex, and the interplay between barriers on different levels may be harder to address. The findings of this review are supported by previous research in the area of practice change and innovation [73,74]. In relation to healthcare improvements and the utilisation of research, where individual practitioner attitudes, knowledge and routines have been the focus of research [74,75], the obstacles are much broader than individual clinician attributes [76]. Attempts to effect change need to take into consideration the complexity of the situation [76]; that is, individual, organisational and cultural factors all need to be considered.

Organisational barriers may begin to be addressed, through the implementation of interventions that have formal support, education and clear referral pathways embedded within them [65]. Communication skills training and clinical supervision represent two strategies to be included. Evidence generally supports the view that communication skills training can improve clinician attitudes to psychosocial care and improve skills and confidence in recognition of psychological symptoms and concerns [77]. Skills based professional development programmes may help build such capacity in clinicians, provide clarity around communication strategies and ease

the perceived burden of providing support. The identification of barriers that specifically relate to provider communication [13,14,40,42,43] and failure of clinicians to ask about distress [40] recognise the need for clearer communication and further support the need for communication skills training. Clinical supervision is recommended by some researchers as a means to support the consolidation and maintenance of such skills over time and translation to practice [52,54,59]. Creating more time within busy workloads may not be possible. However, communication skills training along with clinical supervision might reduce the perceived lack of time by allowing health professionals to integrate these skills into their daily practice.

Barriers that relate to the organisational culture of cancer care may be the most difficult to address; however, organisational shifts that promote innovative and collaborative approaches to care may present a way forward [78].

Limitations of this review

Limitations of this review include the exclusion of articles primarily on title and abstract. However, where the content was not clear or abstract was not available, the whole article was retrieved for further review. This ensured that screening criteria were met. Articles were only reviewed for relevance by one researcher. It is therefore possible that there was bias in the screening and selection process. The author group was consulted during this process, and clarification was sought where there were concerns about inclusion and exclusion criteria. The difficulties and limitations of searching electronic databases for qualitative work are documented, as is the difficulty in determining relevance of qualitative research [79]. The search was not comprehensive, but databases are identified to ensure a clear audit trail. The review is restricted to English language publications. Broad definitions of psychosocial care present a limitation for this review [80]. Is it is difficult to determine what a psychosocial or psychological intervention entails within this context and the expected outcomes for patients and staff [80]. In an attempt to address the heterogeneous evidence and diverse contexts, a meta-narrative approach to the review and aggregation of evidence was used [81]. The inclusion of both qualitative and quantitative research is viewed as a strength. An additional strength of the search strategy is the inclusion of all relevant articles. Articles that were not readily available were obtained on interlibrary loan services.

Conclusion

This systematic review describes factors identified by health professionals and patients as impeding the delivery of psychosocial care to adults with cancer. It is recognised that a deeper understanding of these barriers is required if psychosocial care is to be embedded in routine care. However, on the basis of this review, some recommendations can be made about how existing barriers can be addressed within clinical practice. The recommendations include clear promotion of psychosocial care among patients with cancer. In the light of patient perceptions, tailoring interventions to improve acceptability to patients is important. Clear and open discussion may lead to decreased stigmatisation and reluctance to engage on the part of patients but necessitates attention to clinician perceptions and stigma.

Lack of time as a barrier needs to be considered when implementing psychosocial care. Strategies that allow health professionals to integrate psychosocial care into their daily practice without creating the perception of an additional workload are needed. Capacity and capability building strategies, such as communications skills training, clinical supervision and interventions that clearly map care pathways, will address many of the organisational, cultural and individual barriers identified within this review. Cultural shifts may be made possible by this kind of support and the promotion of clear, collaborative strategies and intervention.

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Conflict of interest

The authors have declared no conflicts of interest.

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