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The new challenge for improving psychosocial cancer care: Shifting to a system-based approach

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Abstract (243 words)

Introduction: There is a need to improve the psychosocial well-being of cancer patients. To date, intervention research has primarily focussed on improving psychosocial well-being through targeting singular aspects of care at the individual patient level. Sustainable, high-quality psychosocial care should address the issues faced by people diagnosed with cancer throughout the care pathway using a systems-based approach.

Aims: To examine the number of intervention trials attempting to improve psychosocial cancer care that have implemented a systems-based approach.

Method: Five journals were selected and relevant studies across all years were extracted. Four criteria, argued to be essential characteristics of system-based change, were assessed: 1) establishing a culture change within the healthcare system/organisation, through designated leaders who endorse organisational goals; 2) adopting a multidisciplinary approach to change; 3) mapping the system and identifying points of leverage; and 4) measuring the impact of change and adapting establish feedback loops.

Results: The search strategy returned 1,174 citations, of which five met the inclusion criteria. Of the intervention studies identified, 3 met none of the four defined criteria for a systems-based intervention, one study met criterion 2 only and one study met all four criteria, however, was not a rigorous study design.

Conclusions: This review of published psychosocial intervention trials in top ranking psychosocial cancer care journals only found one study that met our criteria for evaluating system-based change. This is likely to be a consequence of the significant pragmatic and political barriers to conducting systems-based intervention research.

Introduction

A diagnosis of cancer heightens levels of depression and anxiety [1-3]. Meta-analyses indicate that the prevalence of depression among people with cancer varies between 8% and 24% [4], while any type of mood disorder is experienced by 38.2% [3]. Psychosocial outcomes for people with cancer are a function of a complex array of factors including individual characteristics, disease and treatment characteristics (including side effects of treatment), social support, and characteristics and quality of care provided by the healthcare system (e.g. information provision and involvement in decision-making) [5]. For example, characteristics such as younger age, poorer prognosis, greater symptom burden and more aggressive treatment have all be linked to poorer psychosocial outcomes [6,7]. A review of published intervention and descriptive studies that investigated the psychosocial outcomes of cancer patients found that 95% of the identified papers examined individual predictors and 5% examined the contribution of social predictors to psychosocial outcomes. No papers examined the characteristics of the healthcare systems as potential predictors of psychosocial outcomes. Several meta-analytic Cochrane reviews indicate that there is mixed evidence regarding methods for improving important patient-centred outcomes [8-11], but none of the papers included in such reviews described a healthcare system intervention approach.

The Plug-in approach

Guidelines indicate that psychosocial care should span the entire cancer trajectory, from initial diagnosis, through to treatment, survival, and palliative care [12,13]. Necessarily this involves all members of the treatment team, the primary care physician, family, friends and carers [12,13]. Across the cancer trajectory, people with cancer interact with a complex cancer healthcare system that comprises varying levels and types of healthcare staff, clinics, treatment types, tools, and organisational constructs [12,13]. Yet, research attempting to improve the psychosocial outcomes of cancer patients has typically focussed on one facet of the cancer care continuum. For example, an intervention may focus on a single aspect of care such as a communication between physician and patient regarding diagnosis and prognosis. However, patients interact with a complex range of factors within the health care system [14], which may impact their psychosocial wellbeing. Therefore there is a low likelihood that such truncated interventions will, by themselves, impact positively on overall wellbeing. This type of interventional effort can be labelled a *plug-in* approach since it augments one part of the patient's treatment experience, rather than improving care provided throughout the care pathway. Plug-ins may limit synergistic effects that may have accrued if attempts were made to improve patient psychosocial outcomes throughout the care pathway. Any positive impact from a plug-in intervention may be dissipated by other parts of the care pathway where high-quality psychosocial care is not provided. This lack of a healthcare systems approach may explain the apparent failure of the field in achieving substantive improvements in psychosocial well-being for cancer patients.

Time for a system-based approach

Sustainable, high-quality psychosocial care should address the issues faced by people diagnosed with cancer throughout the care pathway. This requires organisational change, which seeks to improve all aspects of care. Organisational change and development examines the healthcare system as a whole rather than considering parts of systems in isolation [15]. Change in one part of a system is thought to affect the other parts and therefore interventions should focus on the total processes of care. Healthcare system-based strategies may include those focussed on quality management (policies, quality assessment cycles); knowledge management (e.g. training, clinical decision support, reminders), redesign of professional roles, or on the multidisciplinary team [16].

The potential benefits of the systems-based approach are acknowledged and reflected in change strategies for other aspects to improve the delivery of clinical medicine including attempts to improve rates of handwashing in wards [17], appropriate use of thrombolysis for stroke patients [18] and providing evidence-based care throughout the phases of bowel cancer surgery and recovery [19]. The example of increasing handwashing to reduce spread of infection in hospitals requires intervening at multiple levels, including: hospital-wide infection control policies targeting relevant staff provision of resources required to implement these policies such as hand sanitation stations and adequate cleaning staff numbers; the training and education of staff on infection control practices; and monitoring and enforcement of policies with possible contingencies for adherence. Previous evidence indicates that multifaceted intervention approaches to handwashing were more likely than singular intervention strategies to have a pronounced and sustained effect on practice and outcomes [17]. Applying this logic to cancer care may help to improve psychosocial outcomes for cancer patients in a more meaningful way.

Aim

To examine the number of intervention trials attempting to improve psychosocial cancer care that have implemented a systems-based approach

Methods

Search strategy

Five peer-reviewed journals, which have published extensively on psychosocial aspects of cancer care, were selected. Each journal had a credible impact factor for this field (2016 impact factors ranged from 1.312 to 3.095). These journals included Psycho-oncology (est. 1992), Supportive Care in Cancer (est. 1993), European Journal of Cancer Care (est. 1993), Journal of Psychosocial Oncology (est. 1983) and Journal of Cancer (est. 2010).

Medline was searched for publications in these journals on 8th June 2018. Journal titles were used as the search terms and were combined with “intervention.mp” to reduce the number of non-intervention studies identified. Search results were limited to humans and English language publications.

Inclusion and exclusion criteria

Studies were included if they examined the effectiveness of interventions designed to improve psychosocial outcomes for cancer patients. Studies that allocated patients’ or providers’ as the intervention unit of allocation were excluded. These criteria were applied as the nature of systems intervention must develop, implement and evaluate the effectiveness of an intervention across different institutions, therefore focusing on individual patients or providers is inappropriate. Review articles, commentaries, letters and pilot studies or reported secondary analysis of trial data were excluded.

Coding of included intervention trials.

Published intervention trials from the five journals were identified. Two authors (RW and BH) examined returned articles to identify relevant intervention studies. Two authors (BH and HT) then coded each intervention trial against the four proposed system-based criteria.

An extensive review of the literature established a number of common principles of successful approaches to organisational change. The following four criteria were considered essential features of an organisational change intervention in order to successfully change a healthcare system. For the purposes of this review, we have also defined how these features could be integrated into strategies designed improve the quality of psychosocial care.

1. Establish a culture change within the healthcare system/organisation, through designated leaders who endorse organisational goals: To facilitate system-wide change, stakeholders across the organisation need to be committed to a common goal that is informed by shared values [20]. The commitment of senior leaders within the organisation has been identified as critical for change to flow throughout the organisation [21]. Best et al., indicated that due to the complexity of the health care system, designated leadership is essential for large-scale transformative change [22]. Interventions studies were coded as “Yes” for this criterion if the intervention clearly specified that there was designated leadership team(s) supporting the change in psychosocial care throughout the organisation.

2. Take a multidisciplinary approach to change: Successful organisational change requires a commitment from all stakeholders [21]. Within healthcare settings such as cancer treatment centres, this includes management, clinicians, nurses, allied health professionals and others [13]. A key feature of successful organisation change is multidisciplinary involvement, such that intra-organisational boundaries are broken down and staff with different skills, knowledge and experiences collaborate to work towards a common goal [20]. Consequently, interventions were coded as “Yes” if the intervention involved a multidisciplinary approach that sought to involve all relevant staff.

3. Map the system and identify points of leverage: Thorough mapping of the system is another important feature of successful organisational change strategies. System mapping allows those designing the intervention to gain an in-depth understanding of how elements within the organisation are interconnected and can also help identify areas or levers which can be targeted for change [23]. If a cancer treatment centre is attempting to improve the quality of psychosocial care delivered within the centre, this could be achieved through mapping patient flow through the service and identifying specific points or care processes that could be targeted for change. Interventions were coded as “Yes” if they attempted to map the patient journey through the system and identified and intervened on multiple key points.

4. Measure the impact of change and adapt establish feedback loops: Successful organisational change approaches have built-in mechanisms to measure the effect of the change intervention and adapt the intervention strategies if and when required. It is important that measurement systems are viewed as valid and reliable and applied equitably throughout the organisation [22]. This also allows for benchmarking system performance and making decisions at a policy/funding level. Given that healthcare systems are complex and not static but influenced by changing social, political and cultural factors, it is important that interventions have a degree of flexibility [20]. Publications, where performance relating to aspects of psychosocial care were measured, monitored and used to inform intervention strategies, were coded as “Yes”.

If all of the above four criteria were met, the study was then assessed on whether an appropriate research design was used. Studies were judged against minimal research design criteria for evaluating system-based interventions. The included designs were: cluster randomised control trials, step wedge design; multiple baseline design; or a controlled pre-post trials [24].

Test-retest reliability.

Two authors (BH and HT) coded each of the identified interventions against each of the four criteria and the methodological quality. Agreement rates for the coding criteria were 88%. Discrepancies were discussed between the authors until agreement was reached.

Results

The search strategy returned 1,174 citations. Figure 1 illustrates the results of the relevance coding against the inclusion and exclusion criteria. Of the five relevant intervention studies identified, 3 met none of the four defined criteria for a systems-based intervention, one study met criteria 2 only [25] and one study met all four criteria, however, was not a rigorous study design [26].

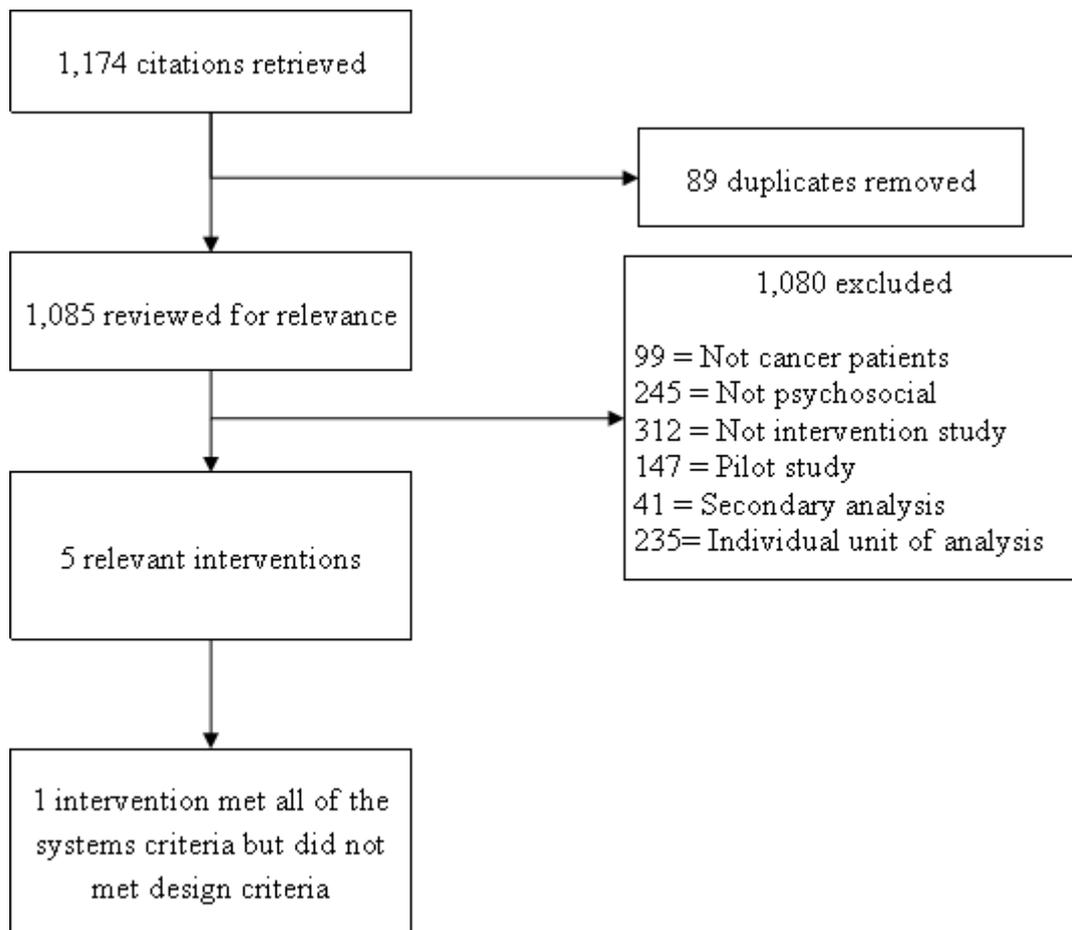


Figure 1. Inclusion and exclusion of studies returned in the Medline search

Despite not meeting the criteria for rigorous study design, one study did meet all the outlined systems-based intervention criteria [26]. Though this study did not explicitly examine psychosocial outcomes, as it was a feasibility study, it was targeted to improve psychosocial

care and was therefore included. Passalacqua et al., demonstrated a model of intervention design with a wide breadth of focus and implemented at the system level. This feasibility study explored the implementation of a quality improvement strategy to improve adherence to evidence-based psychosocial care for cancer patients. Key features of the intervention help to illustrate what a systems intervention approach may entail. Cancer centres were required to implement a minimum standard of care, with some aspects of the interventions able to be tailored to the centres. Multidisciplinary steering committees and improvement teams were appointed at each centre to oversee implementation of the interventions and ensure scientific integrity (*criteria 1*). The study also adopted a whole centre approach that aimed to involve all relevant staff members (*criteria 2*). Intervention strategies were targeted across multiple phases of the patients' journey, these included: communication skills training courses for all clinical staff; provision and endorsement of a question prompt list to patients during their first visit; specialist nurse care navigator assigned to each patient to provide support and advocacy across the cancer journey; routine screening for psychological distress and formalised referral pathways tailored by the centre; routine screening for social needs and formalised response strategy tailored by the centre; and access to a point of information and support for patients and their loved ones, including internet access and trained nursing staff to address cancer-related questions or concerns (*criteria 3*). Passalacqua et al. also referenced that their intervention incorporated a 'plan, do, study, act' cycle approach [27] that involved identifying key measures, implementing a plan, reviewing the process and updating intervention strategies where necessary (*criteria 4*). The study did not meet rigorous design criteria as it was classified as a feasibility study due to having no clinical teams willing to act as a research control group. The findings from this study indicated a high level of adherence to all intervention strategies (>85%), except the question prompt list (78% adherence).

Discussion

There is a lack of evaluation of robust systems interventions

Our search strategy provides a snapshot of system-based psychosocial interventions published in high-ranking cancer journals. We sampled papers from five leading psychosocial cancer journals. One of the five relevant intervention studies met the criteria for a systems-based intervention; however, the design of this paper restricted drawing firm conclusions about the impact on patient outcomes. The findings of this review are surprising given that systems-based interventions could potentially overcome several of the shortcomings of plug-in interventions. This includes having capacity to influence multiple aspects of care, thus having greater potential to have a clinically meaningful impact on patient psychosocial outcomes. Further, by their very nature, systems-based interventions are embedded within health service processes and roles. Therefore, if found effective, these are much more likely to be sustained in the long-term than plug-ins. In addition, this system-based approach allows possible comparisons across organisational units or facilities. Where high performance is apparent, effort can be made to understand the mechanisms by which these desirable goals are achieved that may, in turn, serve as learnings for lower performing units.

Barriers to evaluating system based change

System-based interventions represent a potential mechanism for improving cancer patient psychosocial outcomes. However, there are considerable pragmatic and methodological barriers to the development, implementation and effective evaluation of system-based

psychosocial interventions. These difficulties may account for the lack of research activity in this area. When developing complex, multi-component interventions that attempt to alter many aspects along the care pathway, there is a need to obtain collaboration and commitment across hospital departments, disciplines and individual clinicians. Typically, individual clinicians who are involved in psychosocial research are those who already demonstrate a commitment and desire to improve this important aspect of care. When attempting a system-based intervention there is a need to elicit and gain support from management, and all clinicians administrative staff in the treatment centre.

System-based interventions also require that the unit of intervention to be the treatment centre. Consequently, designs such as the cluster randomised controlled trials, stepped wedge, multiple baseline or controlled before and after trials are required. These designs are associated with logistical complexities including requiring consent and ethical clearance from multiple institutions and committees, and a complex research management structure. They also require knowledge and experience in planning and executing these research designs. Research collaborators may not have the required expertise or may not be willing to deviate from rigid research protocols to accommodate the ‘real world’ implementation of complex psychosocial interventions. Additionally, the research costs associated with these designs are often considerable and pose a barrier if funding cannot be obtained.

System-based interventions require monitoring of a range of indicators suitable for assessing intervention fidelity, impact and outcome. A majority of the existing data capture-systems are not designed in a way that effectively measures these indicators. For example, if we are to improve the quality of care across the entire care pathway, irregular cross-sectional data collection strategies may not provide the necessary mechanism for estimating change over time. While the difficulties in undertaking and evaluating system-based change are acknowledged this should not negate the potential impact on improving psychosocial outcomes.

Future Directions

To capitalise on the synergistic effect of interventions at each phase of a care pathway, the potential strengths of a system-based approach appears clear. A systems-based approach must seek to alter and improve existing care rather than provide additional plug-in elements of care. A system-based approach increases the probability that interventions will be “*hardwired*” and endure as an essential component of regular clinic functioning. Generalisation of the approach is also more likely to occur given that it is driven by the administrative components of the healthcare delivery system rather than external researchers. A focus on building rigorous research in this area is required to determine the effectiveness of large-scale interventions using the systems-based approach. Future research should seek to evaluate the effectiveness of systems-based interventions and are likely to be informed by smaller plug-in scale interventions. The information gained from this research can then be used to target policy and implementation on a larger scale. However, multidisciplinary collaborations between clinicians, policymakers, consumers, behavioural science and health economists may be needed if we are to develop and evaluate the needed landmark studies of the effectiveness of system-based interventions in improving psychosocial outcomes.

What could a system-based intervention look like?

A systems-based intervention targeting the improvement of patient care experiences within an oncology clinic could involve identification of a number of priority action areas that are measured using patient data. Having the support of senior leadership within the clinic and assigning a designated leadership team to drive each priority area would ensure staff buy-in across the clinic (criteria 1). A critical feature would be the consideration of all staff roles for each priority area and using this information to engage and evaluate these staff members (criteria 2). For instance, if considering the area of adequate preparation for treatment, the role of clinicians, nurses and allied health may be important to this area to ensure patients are receiving consistent and important information from each of these disciplinary teams. Identifying the phases in the care trajectory that would need to be targeted for this priority area (e.g., information received by patients prior to treatment initiation, after the first episode of treatment and after treatment has concluded) ensures that intervention is delivered at critical points in the system (criteria 3). Finally, continuous measurement and feedback of this patient experience data is essential to ensure evaluation of intervention effectiveness (criteria 4). To achieve a rigorous evaluation, the project design should be a cluster randomised control trial, step wedge design, multiple baseline design, or a controlled pre-post trial.

Limitations

It is acknowledged that system-based interventions focused on efforts to improve psychosocial cancer care may have been published in other journals than those searched in this review. However, the journals selected publish some of the most influential psychosocial research in the field. We acknowledge that interventions with null findings are less likely to be published. Therefore, it is possible that our results are affected by publication bias. However, it is reasonable to argue that the basic tenants of this paper are accurate and that there are relatively few, if any, well-conducted system-based interventions with appropriate research designs that have been designed to examine the effectiveness of psychosocial interventions.

Conclusions

Only one published systems-based intervention was found in the five selected top-ranking psychosocial cancer journals. While there are inherent difficulties in conducting systems-based interventions, there is a need to examine the effectiveness and cost-effectiveness of such an approach. Such attempts will require treatment centres to acknowledge the potential benefits of a systems-based approach and for multidisciplinary collaboration between clinicians, consumers, and researchers.

Conflict of Interest

The authors have no conflict of interest to declare. No primary data is contained within this manuscript.

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