The C-CARE Psychosocial Assessment In The Clinical Practice Of Breast Care Nurses

Executive Summary of the Multi-Centre Trial

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On behalf of the C-CARE Study Team

North Eastern Metropolitan
Breast Services Enhancement Program

An initiative of the Victorian Department of Human Services

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Summary Report on the Multi-Centre Trial

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ISBN: 0-646-43059-9

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ACKNOWLEDGEMENTS

This research was funded by BreastCare Victoria through the Breast Services Enhancement Program; an initiative of the Department of Human Services, Victoria.

We gratefully acknowledge the following individuals and organisations for the significant contribution they made to the development and /or implementation of this work:

- The many women and men with breast disease who generously shared their time and their thoughts about their care during this project
- The BreastCare Victoria Coordination Unit
- North Eastern Metropolitan Breast Services Enhancement Program Management Committee and Consumer Advisory Sub-Committee
- Associate Professor Michael Henderson, Peter MacCallum Cancer Centre
- Ms Andrea Cannon, Nurse Coordinator Breast Service, Peter MacCallum Cancer Centre
- Ms Philippa Hartney, Manager, Bendigo BreastScreen
- Ms Sandra Mills, Breast Care Nurse, Austin Health
- Ms Sheila Hirst and the Western Breast Services Alliance, Breast Services Enhancement Program
- Professor Sanchia Aranda, Peter MacCallum Cancer Centre
- Dr Anthony Love, School of Psychological Science, Latrobe University

This project was undertaken under the auspices of the North Eastern Metropolitan Breast Services Enhancement Program incorporating St. Vincent's Hospital Melbourne, Austin Health, Peter MacCallum Cancer Centre and The Northern Hospital and in association with Warringal Private Hospital, Bendigo Health Care Group, Mount Alvernia Mercy Hospital, Goulburn Valley Health, Wangaratta District Base Hospital and Mildura Base Hospital.

We thank the Service Directors at each of these centres and the Managers of each of the collaborating breast care nurses for enabling their participation in this work. We are also particularly grateful for the recommendations and support of the Human Research Ethics Committees at each treatment centre involved in this study.

The enormous contribution the nine collaborating breast care nurses have made to this project is gratefully acknowledged. Their enthusiasm for the development and implementation of a process they believed would benefit their practice does not mitigate the generosity of their involvement at each stage of this project. It was a privilege to work with these professionals: thank you Melissa, Maxine, Elizabeth, Jodie, Tina, Kaye, Jan, Sophie and Kathryn.

EXECUTIVE SUMMARY & RECOMMENDATIONS

Background

The North Eastern Metropolitan Breast Services Enhancement Program is a consortium of four Melbourne hospitals working together on a range of projects aimed at improving the quality of services for people with breast disease. The program is one of nine demonstration programs funded by BreastCare Victoria, Victorian Department of Human Services.

This project was undertaken to strengthen the provision of evidence-based psychosocial care to individuals with breast cancer and involved breast care nurses (BCNs) from four hospitals in the consortium and an additional six other metropolitan and rural Victorian health services.

The primary objective was to enhance the skills of BCNs in the identification and appropriate support of psychosocial needs in individuals receiving treatment for breast cancer. This objective was given priority due to:

- *Compelling evidence on the importance of routine psychosocial assessment summarised in the Psychosocial clinical practice guidelines (NHMRC, 2000);*
- *Observation that BCNs generally require support in development of competency in psychosocial assessment, therapeutic communication and appropriate referral of women requiring additional support (Victorian Centre for Nursing Research, 2001);*
- *Consumers consistently identifying psychosocial support as a priority for service improvement (eg: Western Breast Services Alliance BSEP, 2003).*

Therefore the C-CARE, a psychosocial assessment strategy consistent with the recommendations of the *Psychosocial clinical practice guidelines* (NHMRC, 2000) and applicable to the practice context of the BCN, was developed. The C-CARE has three components:

1. A ***practice model*** emphasising early assessment of current levels of distress and psychosocial risk factors as the 'evidence' on which BCN supportive care interventions are based;
2. ***Draft C-CARE psychosocial assessment forms*** that guide initial and subsequent assessments;
3. A ***training package*** focussing on the evidence for psychosocial assessment, the BCN role in the conduct of psychosocial assessment, and provision of appropriate information, counselling and referral to specialist providers.

The C-CARE trial

Between August 2002 and March 2003, nine collaborating breast care nurses (BCNs) recruited a sample of 115 people (113 women, two men) diagnosed with breast cancer to a pilot study of the C-CARE psychosocial assessment in the clinical practice of the BCN. There was an excellent response to the study with recruitment of 91% of the 126 eligible persons newly referred to the BCNs during their three-month recruitment periods.

Each participant was administered the initial C-CARE psychosocial assessment by the second meeting with the BCN and the brief subsequent C-CARE psychosocial assessment at one month, two months and three months after initial assessment. The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), was also completed by participants as an alternate measure of distress at the initial and two-month assessments.

Given the different practice environments of the BCNs, the sample was mixed in terms of time since diagnosis, treatments and stage of disease. Most of the sample (n=99, 86%) had newly diagnosed breast cancer. Additionally, 12 women diagnosed with a recurrence and four women with metastatic disease consented to participate in the study. Approximately half (48%) of the sample had commenced treatment for this diagnosis when the initial psychosocial assessment was conducted by the BCN.

The C-CARE assessments were used by BCNs to elicit and document a range of psychosocial risk factors and psychosocial needs including: the experience of recent distressing life events (35% reported three or more significant events in addition to the current diagnosis); a lack of adult support at home (20%); difficulties travelling to treatment or other practical issues (10%), financial difficulties (20%), specific information needs (40%), and history of significant mental health

problems (20%). At least 10% of the sample was also identified as receiving treatments for mental health problems at the time of referral to the BCN.

Collaborating BCNs reported at least 75% of participants acknowledged feelings of anxiety and 39% feelings of depressed mood at initial assessment. While reported feelings of distress generally declined for the sample over time, approximately one-third of the sample reported increased feelings of distress two months after initial assessment. This is consistent with literature that demonstrates psychosocial well-being of people being treated for breast cancer continues to be challenged throughout the treatment process.

A comparison of the results of the C-CARE distress questions and the HADS self-report distress items indicated a respectable association (88%) between the two methods at initial assessment when the HADS unitary distress score of 15 is taken as the criterion for significant distress. The association between the C-CARE distress questions and the HADS was not as strong at the two-month follow-up (66%), probably due to flaws in the protocol for administration and deficiency in the design of the briefer subsequent C-CARE psychosocial assessment form.

Information on referral and other BCN interventions generated by this study is complex and further complicated by sub-optimal documentation in study records. BCNs reported offering referral to specialist providers to 45% of participants following initial assessment, reducing to 14% following the three-month assessment. The overwhelming majority of these offers of referral were to social work. While this seems to represent a potential burden for local support services, it is unclear which of the referral offers comprised formal referrals or recommendations to address significant concerns arising from the assessment, and which comprised routine multidisciplinary management at some sites.

Participants reportedly accepted 63% of the documented offers of referral and our impression is that participants were more likely to take up services to meet practical support, physical health or informational needs than recommendations to address psychological or emotional needs (approximately one third of offers of referral to psychological services were reported to have been declined by participants).

This study cannot answer the question of the appropriateness of referral, although it is clear that management practices for psychological needs does vary between BCNs and is influenced by professional factors such as BCN experience and additional skills, and local referral networks and resources. Reflecting on whether referral or management strategies recommended by BCNs are consistent with recommendations of best-practice psychosocial care is an important area for further research.

Consumer opinion

The conduct of the research study, including the formal informed consent procedure and implementation of a more structured model of psychosocial assessment did NOT impact negatively on the development of the therapeutic relationship between participants and their BCNs. Furthermore, participants in this research indicated that the content of initial and subsequent assessments was perceived as an acceptable and consistent component of supportive care in this treatment context. In fact, responses to the consumer survey and comments made to BCNs and documented during the trial, were overwhelmingly positive and appreciative of the BCNs provision of opportunities to talk about their feelings and support needs.

Impact on the collaborating Breast Care Nurses

General impact of the study

The nine collaborating BCNs demonstrated significant commitment to enhancing their roles to incorporate universal, psychosocial needs assessment. However, there were costs associated with the change in practice and participation in the study for BCNs, particularly in terms of the time commitment required to administer the study, conduct assessments and manage identified psychosocial needs. Time taken to conduct the assessment did appear to decline with increased BCN familiarity with the model, however the BCNs noted that identification and management of individuals with significant psychosocial needs, or particular cultural needs such as needing an interpreter, generally required an increased time commitment.

Acceptability of the C-CARE model

Collaborating BCNs reported that the C-CARE model, which supports early, systematic psychosocial assessment and periodic review of psychosocial needs, has impacted positively on their practice. All but one reported continued use of the model in routine practice following conclusion of the trial. It is clear however, that implementing stage three and four of the C-CARE model, which encompasses consultation with and referral to other providers, requires further development in some sites.

Although personal, environmental and institutional barriers to implementation of the C-CARE in routine practice were identified during the course of this study, the strategy was supported as a practical, feasible and appropriate addition to BCN practice in a range of treatment contexts.

BCNs recommended a range of amendments to the C-CARE assessment forms to improve their utility in routine practice, and these have been incorporated into the revised forms (Appendix 2). BCNs supported the C-CARE being made available to their peers to guide assessment and documentation of psychosocial needs. Avoiding duplication of paper work was a priority for BCNs, and incorporation of the forms into clinical records was supported as an option for further consideration.

Development of new skills and resources

By participating in this study, collaborating BCNs generally reported improved understanding of psychosocial risk factors and needs of their clients and greater confidence in eliciting these concerns. Several BCNs have also taken steps to forge new referral networks and raise the profile of the psychosocial needs of people being treated for breast cancer at their treatment centres.

During this study BCNs implemented a research program at their site and participated in a larger collaborative research program. This resulted in several team members acquiring new skills in the conduct of research and appraisal of scientific evidence, leading several BCNs to contribute to peer education processes by delivering talks, conference presentations and a workshop.

This process also increased appreciation of the role of reflective practice and professional support in the practice of the BCN. Several collaborating BCNs have taken steps to formalise peer or professional supervision processes during this work.

Conclusions

BCNs identified that this model, which diverged from the more *ad-hoc* assessment of psychological needs in routine practice, facilitated the implementation of psychosocial assessment and early intervention support for study participants. The model also appeared acceptable to the overwhelming majority of consumers surveyed during the trial.

While the study has generally met its stated objectives, caution in the wider implementation of this work is strongly advised.

One of the clearest messages of this study was reinforcement of a theme running through the *Psychosocial clinical practice guidelines* (NHMRC, 2000), that provision of psychosocial care to people being treated for cancer is a team effort. Amendments to the BCN practice protocol have implications for service demand and delivery by other members of the treatment team and local providers outside the cancer treatment network. Efforts to implement systematic psychosocial assessment strategies, or basic screening using self-report instruments, do require significant consultation with other stakeholders. A team approach is required to determine policy on which needs can reasonably be managed in that treatment context, to formalise referral criteria and pathways to other systems of care, and to identify where gaps in services requiring institutional action.

Failure to establish a consultative network for psychosocial care places an unreasonable burden on the BCN and increases the possibility that they will be working outside their competency.

The C-CARE model represents one possible approach to implementing some key recommendations of the *Psychosocial clinical practice guidelines*. The C-CARE assessment is a

complex response to the complex requirement to assessing both current needs and potential risk factors in a way that was meaningful to BCN practice. The C-CARE does not produce a 'score', rather BCNs appraise the level of need based on their full assessment of the client, including their understanding of supportive care strategies already in place for that individual. While this flexibility and depth of information may suit the practice of BCNs more skilled at providing psychosocial care, we suggest that the C-CARE assessment instruments alone will not provide most BCNs with sufficient support to identify those in need of review by psychological services.

Hence the C-CARE is not a panacea and is certainly no substitute for a foundation understanding of the psychological aspects of health or consultation with specialist providers to clarify psychosocial health needs or the severity of concerns. Based on the results of this study, and consistent with the evidence-based guidelines (NHMRC, 2000), the following actions are recommended:

RECOMMENDATIONS

Action 1: Establish or review networks for psychological care

a. While the commitment of one clinician (or one professional group) can make a difference to the psychological well-being of consumers, a team approach to implementation of psychosocial assessment is necessary.

b. Liaison with the members of the treatment team and other stakeholders, including social work and psychology departments, psychooncology or consultation liaison psychiatry departments, is required to determine institutionally acceptable and sustainable approaches to psychosocial assessment and management of complex or significant psychological needs. Consultation with organisations outside the hospital may also be necessary to clarify referral pathways for the review/management in the community of individuals with cancer who also have significant psychological needs.

c. Consultation with key providers including the treatment team, social work, mental health and psychooncology, should include expectations regarding the documentation of psychosocial risk factors, reasons for referral and referral outcomes. Unambiguous documentation of risk/needs and interventions are necessary outcomes of routine psychosocial assessment.

Action 2: Routine psychosocial assessment by BCNs

a. The unique practice context of the BCN makes them a logical choice for taking a lead role in the universal psychosocial assessment of current psychosocial needs and risk of poor outcome, providing they are adequately trained and supported.

b. The C-CARE assessment model provides a sound structure upon which individual institutions may model their assessment and review pathway.

c. Early psychosocial assessment is recommended. Our findings suggest this does not place an unrealistic burden on consumers. A psychosocial assessment such as the C-CARE may be administered at the first practical contact with clients newly referred to a service.

d. Periodic reassessment of psychosocial needs and risk factors is also recommended. Reviews are recommended at major treatment junctures and prior to discharge from BCN care.

e. The revised C-CARE psychosocial assessment forms (Appendix 2) may be considered for use in a range of treatment settings to help implement a systematic approach to psychosocial assessments, to inform decisions regarding referral and the need for more detailed assessment by specialist providers.

f. The use of a previously validated psychological distress screening instrument such as the HADS is hampered by the lack of consistent psychometric data and wide variation in recommended scoring thresholds for 'significant' distress in populations with breast cancer. However, there is a place for psychological screening measures in some treatment contexts and this approach is worth exploring in consultation with other stakeholders as discussed in Action 1.

g. The disadvantage of using a screening measure rather than a more multifactorial approach to psychosocial assessment is that screening may help identify clients needing referral to a specialist provider, such as a psychologist, but it does not generally identify strategies to improve psychological well-being of all people with breast cancer, through the provision of appropriately targeted information, and practical support. The use of a distress screening tool and the C-CARE may provide BCNs with more support in identifying 'significant' distress for referral than the C-CARE alone and still allow BCNs to base their range of intervention recommendations on an early appraisal of psychosocial needs.

h. The revised C-CARE psychosocial assessment forms require further research to ensure assessment questions and associated practices are suitable across all age ranges, for consumers from Aboriginal and Torres Strait Islander communities and people from culturally and linguistically diverse communities.

i. The final psychosocial assessment forms should be sent to the relevant Forms Committees to be approved for use on clinical records.

Action 3: Developing the consultation and referral process

a. Local referral criteria both to the BCN and supportive care providers, should be negotiated with all relevant providers to ensure the appropriate and efficient targeting of services, and to prevent the overextension of the BCN role. Relevant providers include professional providers of practical support, information and psychological services.

b. Development of networks and consultation with local psychological service providers is a priority for many services. Key issues for consideration include:
   - The pathway for the prompt review of persons with suspected significant psychological concerns such as anxiety or depression;
   - Documentation of referral criteria and pathways into these services for management of psychological concerns in people being treated for breast cancer;
   - Appropriate strategies for the care of consumers while they are on waiting lists for psychological services;
   - Safe systems of care for consumers whose psychological needs must be urgently addressed.

c. It would be helpful to document referral pathways; both to the BCN and principal supportive care providers, and make these available to stakeholders. It might also be helpful to document the range of local services provided by peer and consumer groups.

Action 4: BCN professional issues

a. The role and competencies of BCNs in providing psychosocial assessment and care requires consideration at professional and institutional levels.

b. The need to provide significant education on the psychosocial aspects of care in core training and accreditation process for BCNs, and to support the development and maintenance of competency in the provision of psychological care, is apparent.

c. Development of a continuing professional education package on psychosocial assessment and other aspects of psychosocial care is recommended as the entire workforce moves toward enhancing competency in this area.

d. Review information provided to users of the BCN service to ensure it adequately details their role in the provision of psychosocial care.

Action 5: Training and support

a. Ensure that the *Psychosocial clinical practice guidelines* (NHMRC, 2000), have been disseminated to all BCNs. This document provides a solid introduction to the psychological needs of people with breast cancer, risk factors for poor outcomes and further information on interviewing and basic counselling skills.

b. Further training or refresher training on communication and assessment skills is beneficial to all clinicians. Communication skills training programmes are available from a range of providers, including the National Breast Cancer Centre.

c. The brief C-CARE training program implemented for this study provided an introduction to relevant themes and the conduct of the research program. Topics on interpretation, prioritising and management of assessed needs in the context of oncology care requires extension before wider implementation of the training program would be recommended.

d. Formalise clinical case review and supervision processes for staff providing psychosocial care to assist professional learning and development and management of stresses associated with delivering supportive care services.

Action 6: Evaluation

a. Trial the revised C-CARE psychosocial assessment strategy in the clinical setting to determine its costs and benefits to the treatment team and people receiving treatment for breast cancer.

b. Trial of the model in other populations with cancer is suggested.