



ORIGINAL ARTICLE

A Delphi-based approach to developing the contents of an online resource, Care Assist, for male caregivers of women with breast cancer

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Abstract

Objective: Informal male caregivers of women with breast cancer (BC) have significant psychological, emotional, and social burdens that are inadequately addressed by current face-to-face interventions. Online interventions overcome barriers that limit engagement with face-to-face interventions. This study aimed to develop the contents of *Care Assist*, an online supportive care resource for male caregivers of BC patients, through expert consensus.

Methods: A Delphi study comprising two survey rounds and an expert consultation was conducted. In Round 1, experts in BC care rated the importance of 25 content items. In Round 2, they re-rated content items that failed to reach consensus (i.e. 80% agreement) in Round 1 or were newly developed. Free-text responses were also collected. During expert consultation, the resource was reviewed and revised for clarity. Iterative refinement followed all rounds. Quantitative data was analysed descriptively, and qualitative data was analysed using content analysis.

Results: Twenty-two experts participated and reached consensus on 96% of items, with 217 comments provided on: (a) the perceived benefits of Care Assist to caregivers and care recipients, (b) recommendations of newly suggested content items, wording, and use of external links, and (c) concerns regarding information overload and need for tailoring. The expert consultation comments focused on clarifying scope, wording, and information tailoring.

Conclusion: The rigorous Delphi process resulted in the content for a comprehensive online supportive care intervention for male caregivers. Information overload can be minimised through self-identification of needs and utilisation of eHealth to personalise the resource for the heterogeneous male caregiver population.

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KEYWORDS

breast cancer, eHealth, male caregivers, online resource, psycho-oncology, supportive care

1 | INTRODUCTION

In 2021, an estimated 20,825 Australian women were diagnosed with breast cancer (BC).¹ Improved BC screening and treatment advances have led to substantial increases in the number of BC patients and survivors.² This is reflected in the incidence growing globally by 119%, and in Australian women by 84% from 2000 to 2020.³ Increased demands on cancer services have resulted in greater dependence on informal caregivers,⁴ who provide invaluable support to patients, the healthcare system and Australian society. In 2020, approximately 2.8 million Australian informal caregivers provided 2.2 billion hours of care, effectively saving the federal government AUD\$77.9 billion (Australian dollars).⁵ Despite their contribution, they are often having to meet caregiving demands without adequate support or training, and report elevated psychological, social, emotional, and financial burdens.^{6,7} A systematic review of 17 empirical studies revealed that lack of information was the most common unmet need of informal caregivers of advanced cancer patients.⁸

In the context of BC, caregivers are predominantly male (50%–77%), and often the patient's partner.⁹ Further, informal male caregivers of women with BC have their own unique set of vulnerabilities and unmet needs that require support.⁶ This is underpinned by distinct role transitions, mindsets, self-perceptions, coping styles, and help-seeking behaviours.⁷

However, current caregiver support is primarily delivered face-to-face (F2F), and some of these can be accessed via the Australian Government Carer Gateway and the Cancer Council websites. Examples of the available support include F2F services which are often not used by male caregivers due to time constraints, long-distance travel, inflexibility with pre-determined session times, and prioritising the patient.¹⁰ Male caregiver coping styles and attitudes such as task-orientation, suppression, avoidance, and preferred use of less formal services, pose additional barriers to accessing F2F services.¹¹

Online interventions largely overcome these barriers, with studies revealing the acceptability and feasibility of online modalities amongst male caregivers.¹² However, to date, the majority of online interventions cater for the substantially larger female caregiver population, and the reporting quality of studies evaluating them has been poor.^{12–14} Therefore, whilst online interventions have the potential for success, some have not undergone an assessment of their efficacy,^{15,16} and those that have are currently limited by underrepresentation of male caregivers, poor study design, and mixed outcomes.^{7,17,18} Hence, the need for an accessible and efficacious online informational intervention targeting male caregivers remains unmet.

In a formative mixed-methods study conducted by our group ($n = 89$ surveys, and $n = 13$ in-depth interviews),⁹ male caregivers indicated that they needed a comprehensive online intervention that (a) includes educative content, psychosexual support and fear of

cancer recurrence support for caregivers; (b) is interactive and personalised; and (c) is available to them from the point of diagnosis.⁹ Hence, this study aimed to develop and refine the contents of *Care Assist*, an online supportive care resource tailored for male caregivers of BC patients, using the content items suggested by male caregivers in the formative study.

2 | METHODS

This study used a mixed methods research design based on an online Delphi approach and was approved by the South Western Sydney Local Health District Human Research Ethics Committee (reference number: 2020/ETH02557).

2.1 | Participant eligibility and recruitment

Researchers and clinicians in Australia were eligible to participate as experts if: (i) they specialised in at least one of the following disciplines: psychology, social work, psychiatry, medical oncology, radiation oncology, surgery, palliative care, oncology nursing, palliative care nursing, other nursing discipline, public health/health promotion or allied health; and (ii) they had ≥ 5 years of practice as a researcher and/or clinician. They were identified and invited to participate through (a) the Psycho-Oncology Co-operative Research Group (PoCoG), a national cancer clinical trials group with a multidisciplinary membership of over 2500 psycho-oncology and supportive care clinicians and researchers¹⁹; (b) BC trials group,²⁰ a clinical trials research organisation focused on improving treatments and outcomes for BC patients with a membership of 820 clinician researchers; and (c) snowballing. The participants were approached via advertisement in PoCoG electronic newsletters, BC trials group emails, and snowballing from researchers' network in tertiary hospitals. Informed written consent was electronically obtained from eligible participants before they could participate in our study. Participants were screened for eligibility as part of the first survey round. Only data from eligible participants were analysed.

2.2 | Survey design

Results of a formative study of Australian male caregiver information needs in the context of caring for women with BC,⁹ alongside existing literature²¹ informed the initial items ($n = 25$) for the Delphi process. These were categorised into five domains: (1) diagnosis and treatment (2) the ongoing caregiver role (3) practical information (4) survivorship and (5) planning for loss.

To populate the information relating to each of these 25 items, an extensive search of existing online information was undertaken, with a focus on reputable cancer and government health organisations. Once relevant information was identified, permission was sought and granted from the source organisations (BC Network Australia (BCNA), American Cancer Society, Cancer Australia, and the Victorian Government's Better Health Channel) to include and cite their published online information under relevant topics in the *Care Assist* resource.

The resulting 25-item consumer-suggested resource content (Appendix A) was evaluated by Australian clinicians and researchers using a minimum of a two-round e-Delphi approach, adhering to the reporting standard for Conducting and Reporting of Delphi Studies (CREDES)²² (Appendix B).

2.3 | Delphi rounds and expert consultation

In Round 1, participants were presented with a 25-item measure to be completed online via the Qualtrics²³ survey system. They were asked to rate the importance of each item using a 4-point Likert scale (1 - not at all important, to 4 - very important). An item was rated as having reached consensus if at least 80% of participants rated it as *important* or *very important*. Participants were invited to add free-text comments on flow, structure, clarity and wording appropriate to the context of Australian male caregivers of women with BC; and suggest additional items for inclusion.

In Round 2, items which failed to reach consensus, newly suggested items, and Round one items which were similar enough to be merged under a single item were presented in Round 2 and participants were asked to re-rate their importance. A summary of Round 1 responses was provided to participants for reference whilst re-rating items in Round 2. Also, participants could include free-text responses to provide context to their responses and suggestions for new items. Items which failed to reach consensus after two consecutive rounds were removed.

This was followed by iterative content development based on the results. Two investigators (SG, AB) categorised finalised content items into five sections: diagnosis and treatment, the ongoing caregiver role, practical information, survivorship, and planning for loss. Finally, participants who consented to participate in the final expert consultation were grouped based on their expertise (3-4 participants per group), and each group was allocated one section to review for readability, flow, and comprehension of the content and provide free-text annotations within 3 weeks. The lead authors (SG, AB, AG, JS, AP) iteratively reviewed and refined content.

2.4 | Data analysis

Quantitative data was exported into an Excel spreadsheet and descriptively evaluated in IBM SPSS Statistics 26.²⁴ For each item, the percentage of participants rating the item as important or very important was calculated. Content analysis was undertaken on

qualitative data from both Delphi rounds and the expert consultation. Analysis mirrored the four-phase abstraction process from Erlingsson et al²⁵: (1) data familiarisation; (2) creating condensed meaning units; (3) code formulation; and (4) category and theme development. Analysis was conducted iteratively, while incorporating the four criteria that are known to improve research quality and increase trustworthiness²⁶: credibility, confirmability, dependability and transferability. The qualitative data was condensed, coded, and themed by SG, a proportion of the interviews were reviewed, and the coding processes were discussed with a senior researcher (AB), within the team, as a credibility check. Furthermore, the qualitative data was reviewed and discussed by SG, AB, AG, JS, and AP after both Delphi rounds and the expert consultation to resolve disagreements, reach consensus, and further enhance *credibility*. In addition, we have reported our study in detail (see Appendix A to H) to ensure a future researcher can repeat our work, thus achieving *dependability*. Also, we have incorporated respondent validation by providing study results for each Delphi round to the participants to enhance the *confirmability*, *credibility*, and *trustworthiness* of our study. Furthermore, our study findings may be applicable in, and transferable to, other cancer tumour groups as long as the patient is a female and the caregiver is a male, thus demonstrating *transferability*.

3 | RESULTS

3.1 | Participants

Australian BC care experts ($n = 22$) completed both rounds of Delphi surveys. Participants included clinicians and researchers with a mean age of 44.3 years with 77% having more than 10 years of experience. Most participants were clinicians (86%), female (90%) and located in New South Wales (82%). See Table 1 for participant characteristics and Appendix C for individual participant codes and their disciplines. Of the 22 participants, 17 consented to participate in the expert consultation panel. As no social worker participated in the Delphi rounds, a social worker was purposively invited to participate in the expert consultation ($n = 18$).

3.2 | Delphi consensus results

Of the 25 items presented in Round 1, only 'managing wounds' failed to reach consensus (Table 2). Participants provided 177 free-text comments and suggestions (see Appendix D), which led to development of five additional items for inclusion in Round 2. Two of these items were new: '*Fertility, pregnancy and childbirth*' and '*fear of cancer recurrence*'; and three were developed from integrating similar items from the original 25 items (see Table 2 for details). In Round 2, these five items plus 'managing wounds' were presented to participants. Five items reached consensus and 'managing wounds' failed to reach consensus again (Round 1: 68%, Round 2: 46%; see Table 2) and was therefore excluded from the resource. Round 2 participants provided 40

TABLE 1 Participant characteristics

Characteristic	Number of participants (n = 22) (%)
Age, mean ± SD, years	44.27 ± 9.341
Under 40	5
40–50	13
Over 50	4
Gender	
Male	2 (9%)
Female	20 (90%)
Clinician, researcher or both	
Clinician	13 (59%)
Researcher	3 (14%)
Both	6 (27%)
Discipline	
Psychology	5 (23%)
Oncology nursing	5 (23%)
Allied health	5 (23%)
Medical oncology	3 (14%)
Radiation oncology	2 (9%)
Surgery	2 (9%)
Palliative care	2 (9%)
Other nursing discipline	2 (9%)
Public health/health promotion	1 (5%)
Years' experience in discipline	
5–10 years	5 (22%)
10–15 years	8 (36%)
15–20 years	6 (27%)
More than 20 years	3 (14%)
Primary location in Australia	
New South Wales	18 (82%)
Victoria	1 (5%)
Western Australia	2 (9%)
South Australia	1 (5%)

additional free-text comments and suggestions (see Appendix E), which were reviewed by the lead authors and actioned. Overall, 96% total consensus was reached after both Delphi rounds.

3.3 | Qualitative results

Three major themes emerged from the 217 free-text comments across both Delphi rounds: (1) benefits of the content items, (2)

recommendations for the resource content, and (3) potential concerns to address regarding the content items detailed in Appendix F.

In total, 105 comments (Round 1 = 85, Round 2 = 20) were based on the perceived benefits of the resource to both male carers and their care recipient. For carers, comments included improving understanding, empowering decision making, developing more effective coping styles and managing psychosexual concerns. For care-recipients, participants perceived that the resource could reduce educative burdens and aid emotional support during their BC survivorship journey. Participants also suggested that the resource could improve dyadic congruence (consistency in perspective) and minimise conflict. See quotes below.

This is likely to... assist [caregivers attain] empowerment and self-determination in their healthcare choices – P01, General Information

Family and partners need clear information about the type of cancer, so the woman does not need to provide more information to them when she is trying to deal with her own concerns and fears – P21, General Information

Polarising views arose regarding the inclusion of wound care information in the resource, with some participants stating it could prevent harms to the care-recipient (P4), whilst others thought it could exacerbate harms (P17).

I have seen a male carer handle a patient's wound incorrectly and increase the risk of infection and pain – P4, Managing Wounds

“The general information on wound care may give some patients and partners the impression they should self-manage any wound issues, and I feel they should be advised on what to do as some of the general information may contradict what should be done with particular skin care during RTx or post-op dressings.” – P17, Managing Wounds

In addition, 86 comments (Round 1 = 71, Round 2 = 15) suggested improvements to the resource content, structure, timing (e.g., information overload at diagnosis), information source (e.g., who to deliver what information) and inclusiveness (e.g., resource is gendered and heteronormative). See Appendix F for more quotes.

Part of reducing the risk of lymphoedema as a side effect is engaging with Early Intervention i.e., a

TABLE 2 Overall consensus for content items

Response Category	Level of consensus (%)	Mean rating (SD) ^a	Median rating
Round 1			
General information about breast cancer	100	3.77 (0.43)	4
Treatment types	100	3.77 (0.43)	4
Factors determining treatment pathways	100	3.68 (0.48)	4
What to expect from each treatment	100	3.68 (0.48)	4
Roles of healthcare professionals your care recipient May see	95	3.50 (0.60)	4
What questions to ask healthcare providers at each stage	95	3.59 (0.59)	4
Side effects of each treatment type	100	3.82 (0.40)	4
Life after treatment	100	3.64 (0.49)	4
How to manage emotions	100	3.91 (0.29)	4
How to manage stress	100	3.95 (0.21)	4
How to manage the sexual relationship with the patient	100	3.77 (0.43)	4
Information about trusting healthcare providers	100	3.41 (0.50)	3
How to provide emotional support for the patient	100	3.91 (0.29)	4
Direction on how to be supportive	100	3.91 (0.29)	4
Knowledge of possible caring responsibilities	95	3.32 (0.57)	3
Managing wounds	68	3.14 (0.89)	3
Information on how to encourage healthy living to your care recipient	95	3.32 (0.57)	3
Information on how to communicate with the patient	100	3.86 (0.35)	4
Managing side effects	91	3.50 (0.67)	4
Managing multiple caring responsibilities	100	3.55 (0.51)	4
Employment, legal rights and financial support	95	3.64 (0.58)	4
Time management	86	3.14 (0.64)	3
Day-to-day practical issues	86	3.05 (0.58)	3
Preparing for the loss of the patient	95	3.68 (0.57)	4
Coping with the loss of the patient	91	3.59 (0.67)	4
Round 2			
Managing wounds	46	2.45 (0.51)	2
Fertility, pregnancy and childbirth	82	3.18 (0.73)	3
Fear of cancer recurrence	100	3.64 (0.49)	4
Expectations and side effects of treatment ^b	96	3.73 (0.55)	4
Communicating and providing emotional support to your care recipient ^c	100	3.73 (0.46)	4
Managing caring responsibilities and day-to-day practical issues ^d	96	3.64 (0.58)	4

^aStandard Deviation.

^bMerged 'what to expect from treatment,' 'side effects of each treatment type,' and 'managing side effects' from Round one.

^cMerged 'directions on how to be supportive,' 'how to provide emotional support' and 'how to communicate' from Round one.

^dMerged 'knowledge of possible caring responsibilities,' 'managing multiple caring responsibilities' and 'day-to-day practical issues' from Round one.

measurement of the arms prior to any treatment/surgery and monitoring for 2 years after. This is not mentioned in any current information available. – P11, Side Effects of Treatment

Also, 26 comments (Round 1 = 21, Round 2 = 5) highlighted concerns regarding the variable utility of the resource, and perceived lack of personalisation of resource content that could result in information overload and potential distress.

Could be very confronting given majority of patients have early risk disease/good prognosis – P13, Preparing for the Loss of the Patient

3.4 | Expert consultation

Five groups of 3-4 experts were formed to review each of the five sections for content readability, flow, and comprehension. Three of the groups undertook their review through group consultation (Zoom meetings), whilst the remaining two gave iterative feedback via commenting on a shared Google document. A summary of the collective and section-specific comments from the expert consultation are detailed in Table 3.

These comments informed iterative revisions of *Care Assist*, with key modifications presented in Appendix G. The overall structure and content of the final intervention is presented in Appendix H.

4 | DISCUSSION

This paper reports on the Delphi research approach used to reach expert consensus on the content of an online psychoeducational

resource to support male caregivers of women with BC. Participating experts reached 96% consensus on the content items, with qualitative feedback highlighting the benefits of the content, recommendations for its improvement and potential concerns that need to be addressed to improve the resource. Experts affirmed the inclusion of information relevant to diagnosis and treatment, psychological and psychosexual wellbeing, practical responsibilities, survivorship, and preparing for and coping with the loss of their care-recipient.

Based on the Delphi, inclusion of additional resource content information on 'FCR' and 'fertility, pregnancy, and childbirth' was recommended. There is clear evidence supporting the inclusion of 'FCR', as it is consistently rated as one of the highest unmet needs of cancer survivors and caregivers.²⁷ However, most studies regarding information needs of informal caregivers of BC patients, including our formative study, do not mention 'fertility, pregnancy, and childbirth' as a need.²⁸ Experts justified inclusion of this item to inform male partners about family planning decisions that may affect the sexual relationship. A qualitative study on cancer patient and partner perspectives of fertility concerns substantiated that fertility decision-making is important to renegotiate relationship trajectories and relational coping for dyads.²⁹

Experts also suggested adding information related to hereditary/genetic information and lymphoedema screening which were not suggested by male caregivers in our formative study.¹⁰ Inclusion of

TABLE 3 Summary of expert-consultation comments across the resource and within respective sections

Section	Expertise	Comments
1: Diagnosis and treatment	<ul style="list-style-type: none"> • Medical oncology (x2) • Radiation oncology • Surgery, palliative care and oncology nursing 	<ul style="list-style-type: none"> • Defining the nature of the relationship between the male caregiver and care-recipient (e.g., partner, son, etc.) so information is better tailored.
2: Ongoing caregiver role- information for partners	<ul style="list-style-type: none"> • Psychology, allied health • Psychology • Public health/Health promotion, allied health • Oncology nursing 	<ul style="list-style-type: none"> • Integrate more normalisation techniques in the psychoeducational resource • Integrate more visual content. • Re-consider advice that increases mental load on BC patient • Rephrase the title of the second section as it is also relevant to male caregivers who are not partnered to their care-recipient
3: Other practical information	<ul style="list-style-type: none"> • Allied health (occupational therapist) (x2) • Social work 	<ul style="list-style-type: none"> • Use gender neutral pronouns • Information related to centrelink and the external breast prosthesis reimbursement may change, so best to not add overly specific details but rather direct to links and contacts.
4: Survivorship	<ul style="list-style-type: none"> • Nursing • Psychology • Allied health (Dietician) • Oncology nursing 	<ul style="list-style-type: none"> • Target certain dietary advice to both the caregiver and the care-recipient • Removing repeated information • Use bullet points for some information • Personalise messages to younger caregivers who have higher risk of FCR
5: Planning for loss	<ul style="list-style-type: none"> • Psychology • Palliative care medicine • Oncology nursing 	<ul style="list-style-type: none"> • Clarify normal grief and complicated grief • Clarify young children express their feelings through externalised and internalised behaviours • Incorporate more available support for palliative care

Note: Collective comments: Widen scope by including metastatic BC in the content; consider those with lower health literacy and culturally and linguistically diverse populations, improve wording, accuracy, structure, add newly suggested inclusions, and link to further booklets and factsheets, tools, and support lines.

hereditary information is supported by a qualitative study of 50 informal caregivers of women with BC (74% were male), which found genetic risk to be a higher priority than self-care, psychosexual concerns and caring responsibilities.²⁸ Whilst lymphoedema screening is not currently a standard of care, a number of pilots are underway in Australia,³⁰ supporting greater inclusion of this information in the resource.

The item relating to managing wounds was initially included in our resource because it was suggested by male caregivers in our formative study¹⁰ and echoed by an integrative review affirming that informal caregivers undertake wound management, yet have limited support and training.³¹ However, this item failed to reach consensus, with paradoxical views expressed by participants, including some suggesting that the generic information included could cause harm if it conflicts with more wound-specific recommendations from the BC nurse. Despite evidence supporting the need for 'wound management' resources, experts in our study highlighted that such information is better sourced from the BC care team to prevent self-management or potential harm. This view is reflected in Tinelli et al.'s survey of clinicians on wound management changes during the COVID-19 pandemic as they emphasised the need for a collaborative effort to digitise and personalise clinician-sourced wound management resources.³² Therefore, there is a strong imperative for clinician-prescribed wound care management resources for informal caregivers. However, this is currently outside the scope of the *Care Assist* resource, and hence was removed.

Experts noted that the perceived utility of the resource may vary depending on male caregiver and care-recipient factors including level of involvement in caregiving, relevance to their care-recipient's type and stage of BC, role transitions, and relationship to the care-recipient. It was noted that sections such as 'preparing and coping for the loss of your care-recipient' would not be relevant and may be distressing to male BC caregivers whose care-recipient has early BC and has a good prognosis. Furthermore, sections such as 'managing caring responsibilities', which included information about possible caring roles (including caring for children) and effective caring strategies, could be inapplicable to some caregivers depending on several contextual factors such as life stage, changing roles and skills of male caregivers over time.²⁸ However, it is presumptive to assume that male caregiver age correlates to role transitions and care skills, further stressing the need for tailoring the resource.

The need to include strategies for tailoring the resource content was a recurring suggestion raised by experts in our study. Tailoring is defined as developing individualised information based on key individual difference variables or characteristics.³³ Experts in this study cautioned that generic information risked causing information overload. The literature substantiates that such overload may lead to disengagement with the content or undue distress if confronted with information that lacks relevance.³⁴ Tailoring can occur via self-guided customisation, researcher-guided personalisation using algorithms or both.³⁵ Participants in

our study suggested the use of question prompts to self-identify needs for a customisable resource. However, it is possible for caregivers to be unaware of their gaps in knowledge.³⁶ On the other hand, researcher-driven personalisation alone may reduce autonomous self-determination of health information needs and priorities.³⁷ Therefore, both methods will be used to optimise the tailoring of the *Care Assist* online resource. This will address: (a.) the dynamic and heterogeneous male caregiver population,³⁸ (b.) the range of caregiver roles and responsibilities, and (c.) the quantity and urgency of desired information.³⁹

5 | STUDY LIMITATIONS

The participants were largely females located in New South Wales, Australia and the extent to which they represented the views of health professionals more broadly is unknown. Therefore, future studies should incorporate a more diverse participant population. Further, the developed content was limited to the English language and not reviewed for its 'cultural appropriateness' to culturally and linguistically diverse and first nations groups. As culture and demographics are known to alter the efficacy of psychoeducation,⁴⁰ future work should cater for these populations. The resource is also highly gendered and heteronormative in nature and may not be, in its current form, generalisable to other cancer populations or non-heterosexual and non-monogamous relationships. Further research is needed to understand how to support all types of caregiver-care recipient relationships.

6 | CLINICAL IMPLICATIONS

The *Care Assist* resource is perceived by experts to be beneficial in supporting male caregivers of women with BC. However, integration of computer-based tailoring techniques will cater for the heterogeneous male caregiver population. This study also revealed the need for tailored, clinician-led resources to support male caregivers in managing wound care for their care-recipients.

7 | CONCLUSION

In this study, the *Care Assist* resource was developed and perceived to benefit male caregivers towards reducing educative burden, while improving understanding, coping, emotional support for the care-recipient, and dyadic congruence between the caregiver and care-recipient. Despite the perceived benefits, the heterogeneous nature of the male caregiver population requires self-identified customisation of information needs, and researcher-guided personalisation using e-health tools. The *Care Assist* resource ultimately addresses an important gap in support for male caregivers of women with BC.

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CONFLICT OF INTEREST

There is no conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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