Professionally-led metastatic breast cancer support groups: are they worthwhile, and if so, how and by whom should they be implemented?

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BACKGROUND

Support groups can improve psychosocial wellbeing for people with breast cancer. Yet the utility of groups for those with metastatic breast cancer (MBC) remains underexplored. There is also little understanding of the factors influencing their set-up and sustainment.

AIMS

Our aim was to: (1) investigate the value of stage-specific MBC groups; and (2) identify system- and organisational-level factors influencing implementation and sustainment in Australia.

METHODS

Semi-structured interviews with people with MBC, partners, group facilitators and key informants. Purposive sampling and communityrecruitment techniques. Data were analysed thematically. Findings were triangulated across datasets. Implementation determinants were identified using the Consolidated Framework for Implementation Research.

PARTICIPANTS (n=83)



People with MBC: n=28; age 34-75 years; median age = 56 years

Partners of people with MBC: n=16; age 40-81 years; median age = 57 years

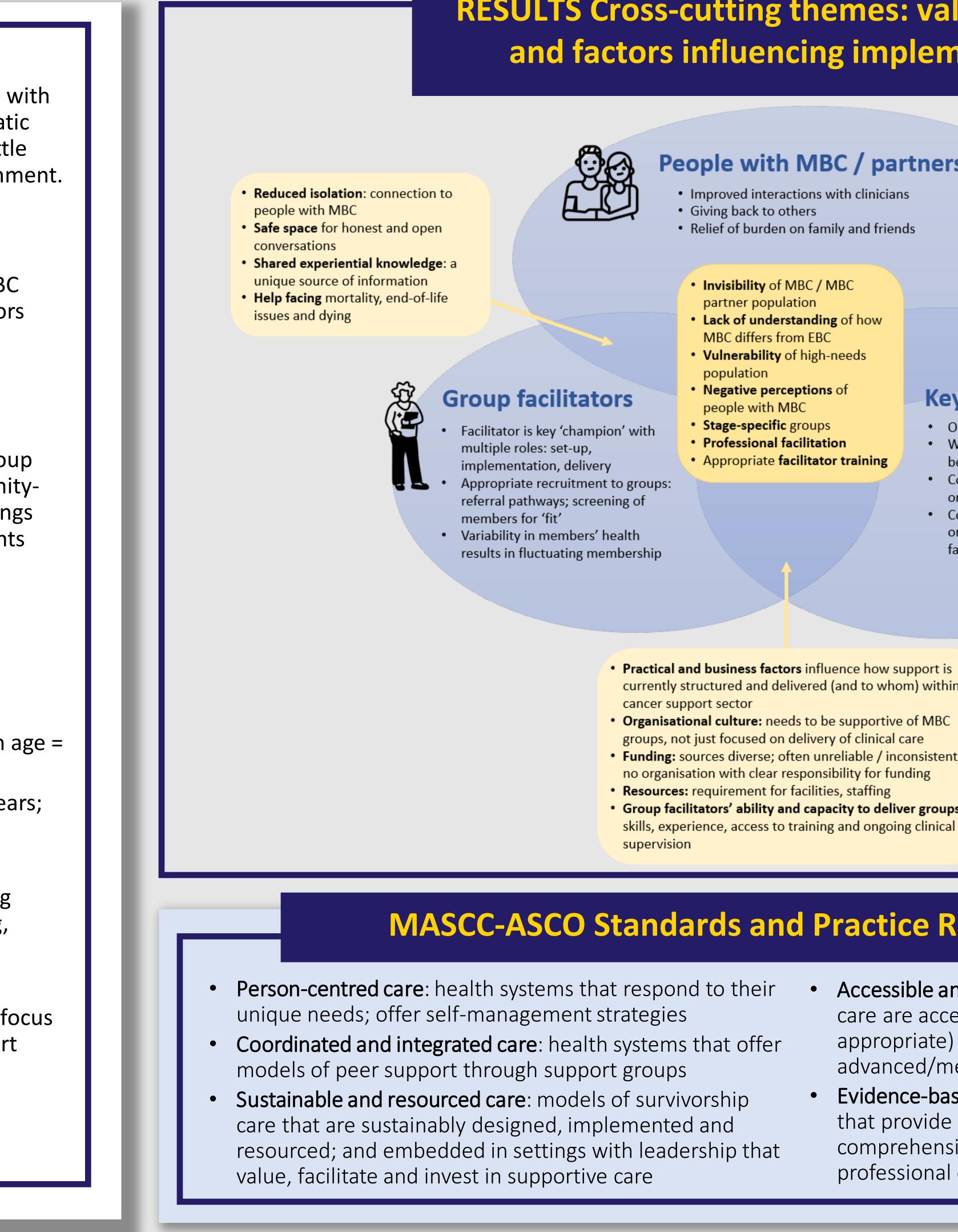


Support group facilitators: n=20; 45% had nursing background; 55% had backgrounds in counselling, social work or other



Key informants: n=19; from organisations with a focus on supportive care (79%), advocacy (68%), support group leader training (37%), research (32%), and delivery of MBC support groups (26%)

The D/ffodil Centre



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RESULTS Cross-cutting themes: value of groups and factors influencing implementation

People with MBC / partners

- Improved interactions with clinicians · Relief of burden on family and friends
- Invisibility of MBC / MBC Lack of understanding of how Vulnerability of high-needs
- Negative perceptions of Professional facilitation Appropriate facilitator training

Key informants

- Out of scope
- Which organisation should be responsible for groups?
- Cooperation across cancer organisations
- Concerns about risk: organisational, patient, facilitator

- Support groups not appropriate / of interest to everyone with MBC
- Support groups are one element of holistic care
- Alternatives: social media; family and friends; other community activities
- Less interest to those who are working, low disease burden/impact (i.e. 'well'), wanting to distance themselves from MBC diagnosis



 Practical and business factors influence how support is currently structured and delivered (and to whom) within

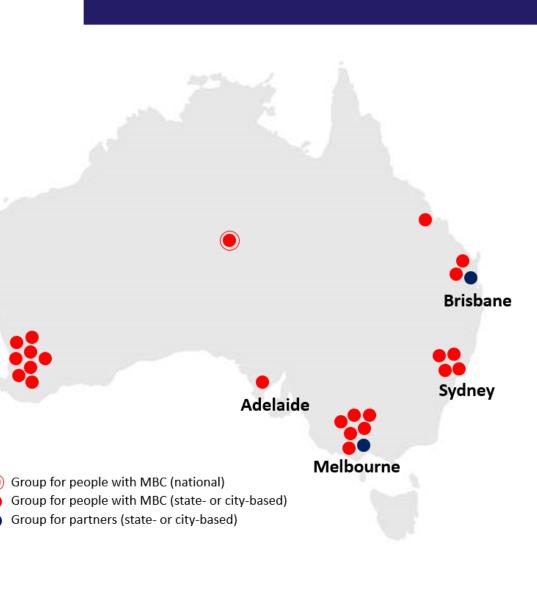
• Organisational culture: needs to be supportive of MBC groups, not just focused on delivery of clinical care • Funding: sources diverse; often unreliable / inconsistent; no organisation with clear responsibility for funding Group facilitators' ability and capacity to deliver groups:

MASCC-ASCO Standards and Practice Recommendations

ir	•	Accessible and equitable care: models of cancer survivorship
		care are accessible (i.e. affordable, acceptable, available,
er		appropriate) and equitable for all people affected by
		advanced/metastatic cancer.
	•	Evidence-based and comprehensive care: health systems
		that provide evidence-based best practice and

comprehensive supportive care programs; ongoing professional development of health care professionals

RESULTS Service mapping



15 organisations delivering

• 25 groups in total

Most organisations offer 1 group

- 1 group (n=12)
- 3 groups (n=2)
- 7 groups (n=1)

Type of organisation

- Community-based (n=6)
- Cancer centre/hospital-based (n=9)

RECOMMENDATIONS

- . Equity of access: Address gaps that exist in equitable access to appropriate services for people with MBC/partners, i.e. importance of inclusivity / proper resource distribution across cancer trajectory
- 2. Access to peer support: Establish systems that allow people with MBC/partners to connect to peers in a way that aligns with their goals and respects their personal agency
- **3. Market versus care logics:** Determine whose responsibility it is to deliver smaller, on-the-ground interventions given larger cancer NGOs are prioritising delivery of mass-reach interventions with easier-to-demonstrate impact over more resource intense service delivery options such as support groups
- **4.** Sustainability: Ensure models of MBC/partner support group are sustainably designed and implemented, including adequate resourcing (human resources, facilities, leadership)
- 5. Health professional training : Develop a specialised training program for health professionals who wish to run MBC groups
- 6. National Framework: Develop a national framework that informs the governance, standards, recommended delivery model and running of MBC/partner groups

A partnership between



