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Full Reference: Smith AL, Lewis S, Daly M, Dinner F, Franklin M, Hamilton M, Hirsch P, Hobbs K, Kirsten L, Lentern S, Li Z, Mackie G, Mazariego C, McAuley R, O'Brien M, O'Reilly A, Taylor N, Tobin L, Persson J, Boyle F. Professionally-led metastatic breast cancer support groups: are they worthwhile,

and if so, how and by whom should they be implemented?

Conference/Meeting Name: Multinational Association for Supportive Care in Cancer (MASCC)

Location: Lille, France Dates: 27-29 June 2024

Presentation Type: Oral poster



The Porte de Paris, just a few minutes' walk from the Lille Grand Palais where the MASCC conference was held 27-29 June, 2024, Lille, France

Multinational Association of Supportive Care in Cancer Conference, Lille, France

The annual MASCC (Multinational Association of Supportive Care in Cancer) conference specializes in supportive care in cancer. It is a leading event in the field of supportive cancer care. Supportive care includes managing the symptoms and side effects of cancer and its treatment, as well as addressing the psychosocial concerns of patients and their families. The year MASCC collaborated with the Association Francophone des Soins Oncologiques de Support (AFSOS) to host its 2024 conference.

The theme for the MASCC/AFSOS/ISOO 2024 Annual Meeting was "Empowering People Impacted by Cancer and Living with Toxicities". Key themes included:

- Home Care and Extending Supportive Care
- Management of Emerging Toxicities
- Innovative Implementation of Supportive Care in Cancer
- Quality Improvement in Supportive Care

The conference is the highlight of the cancer supportive care research and clinical communities as it brings together delegates from around the world. This year the conference was attended by more than 1400 delegates from 56 countries.

Key Invited Speakers included renowned medical oncologist Prof Hope Rugo, Professor of Medicine, Breast Cancer Director, UCSF Helen Diller Family Comprehensive Cancer Center, San Francisco. Prof Rugo spoke about the management of emerging toxicities, especially those associated with a new and exciting ('revolutionary' according to Prof Rugo) class of drug, the antibody-drug conjugates (ADCs). Prof Rugo referred to the ADCs as 'smart bombs'. The ADCs comprise an antibody joined to a chemotherapy drug. The antibody is designed to bind to a specific target on the cancer cell, often one that is overexpressed by the cancer cell. This way the chemotherapy can be more toxic than usual as it is delivered only to the cancer cells, unlike traditional chemotherapy that is delivered systemically and especially to fast-growing cells. Consequently, the side-effects are less. Effectiveness results have also been incredible in cancers such as metastatic breast cancer resulting in extended survival in many patients.



Conference highlight

The highlight of the conference for many was the half-day workshop on 'Exercise for patients with metastatic breast cancer (MBC): effects and patient perspectives – results of the PREFERABLE Project'. The workshop was chaired by the Project lead, Professor Anne May from The Netherlands and included presentations by key researchers and consumers involved in the project. Sessions included Dr Dorethea Clauss talking about the benefits of exercise on physical fitness in people with MBC, on biomarkers and on patient reported outcomes (PROMs), which were all significant. Critically, data were also presented on the cost-effectiveness of the study.

What I can bring back to Australia from the conference

Vicki Durston, Director of Information, Support and Advocacy at Breast Cancer Network Australia, who was also at the conference, and I are incredibly excited about PREFERABLE exercise in metastatic breast cancer study and the potential to implement this in Australia. I have worked closely with BCNA in the past and hope that the connections that we made at the conference will help to move this research into routine clinical care for people with metastatic breast cancer, and possibly one day for all metastatic cancers. Exercise has been shown to have powerful effects on quality of life, fitness and biomarkers. If exercise was a drug, all patients with metastatic breast cancer would be being prescribed it! As a metastatic cancer supportive care and translational researcher, I am always looking for new research that can be implemented in Australia to benefit people with cancer.

Personal highlight

I was fortunate enough to be invited to dinner by Richard Paxman, whose company Paxman Scalp Cooling developed the scalp cooling technology that is used to help patients receiving chemotherapy retain their hair. The story behind the company was incredible. The company originally produced cooling technology for beer, but when Richard's mum Sue was diagnosed with breast cancer and experienced considerable emotional trauma when she lost her hair, Richard and his father Glenn vowed to apply their technology to help cool the scalp during chemotherapy to reduce the amount of chemotherapy reaching the hair follicles. As someone who has personally benefited from using the Paxman technology, I was honoured to spend the evening with them and their incredible team.

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

Andrea L Smith, 1 Sophie Lewis, 2 Michele Daly, 3 Fiona Dinner, 4 Marika Franklin, 2 Melanie Hamilton, 2 Pia Hirsch, 5 Kim Hobbs, 6 Laura Kirsten, 7 Stephanie Lentern, 2 Zhicheng Li, 8 Grace Mackie, 2 Carolyn Mazariego, 8 Ros McAuley, 9 Mary O'Brien, Amanda O'Reilly, 10 Natalie Taylor, Lisa Tobin, 11 Jasmine Persson, Frances Boyle 2

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%)

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



- · Safe space for honest and open · Shared experiential knowledge: a
- unique source of information
- Help facing mortality, end-of-life issues and dying



Group facilitators

multiple roles: set-up,

members for 'fit'

implementation, delivery

· Variability in members' health

Facilitator is key 'champion' wit

· Appropriate recruitment to groups:

referral pathways; screening of

results in fluctuating membership

People with MBC / partners

- Improved interactions with clinicians
- Giving back to others
- · Relief of burden on family and friends
- Invisibility of MBC / MBC partner population
- Lack of understanding of how MBC differs from EBC
- Negative perceptions of
- people with MBC
- Stage-specific groups Professional facilitation
- Appropriate facilitator training

Which organisation should be responsible for groups? Cooperation across cancer

Out of scope

Key informants

 Concerns about risk: organisational, patient, facilitator

organisations

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

- 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
- Resources: requirement for facilities, staffing · Group facilitators' ability and capacity to deliver groups: skills, experience, access to training and ongoing clinical

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

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

MASCC-ASCO Standards and Practice Recommendations

- Person-centred care: health systems that respond to their unique needs; offer self-management strategies
- Coordinated and integrated care: health systems that offer models of peer support through support groups
- Sustainable and resourced care: models of survivorship care that are sustainably designed, implemented and resourced; and embedded in settings with leadership that value, facilitate and invest in supportive care
- Accessible and equitable care: models of cancer survivorship care are accessible (i.e. affordable, acceptable, available, 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



¹The Daffodil Centre, The University of Sydney, a joint venture with Cancer Council NSW; ²Faculty of Medicine and Health, The University of Sydney; ³consumer representative, Sydney; ⁴consumer representative, Melbourne; 5ABC Group, Brisbane; 6Westmead Centre for Gynaecological Cancers; 7Nepean Cancer Care Centre; 8School of Population Health, University of New South Wales; 9 breast cancer support group facilitator, Melbourne; 10 cancer support group facilitator, Sydney; 11 consumer representative, Breast Cancer Network Australia. Project funding: Prof Martin Tattersall ECR Award, University of Sydney. ALS received a 2024 Sydney Health Partners Travel Scholarship. Images: The Noun Project (Monkik; The Pyramid School); Flaticon (Baander).



