Study Group Notes

Study Group: Rehabilitation, Survivorship and Quality of Life
Chair: Dr Ray Chan, Australia
Vice-Chair: Dr Margaret Fitch, Canada

Meeting: Annual Meeting of Study Group
Vienna, Austria / Conference Centre
Date: Thursday, June 27, 2018 (1 hour)
Attendance: 52

Introduction of New Chair and Co-chair

Following the resignation of the former Chair of this group, Dr. Raymond Chan (Australia) and Dr Margaret Fitch (Canada) were appointed to the leadership roles of the study group. They have been meeting regularly over the past year and forming ideas for how to proceed with meaningful, productive work (see below).

Re-conceptualizing Name of Study Group

The issue has been raised that the name of this group is very broad and could be confusing. There is a need for a strategic consideration regarding the change in name.

Within the room, one-third indicated they were in attendance because of survivorship, one-third because of rehabilitation and one-third because of quality of life. When asked for feedback, participants made the following points:

- Survivorship is a ‘lovely’ term because it is so inclusive; it incorporates all the other terms and perhaps they could be dropped; wondered however if adding ‘wellness’ would be helpful
- At times rehabilitation is defined too narrowly; in its full conceptualization, it includes everything
- It is important address the full spectrum of survivorship and include all concepts
- Survivorship includes the full spectrum and all nuances
- Important to ensure that survivorship includes those with metastatic disease in the definition
- UK definition phrased as “living with and beyond cancer”; this incorporates all
- It is important to define all terms and be clear about each one; be certain to be inclusive
- Could the use of holistic help? Includes all things from diagnosis; rehab helps you get there; full complement needed
• Could the use of subgroups be helpful? A number of individuals thought this would be a helpful approach.

The question about the need to change the name will be circulated to all study group members; responses will be collated and a subsequent decision made about how to proceed from there based on the responses.

Awards from the Study Group

This past year the study group was able to acknowledge three individuals for their work as Trainees and Junior Investigators. The award criteria were modelled after those used by the Fatigue Study Group. The abstracts submitted to the conference in our topic areas were considered. These criteria will be circulated to the whole study group and any feedback is welcomed. We plan to continue to make these awards annually. The three awardees presented their work at the end of the business meeting. The awardees included:

Dr Jacqui Frowen (Junior Faculty Member)
  • Prevalence of patient-reported dysphagia and oral complications in cancer patients: An Australian study

Dr Micah D J Peters (Junior Faculty Member)
  • Cancer care experiences and unmet needs of lesbian, gay and bisexual people with cancer: A systematic review of qualitative evidence

Dr Xiaotao Zhang (Trainee)
  • Malnutrition and overall survival in older patients with cancer

Proposals for Work over 2018-2019

Proposals were presented for two pieces of work to be completed under the auspices of the study group over the next year:

1. Survey study: Implementation of Exercise Guidelines into Routine Clinical Care

2. Survey study: Patient-Reported Outcomes (PRO) Data Collection in Routine Care and Subsequent Actions in Benchmarking, Clinical Responses and Research/Education

We are looking for Expressions of Interest for involvement as Investigators (team for the study). The commitment would be as follows:

- Able and willing to actively participate in monthly – bimonthly teleconferences over the project period
- Provide intellectual input/feedback to the study in a timely manner (respond emails from the within 2 weeks)
- Act as local and regional champion to facilitation participation of the survey
- Contribute to writing up of the study report and manuscripts

We are also looking for expressions of interest for a Junior Researcher (post-doc) Mentoring Program (new concept). The mentoring opportunity for the junior research comes from the Chair/Vice-
Chair/Investigating team for the project. The individuals will receive a Certificate of Completion and $500 award as well as be an author on the subsequent publication. (Money to support this work was given to the study group by the MASCC Board.)

Criteria for Junior Investigator:

- Completed a PhD or equivalent

Role for Junior Investigator:

- Take a lead, coordination role for the research team
- Organise regular investigator meeting and application of ethics and other approvals as required
- Receive mentorship from the Chair/Vice-Chair/Investigating team
- Participate as a co-author on subsequent publications

The proposed timeline for the projects is 12 months as follows:

- EOI (2 months)
- Protocol development (2 months)
- Ethics application (2 months)
- Survey administration (2 month)
- Data analysis and writing up (4 months)

The call for expressions of interest will be circulated to the entire study group soon after the meeting. Expressions of Interest should be sent to the Chair of the study group (Raymond.Chan@qut.edu.au). They will subsequently be reviewed by both the Chair and the Vice-Chair. If there are concerns in final selection for the Junior Investigators, other individuals from the MASCC staff will be drawn into the process (e.g., Editor of SCC Journal, Study Group Co-ordinator, MASCC Co-ordinator). Subsequently, teams will be formed and the work of formalizing the scope of each project will proceed.

Discussion:

- It was suggested that the criteria for the Junior Investigator include Masters – many individuals in their own country have a Masters degree and are engaged in excellent work.
- These are large fields; will be important for the teams to scope out the work so that it is feasible and does not overlap unnecessarily. Also, the aims need to be achievable.

Environmental Scan of Members at Meeting

Dr. Chan asked the members to consider the following questions:

1. What is the international leadership role of the SG in the agenda of rehabilitation, survivorship and quality of life issues?
   - What are the key gaps?
   - What would be “timely” for us to address?
   - What are already covered by groups other than MASCC?
   - What collaborations do we need to maximise our impact?
   - What would be our next initiatives?

2. Key issues raised to date for the study group to consider:
   - PRO in routine care
   - Implementation of exercise guidelines
Discussing Financial Toxicity and its impacts

Discussion

- Important to build on what has been done already. For example, there are many guidelines for physical exercise – do we craft another one or endorse what is already in existence? We ought to consult with Fatigue Study Group as they faced the same issue. They ended up reviewing what was out there in terms of guidelines and developing a position paper (focused on what they could endorse). It is important that we ‘do not reinvent the wheel’
- Who is in this group? Are there patient advocates? The kind of issues that we discuss are of most importance to patients and caregivers.
- Integration across the cancer continuum...anabolic competence
- Care of Transgender individuals with cancer – almost no literature to support practice – this study group would be a good home for this topic

Invitation to make suggestions for study presentations next year

Dr. Chan invited individuals to suggest topics for the study group presentation at next year’s annual conference. The conference themes include survivorship, sexuality and technology in particular. Suggestions included financial toxicity, care of LGBT individuals, exercise prescriptions, late and long terms effects and their follow-up (how to do it well in the community and collaborate with other disease groups (CAD, Diabetes, Obesity, B/P, Hypercholesterol).)

Next steps

The notes for this meeting will be circulated together with the calls for expressions of interest for the two projects. The overall plan for the year will be as follows:

- Completion of the two survey studies
- Establishing an effective platform for ongoing communication between SG members
- Establishing collaboration with researchers interested in Financial Toxicity

Presentations by Awardees

The three awardee presentations were offered to close out the meeting.

Next Study Group Meeting

The next meeting of the study group will be held in San Francisco during the annual meeting of MASCC between June 21-23, 2019.