

**COSA Cancer Survivorship Conference 2021**

**Workshop: Cognition and Cancer Survivors 18/3/21**

**coordinated by A/Prof. Eng-Siew Koh and A/Prof. Haryana Dhillon**

**Summary of key themes and discussion points**

**Facilitator/s:**

**Eng-Siew Koh and Kim Kerin-Ayres**

- Not being afraid to ask about and broach the topic of cognition in cancer survivors, and cognitive changes, and the concerns of the client, their carers
- To ask about cognitive changes systematically and serially over time, and look for opportunities to explore cognitive changes in a sensitive way
- To maintain hope
- To validate the concerns of the client, their carers, their community about cognitive changes, as this is often an 'invisible' concern, and also requires an appreciation of the pre-morbid personality/functioning of the client before their cancer diagnosis and treatment
- To explore and screen for what other symptom clusters may be occurring, and other related issues that can be corrected / addressed (eg fatigue, anxiety)
- Develop a greater awareness about carer distress as it relates to the screening and management of cognitive changes

**Haryana Dhillon**

- There are complex issues that feed into CRCI
- Understanding the priorities and at what time-points is critical to ensure that clients and carers are linked into available resources
- Beyond the acute cancer care team, look for other eg community based options esp. Allied Health, identify goals and put these into place
- When recommending particular psychological interventions, it is important to identify who is trained to undertake cognitive rehab. (akin to FCR interventions)
- An excellent open-ended question for a client is "What is your superpower?" (ID their own strengths)

**Kerryn Pike and Lindsay Scudder**

- Discussion of when to refer to neuropsychology, issues with access and cost acknowledged
- Would be helpful to have a current list of neuropsychologists across Australia, and esp. those with an interest in this area
- Screening for CRCI should be embedded into standard screening processes, as for other cancer symptoms and issues
- Appreciating the challenges and sensitivities of dealing with a client and their family accounting for issues of insight or lack thereof
- Taking a whole 'systems' approach to the management of CRCI ie family management and the client's broader community

### **Janette Vardy**

- Again emphasized the need for inclusion of partners and families in managing CRCI, and their entire support community including workplace, social networks etc
- Focus on the emotional / practical aspects of coping and interventions
- Need to better address disclosure aspects ; discussed the emotional burden of trying to maintain a façade of coping

### **Priscilla Gates**

- Symptoms clusters (eg fatigue) often neglected as causative and/or contributing factors to CRCI – importance of addressing/investigating these
- Engagement of Social workers and other professionals in return to work plan/initiatives
- Exercise Physiologist suggestion of a “fatigue tracker” and a “think tank” used as a daily monitor
- Value of peer support especially from those who have experienced CRCI themselves

### **Amanda Hutchinson**

- ‘Normalisation’ of CRCI as an issue ie something that is talked and asked about similar to other physical symptoms such as nausea, and part of the symptom screen that is part of the routine, general screening process and covered during clinical encounters
- Note there may be a disconnect in that the client looks well but is not functioning well (family/social roles etc)
- We accept that at the current time there is no routine reliable screening measure for CRCI, and there needs to be more work/research done in this area to progress this
- With respect to practical interventions, suggest that activities be chosen reflecting the wishes and preferences of the client, and that they be an active participant in this process

### **Heather Green and Daniel Coro**

- Validation of the client/carer concerns
- Ensuring that interventions fit in with the client’s preferences
- An excellent open-ended question for a client is “Have you had a go in managing this yourself?”
- Keeping interventions quite simple eg making lists, re-doing familiar tasks undertaken before
- Utilising social work as a conduit for other services/linkage eg RTW services, employment rehab.
- Clinical psychology review for prioritisation – what is the next best steps for the client?
- Sharing list of collated resources, reinforce the use of these, and also advocating locally and more broadly for where the current gaps in care and knowledge are

### **Current research trials (Janette/Heather)**

- Evidence supporting use of Brain HQ (improving self-reported symptoms)
- Very little if any evidence supporting pharmacological / drug interventions for CRCI (with exception of specific clinical circumstances eg post whole brain radiation for brain metastases patients)
- Very few trials recruiting currently in Australia for clients with CRCI
- Possible for interested clients to be placed on a broad wait list

### **Summary of key points and recommendations**

- We should work to **increase awareness and validation of** cancer-related cognitive impairment / changes, which are often ‘invisible’ and overlooked compared to other symptoms
- Healthcare teams should be asking about and **addressing cognitive changes systematically and serially** over time, and actively look for opportunities to explore these cognitive changes in a sensitive way especially with regard to disclosure, client insight and carer dynamics
- **Screening for CRCI should be embedded into standard screening processes**, as for other cancer symptoms and issues
- Healthcare teams should be **exploring and screening for what other symptom clusters** may be occurring, and work to address these (eg fatigue, anxiety, fear of cancer recurrence)
- in a setting
- **CRCI should ideally be managed by taking a whole ‘systems’ approach** ie inclusion of family and the client’s broader community
- Broad agreement to
  - share list of **collated resources** and reinforce the use of these
  - seek to build a national listing of psychologists and neuropsychologists with interest and relevant skills
  - advocate locally and more broadly to address current gaps in care and knowledge,
- At the current time there is **no routine reliable screening measure for CRCI**, and there needs to be **more work/research done** in this area to progress this
- Both **acute and community-based healthcare teams** esp. Social Work and Clinical Psychologists can act as **central conduits for referral** to relevant Allied Health and other services in managing CRCI, acknowledging that screening and referral pathways are not well articulated to date
- Consideration should be given as to the **training and skillsets of healthcare teams** working in the field of CRCI
- **Practical interventions should ideally reflect the preferences of the client/carers**, who should be an active participant in this process
- **There is a lack of interventional trials in this space in Australia** – more focus needs be placed on improving outcomes for clients and communities affected by CRCI.