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Full Reference:

Invited Oral Presentation

Rebekah Laidsaar-Powell. *Recognising and supporting carers experiencing distress: The urgent need for tailored psychosocial support for cancer carers*

Poster Presentations

Rebekah Laidsaar-Powell, Sarah Giunta, Phyllis Butow, Sandra Turner, Dan Costa, Christobel Saunders, Bogda Koczwara, Judy Kay, Michael Jefford, Penelope Schofield, Frances Boyle, Patsy Yates, Kate White, Annie Miller, Ilona Juraskova. *Improving carer engagement in cancer care: Mixed methods evaluation of the eTRIO educational module among oncology health professionals*

Rebekah Laidsaar-Powell, Sarah Giunta, Iona Gurney, Claire Hudson, Lisa Beatty, Joanne Shaw *Co-design of an online Cognitive Behavioural Therapy (iCBT) intervention for cancer carers with anxiety or depression: Development of CarersCanADAPT*

Conference/Meeting Name: Psycho Oncology Co-Operative Group (PoCoG) ASM, Clinical Oncology Society Australia (COSA) ASM

Location: Melbourne, VIC, Australia

Dates: 31st October – 3rd November 2023

Presentation Type: Invited Oral Presentation, Poster Presentations



With the support of a Sydney Cancer Partners Conference Support Grant, I was able to attend two key oncology meetings of crucial relevance to my work.

The first conference I attended was the PoCoG ASM, which was a one day conference dedicated to psycho-oncology research and practice. The day was hugely valuable, with highlights including the first session which saw presenters from Community Organisations such as the Leukaemia Foundation, Ovarian Cancer Australia, and Sock It To Sarcoma present on the collaboration opportunities and synergies between research and community organisations. A personal highlight was giving an invited talk in a session on tailoring psychological support to people affected by cancer alongside two research mentors of mine, A/Prof Lisa Beatty and Prof Jill Newby. Both Lisa and Jill are leading academics in the field of online cognitive behavioural therapy interventions for people with anxiety and depression, which is the area of my Cancer Institute NSW Fellowship which I commenced this year. It was a pleasure to be able to network with academics who are so skilled and experienced in this exciting field. We had productive conversations about the tailoring of psychosocial interventions is warranted (vs general models of care). I was able to present on the urgent need for interventions to be tailored to the unique needs of family carers – as currently most interventions delivered to carers were originally designed for patients and have not been adequately adapted.

The second conference I attended was the COSA ASM. It was an exciting and well curated program with many supportive care, psychosocial, and health services sessions which I was able to attend. Some highlights were the plenary on Geriatric Oncology, and the insights from a geriatrician, medical oncologist, and nurse. I reflected after this session about the crucial role of the family carer in the geriatric oncology setting, which was highlighted by a question from a person in the audience who was the carer to an older family member.

The lunchtime poster viewing sessions were busy, and I was able to discuss my research with existing as well as many newly found colleagues and potential collaborators.

Over the course of the COSA conference there were sessions on designing and evaluating online interventions, which is a key research interest of mine. It was beneficial to hear about emerging methodologies and approaches which I am currently exploring in the context of my own upcoming RCT of an online intervention. There were some very insightful and practical takeaways in the session *Successes and challenges of embedding digital health programs for people living with cancer in diverse healthcare settings* chaired by Ursula Sansom-Daly and Christina Signorelli – particularly relating to project management, recruitment, and clinical implementation of online interventions. For example, there was very insightful discussion about best avenues to recruit people with cancer for online interventions across Facebook, GP clinics, pharmacy advertising which I will apply to my own recruitment strategies.

This was also one of the first national conferences I have been able to attend since the beginning of COVID, and it was wonderful to reconnect in person with many colleagues from across Australia. I was able to meet people that I have been virtually collaborating with for years, and it was special to be able to have conversations in person. I was able to attend breakfasts and dinners with colleagues, and I left the conference with strengthened collaborations and concrete plans for future research.

I am immensely grateful to Sydney Cancer Partners and the Cancer Institute NSW for their support of me attending these conferences.



Co-design of an online Cognitive Behavioural Therapy (iCBT) intervention for cancer carers with anxiety or depression: Development of CarersCanADAPT



Dr Rebekah Laid Saar-Powell, Sarah Giunta, Iona Gurney, Claire Hudson, A/Prof Lisa Beatty, A/Prof Joanne Shaw

Introduction

Family/Friend carers report high levels of anxiety, depression, and unmet emotional needs.

Key barriers to carer engagement in psychological support exist: time, availability, cost, prioritising the patient.

Many existing psychological interventions are not comprehensive or carer relevant.

Existing psychological interventions for cancer patients could be adapted to meet the needs of carers.

iCanADAPT is an established, effective self-directed internet delivered Cognitive Behavioural Therapy (iCBT) program for patients.

The aim of this study was to use co-design to adapt an established cancer patient iCBT program (iCanADAPT) to target the unique psychological needs of carers, for development of the CarersCanADAPT iCBT intervention.

Materials and methods

Design:

Semi-structured qualitative interviews with think-aloud cognitive walkthrough of the eight iCanADAPT iCBT lessons to provide input on carer-relevant content.

Carers invited for follow-up interview to provide feedback on proposed changes

Participants:

Psychologists and social workers working in oncology setting. Recruited via professional networks.

Cancer carers. Recruited via participation in previous psycho-oncology research.

Analysis:

Qualitative data analysed via interpretive description in NVivo12 software.

Results

What do psycho-oncology staff recommend for a carer-focused online therapy program?

N=17 Psycho-Oncology Staff Interviewed. Profession: 9 Psychologists; 8 Social Workers

Years working with carers: Average 10 years (Range 1-45+)

Lessons, activities, storylines should reflect the carer experience and carer-specific concerns

| Carer overload | Emotional isolation | Helplessness | Anticipatory grief | Guilt | "Forbidden" thoughts and feelings |
|--|---|---|--|---|--|
| <ul style="list-style-type: none"> - Many carers experience role overload and lack of time/energy - Many feel unable to prioritise their own wellbeing | <ul style="list-style-type: none"> - Lack of sustained social support and understanding from others - May not share emotions to protect patient | <ul style="list-style-type: none"> - Lack of control over their own situation - Inability to plan - High levels of uncertainty | <ul style="list-style-type: none"> - Feelings of loss of a planned future for some - Experiencing future grief / bereavement | <ul style="list-style-type: none"> - Feel guilty for finding caring difficult - May feel like they can't 'complain' - Can feel guilt for being 'healthy' one | <ul style="list-style-type: none"> - Some secretly wish they weren't a carer - Many express wanting the experience to be over - Linked to guilt |

"I cannot tell you how many times I have had loved ones confess that they would like it to be over and they feel dreadful for saying that ...but what they're really expressing is that they're all out of capacity." Psychologist

Important foundational work in addressing carer concerns and barriers to use

| | | |
|------------------------|---|--|
| Empathy and validation | Crucial importance of validating that being a carer is hard | <p>"Being a carer is stressful... but it's acknowledging that and saying "yes, being a carer is stressful, here is how you get support.""</p> <p>Social Worker</p> |
| Prioritising self-care | Importance of prioritising oneself, within practical boundaries of being a carer (limited time, many roles) | |
| Normalising concerns | Normalising carer concerns, letting them know other carers feel similarly | |
| Tone and language | Not minimising caregiving experience, framing therapy to overcome mental engagement barriers | |

"It's giving permission to say, this is really hard and it's okay to look at some strategies for keeping you well...It's about strengthening your capacity to provide ongoing care." Psychologist

Traditional CBT and Third-Wave CBT Approaches to address carer concerns

Many clinicians used Acceptance and Commitment Therapy (ACT) in the cancer setting, recognising that carers need techniques to unhook from difficult (but often valid) thoughts and emotions

Many advocated using a combination of traditional CBT (e.g. cognitive restructuring) and ACT techniques for carer distress

"Carers need separate strategies for what to do with thoughts that are unrealistic, and thoughts that hurt because they're true." Psychologist



"I like the idea of being able to work through it at your own pace and do it online . . . Not everybody feels comfortable fronting up to a psychologist"

Carer

What do carers want in a carer-focused online therapy program?

N=15 Cancer Carers. Relationship to patient: 12 spouses; 2 Adult Children; 1 Parent.

Cancer Stage of patient: 2 Early Stage; 9 Advanced Stage; 4 Not sure.

Carer preferences and attitudes

- Reflective of carer specific experience: roles and responsibilities, carer worries, relationship issues, depressive thoughts and burden, coping strategies.
- Importance of having relatable storylines and characters
- Appreciated diversity – ethnicity, gender, body types
- Characters, design, content and usability of intervention must be considered to engage users
- Overcome carer-relevant barriers e.g. ensure low burden of "homework", online format
- Preference for accountability / motivation from social worker or psychologist
- A sub-set of carers (n=8) completed a follow-up interview: reported high acceptability of the carer-relevant content, storylines, and characters.

Conclusions

- Development of programs that target carer-specific needs and distress are urgently needed.
- Co-design methodology enables the needs and perspectives of key stakeholders to be reflected.
- An effectiveness-implementation RCT will be conducted to examine efficacy of the CarersCanADAPT iCBT program for carers with mild-moderate anxiety or depression.

Acknowledgments

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Improving carer engagement in cancer care: Mixed methods evaluation of the eTRIO educational module among oncology health professionals



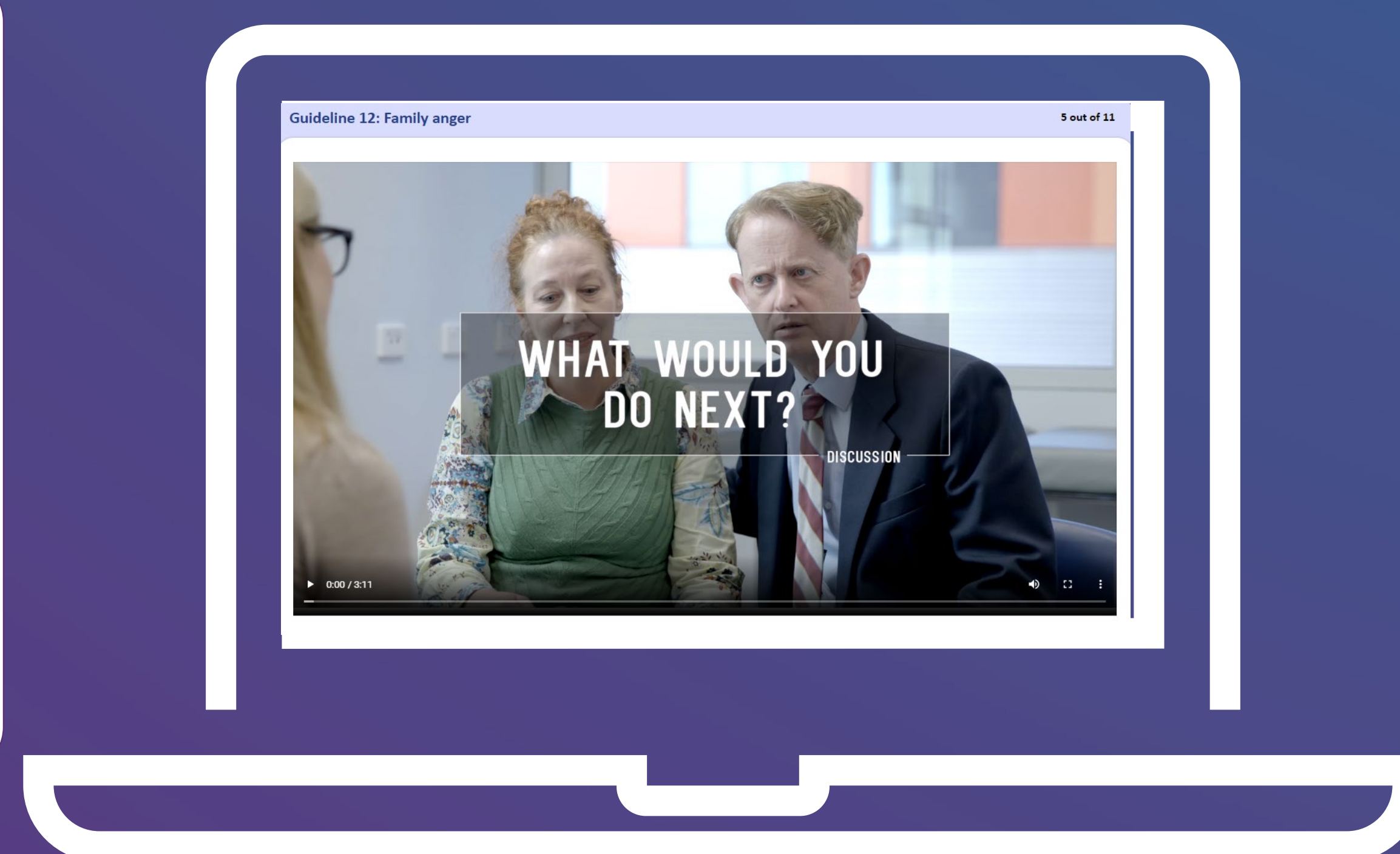
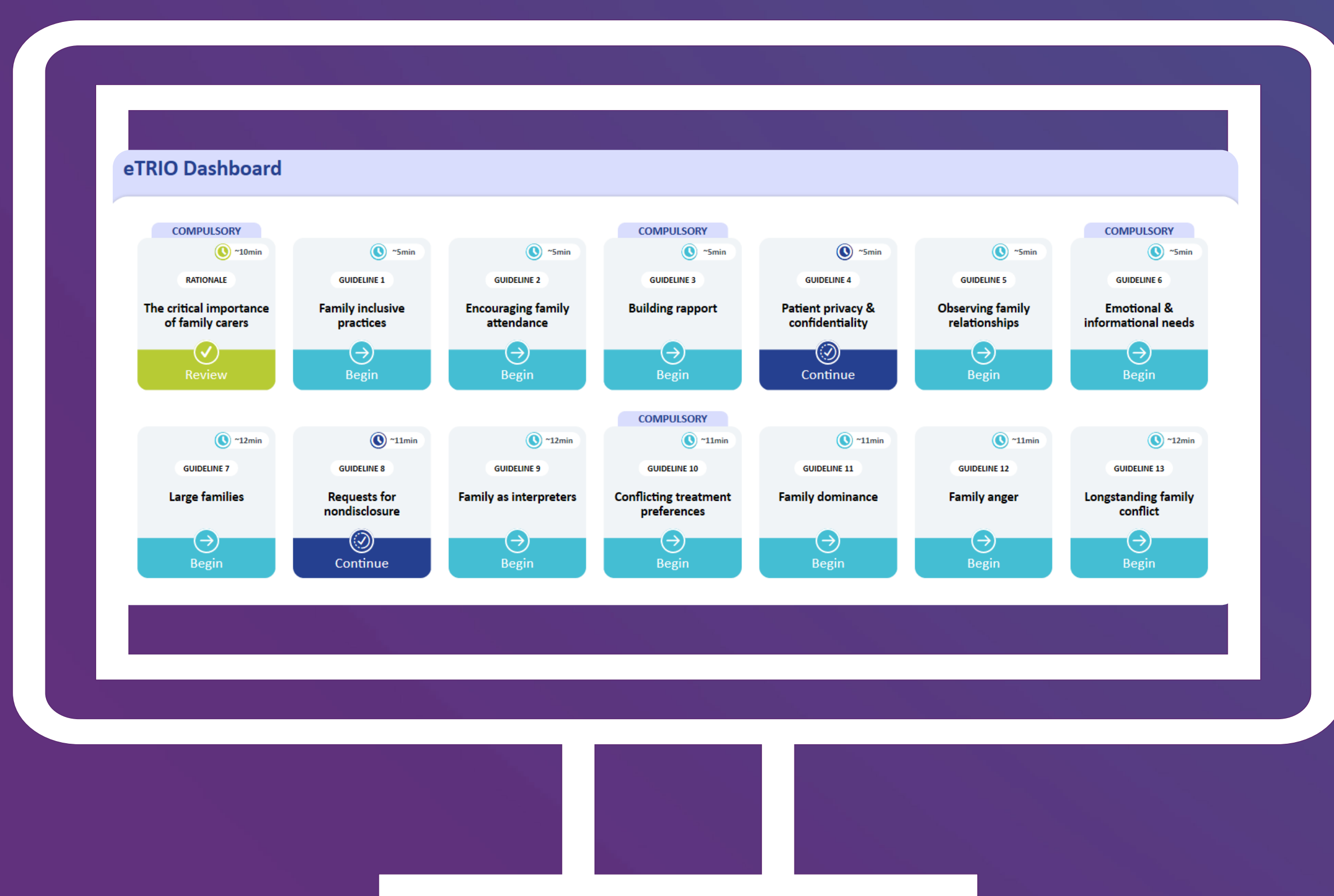
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BACKGROUND:

- Family / friend carers are often heavily involved in cancer care
- Many carers feel unprepared for the caregiving role or overlooked by health professionals (HPs)
- HPs report barriers to effectively engaging with carers and receive little training on carer communication
- Our group co-designed an online module (eTRIO) for oncology HPs to improve effective carer involvement in cancer care.
- **AIM:** To assess the usefulness, effectiveness and implementation potential of the eTRIO education program in improving oncology HP confidence communicating with carers, attitudes towards carers, and knowledge of strategies.

METHODS:

- Design**
 - Pre/post intervention study with 12 week follow up
- Participants**
 - Oncology health professionals (oncologists, nurses, allied health oncology workers e.g. social workers / OTs)
- Measures**
 - Administered at baseline, 1 and 12 weeks post-intervention
 - Assessed self-efficacy in carer communication (13 items), applied knowledge (7 items), and preferences for carer involvement in decision-making (1 item).
 - Post-intervention qualitative interviews (subset)
- Analysis**
 - Quantitative data: analysed with linear mixed models, in R
 - Qualitative data: analysed and interpreted according to Proctor et al.'s (2011) implementation outcomes



"I've used [eTRIO] a lot. I mean, every day... and it's helped me just to think about what I'm saying ...and acknowledging the importance of the carer and the role they play.- (HP12, Clinical Nurse Consultant)

RESULTS

Oncology HP Demographics

- Post-intervention n=46; 12 week follow-up n=41
- HPs included: 16 nurses, 12 social workers, 4 doctors, 4 psychologists, 10 other allied health
- Gender: 90% female, 10% male
- Years in oncology: mean 11.5 (range 0-35) years

Effectiveness Analysis

- Health professionals showed a **statistically significant increase in self-efficacy in communicating with carers post-intervention** (CI [12.99, 20.47]),
- Significant increase in self-efficacy was **maintained at 12 week follow-up** (CI [8.00, 15.72]).
- There was no significant change in knowledge or attitudes at any time points.

User Analytics

- Average time spent on the module was 66 minutes
- Participants logged in an average of 6.8 times (range 1-16 logins).
- Deep engagement with content involved downloading summaries (n=35), watching videos vignettes (n=30), and engaging in interactive activities such as sorting cards or popping content bubbles (n=21)
- Few participants used the bookmark (n=2) or print page (n=1) features

Implementation Analysis (n=15)

- Implementation analysis guided by Proctor et al.'s (2011) outcomes

Feasibility: Finding time to complete the module was difficult despite "short" sections and the time commitment being "fine".

Acceptability: "I think [eTRIO] was quite comprehensive across all the sort of scenarios that we actually face day to day." (HP9)

Appropriateness: Clinical scenarios were "relatable", "realistic" and "quite common".

Adoption: Some HPs said they had "already used some of the [eTRIO] strategies" successfully at work.

CONCLUSIONS

- eTRIO provided HPs with confidence to effectively include and support carers, and to manage complex situations such as family conflict.
- These gains are noteworthy, as conflict with families/carers is a contributor to HP burnout and anxiety.
- Qualitative implementation analysis deemed the module feasible, acceptable, appropriate and able to be adopted into clinical practice.
- eTRIO is brief, relevant and easy to disseminate, making it a suitable professional development tool for improving carer engagement.



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