Pathways to Wellness: Colorectal Cancer Shared Care Project

Executive summary

Colorectal cancer (CRC) is the third most common new cancer in Victoria. With five year survival rising to 67% in 2009-2013 (Cancer Council Victoria 2015), increasing numbers are placing pressure on acute hospital follow-up models. Shared care (SC) could provide a mechanism to deliver supportive care and surveillance follow-up post-treatment. CRC SC has been implemented in Australia and other jurisdictions. Randomised controlled trials comparing oncologist and primary care follow-up of breast cancer, colon cancer and melanoma survivors identified no important differences in outcomes and reported that SC is safe, feasible and acceptable (McCabe et al. 2013).

The Department of Health and Human Services and North Eastern Melbourne Integrated Cancer Service (ICS) funded a pilot of CRC SC at Monash Health (MH) and Eastern Health (EH). These health services are the largest public providers of CRC treatment in their respective regions. Collectively, 49% of Victorian CRC patients live in the Southern and North Eastern Melbourne ICS regions. Southern Melbourne ICS and Eastern and Southern Melbourne Primary Health Networks partnered to deliver the project. The University of Melbourne analysed (survivor) participant data.

The project aimed to design, implement and evaluate guideline-directed, recovery-focused, SC follow-up for risk stratified CRC survivors, in partnership with consumers and primary care. Co-design approaches were employed to design and agree a SC plan, risk stratified pathways and processes. A care coordinator was employed. Survivors treated with curative intent surgery and chemotherapy for stage I-III colorectal cancer were eligible for SC. Survivors of low rectal cancer were usually excluded. Survivors received an intervention comprising two components:
- interdisciplinary supportive care assessment, risk assessment and referral
- hospital coordinated SC and a SC plan.

We evaluated experiences of routine care and SC at baseline and post-intervention.
Evaluation included:
- routine care surveys and audits
- baseline and six month post-intervention EORTC C30 and CR 29 quality of life questionnaires
- six month interviews
- baseline and 12 month post-intervention Picker Care Coordination and satisfaction surveys
- baseline and 12 months post-intervention GP and Specialist surveys

In total, 122 CRC survivors were offered SC (87 MH, 35 EH). Of these, 114 (93.4%) accessed SC and 100 (81.9%) consented to the study. At EH 25 consented to the SC study and at MH 75 accessed the study. A competing ctDNA clinical trial impacted recruitment at EH. All Colorectal Service specialists consented to participate. Just two GPs opted out. Overall CRC SC was highly acceptable and easy to ‘sell’ to participants.

At baseline, 51% of participants were aged 70 or over and 54% were male. Just 16% lived outside of metropolitan Melbourne and none identified as Aboriginal or Torres Strait Islander. They hailed from 29 different countries and approximately 1 in 5 spoke a language other than English. The MH catchment was more ethnically diverse. MH and EH study participants had an average of 3.4 and 2.28 comorbidities respectively. Hypertension, diabetes, COPD and AF were amongst the most prevalent comorbidities recorded.
Most (83/100) had colon cancer; 17/100 had rectal or recto-sigmoid cancer. Approximately 4 in 5 (79/100) participants had stage II or III cancer. All participants were treated with surgery, 39 received chemotherapy and 3 participants received neo-adjuvant chemo-radiotherapy. All EH SC was provided in the public health system. Many, 30/75 (40%) MH study participants received SC incorporating private surgical practices.

Almost all, (98/100) participants completed EORTC baseline questionnaires. Participants with stage I cancer who were recruited early after treatment completion had lower physical and role functioning scores compared with stage III participants. The most common symptom reported was fatigue for all stages of cancer. Participants with stage III cancer reported higher fatigue scores and were more worried about their weight. Participants reported minimal difficulties with all other single symptom items irrespective of stage of disease. Males had more problems with sexual functioning than females. Similarly six month post-intervention data reflected minimal difficulties across most symptom items. At six month qualitative interviews, 11/28 (39.3%) found completing the EORTC questionnaires useful and 15/28 (53.6%) indicated that it was not important to discuss problems post-treatment. A shorter needs assessment/screen may be better received by CALD and disadvantaged participants.

Information needs were higher than referral needs; 377 information resources were provided to the 100 participants. Top topics were: diet, exercise, managing fatigue, pelvic floor exercise, managing bowel continence and managing fear of cancer recurrence. In total, 39/98 (39.8%) participants accepted referral/s; 70 referrals were made. Many referrals aimed to address lifestyle-related risk of recurrence rather than supportive care problems. Top services referred to were: Dietetics, Wellness and life after cancer program, Exercise Physiology, Physiotherapy and Continence Services.

The Wellness and life after cancer program was tailored to CRC survivorship needs in consultation with Cancer Council Victoria. Eight workshops were delivered at community health services across south-eastern Melbourne. While positively evaluated, recruitment to the tumour-specific workshops was challenging and not always targeted to those most in need. Both health services have sustained access to generic cancer wellness workshops. It may be prudent to build capacity and referrals for the generic program before implementing tumour-specific survivorship programs.

For most, SC delivered tests in line with surveillance guidelines. A sample audit of 80 CEA blood tests found a mean of 98 and median 92 days between tests (target 90-93 days). Compliance with annual CT scans was strong (mean: 364 days, median 362 days). Colonoscopy was often delayed at one health service due to waiting lists. Despite overall strong compliance with follow-up, some participants delayed attending tests, required repeated reminders or failed to attend appointments. Some disadvantaged and CALD populations require additional support to adhere to follow-up. There was one incident of a GP not flagging an elevated CEA result that was quickly detected by the SC coordinator who tracked all results. There were no other safety concerns. Mechanisms for rapid re-entry to hospital clinics worked well; SC coordinator support was required until (recurrence) treatment planning commenced.

Participants valued care coordination and a single point of contact at the health services. Care coordination assisted participants at risk of becoming lost to follow-up and prevented at least 42
unnecessary or duplicate appointments at MH. Care coordination was less effective for private clinics if they did not copy the care coordinator into correspondence.

Evaluation findings indicate that the SC plan and/or its delivery method could be further improved. Three in four interview participants used the follow-up plan effectively but (16/28, 57.1%) were not aware that the plan included a diagnostic and treatment summary and 7/28 (25%) were not sure that they found the plan easy to follow. Memory difficulties, anxiety and CALD status impacted some participant’s use of the plan. Lack of clinic space necessitated telephone and postal delivery of most plans. Providing face-to-face plan delivery is highly recommended with disadvantaged cohorts.

At six month interviews, 25/27 (92.6%) participants reported confidence or high confidence in GP CRC follow-up. At 12 months post-intervention, 37/43 (86.1%) were very confident, confident or somewhat confident with GP CRC follow-up. Having a long-term relationship with a GP, good rapport, trust in the GP and speaking the same language supported high confidence in GP SC. Reduced confidence in GP follow-up was related to perceptions that the GP was not part of the cancer team, lacked specialist knowledge or was unhelpful.

At 12 months, benefits of GP follow-up were themed as: reassurance, familiarity, confidence, less travel and waiting times, accessibility, detailed discussion about other health issues/ cancer treatment effects, and the crucial role for GPs in overall care and referrals. At 12 months, 41/42 (97.6%) reported combining cancer and other condition follow-up in a single GP visit. At six month interviews, 21/26 (80.8%) participants were likely or very likely to recommend SC to others. Almost all, 92.3% preferred GP involvement in CRC follow-up care; 65.4% for SC and 26.9% for GP only follow-up.

GP evaluation was impacted by low survey response rates; 24 /47 (51.1%) of GPs eligible for 12 month surveys provided feedback. GPs rarely wrote to specialists following CRC reviews but 23/24 (95.8%) reported receiving correspondence always/most times following specialist reviews. Satisfaction with the SC plan and care coordination provided was high and 22/24 reported that it is sustainable for them to continue to participate in SC. Given limited survey responses, it would be useful to verify these findings with other local CRC SC projects.

At final surveys, specialists and GPs supported SC for stage I-III CRC survivors. Specialists’ surveillance preferences varied for frail, elderly patients and those with low rectal cancer. Including higher risk cohorts in SC entails some variance to pathways. Pathway variance impacted the ability to use systematic approaches. Access to electronic SC plans that could be easily updated and shared across hospitals and primary care would greatly aid implementation.

Business cases estimate that 1,189 and 1,020 appointments will be shifted to general practice after 5.5 years of SC implementation at MH and EH (based on 2013 ASCO Guidelines preferred by surgical services). MH is sustaining CRC SC beyond the pilot project. EH could not allocate ongoing funding. CRC SC could benefit from a state-wide implementation approach once current guideline reviews are finalised and My Health Record pathology sharing functions are fully operational. Risk management frameworks will need to consider the impact of changing guidelines on SC business cases and resource requirements.
Key messages

Shared care model

- Colorectal cancer (CRC) shared care (SC) is a feasible and safe model of follow-up care that is acceptable to cancer survivors, specialists and GPs.
- The majority of six month interview participants (70.8%) indicated that they would choose SC/GP follow-up over hospital-based follow-up.
- Reduced waiting time, travel and benefits associated with involving their GP in after care were the most cited reasons for preferring SC.
- SC can halve specialist clinic attendances following treatment with curative intent for CRC.
- Early data suggests that it is sustainable for GPs to participate in CRC SC.
- Most, 41/43 (95.3%) twelve month survey respondents combined CRC and other health condition follow-up in a single GP appointment.
- Specialists and GPs support SC for patients with stage I-III CRC; specialists often delay commencement for survivors with low rectal cancer/chemotherapy-related toxicities.
- Variance to pathways made it difficult to utilise GP practice reminder systems.
- Implementing SC with disadvantaged communities requires more care coordination.
- SC can be effectively implemented with private surgical practices, public health services and GPs, if private specialists copy the care coordinator into correspondence.

Shared care plan

- Three in four interview participants used their SC plan effectively.
- Participants were more likely to value the follow-up plan than the diagnostic/treatment summary; 15/28 (53.6%) interview respondents could not recall the diagnostic and treatment summary.
- Some participants could not remember receiving the SC plan that was mailed along with supportive care information. Some participants did not self-manage or use their care plan. Face-to-face plan delivery is recommended with CALD and disadvantaged populations.
- GP respondents supported the information provided in the SC plan.

Supportive care

- Most participants highly valued access to a single point of contact to coordinate care.
- The majority of participants reported no/a little difficulty across most domains on baseline EORTC quality of life questionnaires; many did not value completing questionnaires. Administering a short screen/needs assessment earlier and risk stratifying access to supportive care could increase impact.
- In total, 70 referrals were made to services including: Continence Physiotherapy, Dietetics, Community Rehabilitation Services, Exercise Physiologists, and Cancer Non-Government Organisation support services.
- A minority of participants experienced multiple high impact supportive care problems and required more intensive support.