Advance Care Planning




Advance Care Planning in COVID-19

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Summary

- History of pall care response to COVID-19
- Remembering the uncertainty
- ACP for existing patients
- ACP for new patients
- ACP for COVID-19 patients
- Decision-making when overwhelmed
- Ethics – principle and practice
- Triage in the context of COVID-19

History of Australian pall care COVID-19 response

Jan-Feb-March 2020

- Recognition of looming pandemic
- Palliative care response – ACPCWG created under PCA
- Challenges to communicate to government
  - Maintaining core business – continuity for old and induction of new patients
  - Adapting practice to infection control and PPE – ours is a high contact activity
  - Pall care for patients with COVID-19 – designing clinical palliative care for a new disease
  - Concurrent curative/palliative care – preparing for poor outcomes (US and UK)
  - Recognition of ACP as vitally important and issues of triage

Dealing with Uncertainty

- New disease
  - Unknown pathophysiology with unknown Morbidity and Mortality
  - Risk factors and risk groups
  - Treatment unknown
- Unknown epidemiology
  - Transmission and degree of contagion
  - Control measures uncertain – could and when might a vaccine be developed?
- Unknown prognosis for infected people
  - Duration of illness and long-term sequelae – long COVID
- How to prepare?
  - Preparing the community – engagement, prevention and response
  - Preparing individuals – ensuring preferences are considered and communicated, and possibly for the necessity of triage
- Australia did a great job

ACP for those with known diseases

- Why is this important in a pandemic?
  - To be sure that people do not get treatment that they don't want
  - Particularly for those with known pathology
- Engagement in discussion with patient or their SDM
  - Very broad public awareness of the issues of the pandemic
- Ensuring documents up to date to reflect wishes, and family aware, particularly for RACFs
- Distribution to places of care – RACF, GP, Hospital
- Education of clinicians about importance of knowing and respecting patient preferences
- Best done before local outbreak, before quarantine and PPE

ACP for new and prospective patients

- For well people and those with a new diagnosis other than COVID-19
- Have they already engaged in ACP?
- Where are the documents?
- Discussions in the context of likely impact of COVID-19
- Engage with family, documentation and distribution
- Challenges of reduced and delayed treatments for other conditions
    - Now seeing more advanced disease at presentation

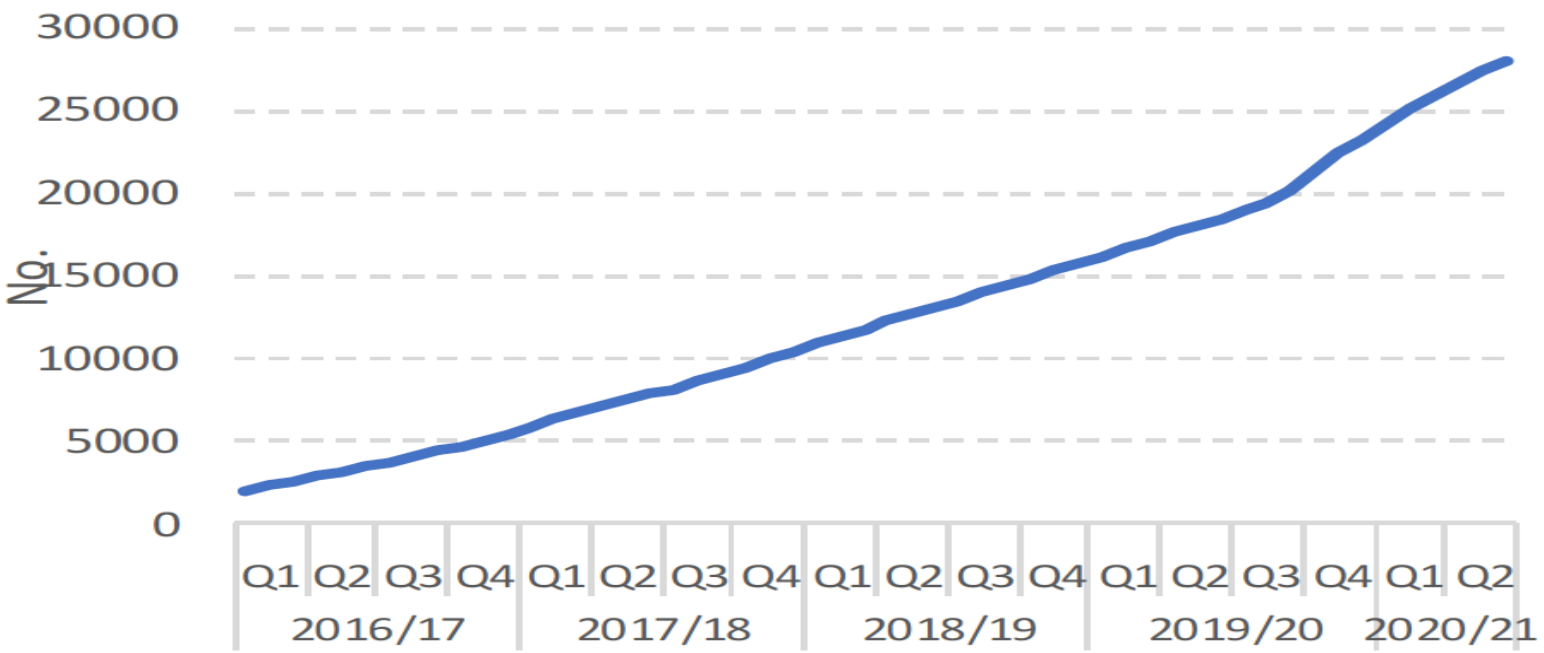
ACP for COVID-19 patients

- ACP discussions at the time of diagnosis
  - For most fit young people, the goal is cure
  - For older, sicker and frailer people, sensitive and candid ACP may find other goals given growing understanding of C-19 – ceiling of treatment
  - However, even those >90+ have a greater than 50% chance of survival
- Much harder to engage in ACP once a person is very sick
  - PPE and delirium
- Concurrent curative and palliative care
  - Preparing for a high likelihood of death while significant chance of survival
  - Providing emotional support is hard from behind a mask
- Carer/healthworker compassion fatigue

ACP for COVID-19 in Australia

- Qld – surge of interest in March last year – OACP

Figure 1: Cumulative number of SoCs received, Queensland, to Dec 2020



ACP for COVID-19 in Australia

- ACP Australia
  - Surge in inquiries in March/April but plateaued since
- Remote areas of Qld
  - Good discussions were held in some indigenous communities where significant fears were held for major outbreaks of C-19
  - Not everyone found it easy, but the door was opened and some were able to step through
  - Groundwork for future engagement
- Has not been an easy time for large numbers of the elderly
  - loneliness and despair
- Through leadership, community engagement and a sense of civic duty, Qld has got off lightly

Decision making in a pandemic crisis

- When the supply of treatment cannot meet the demand
  - Don’t treat people who don’t want it – ACP
  - Don’t treat people who are not going to benefit
    - ACP and clinical judgement – ARP
- Those on the boundary – when ACP is not enough
  - Experiences elsewhere
    - Ceiling of treatment – can be agreed through ACP
    - Rigorous decision-making – clinical exclusion
    - Profiling – risk profiling, not individual care
    - Blanket NFR, or not for transfer to hospitals

Ethics – principle and practice

- Core principles
  - Autonomy/Justice/Beneficence/Non-maleficence
- In disasters, shift from interest of individual to interests of the community of individuals
- However
  - How do you distribute care that comes in quanta when there are more people than treatments?
  - How do you deny people the right to have treatment from which they would benefit when you cannot provide it?
  - How do you avoid harm to those who are denied treatment?
- These issues are not resolved by ACP
- Triage may become necessary

Triage in COVID-19

- Triage imposes decisions on patients to deny treatments that may have been beneficial – real issue of C-19 elsewhere
- Requires non-discriminatory discrimination between people who might benefit, but on what grounds?
  - Greatest benefit for the greatest number? calculation
  - Greatest benefit for the community? Essential workers? Reward for taking risks? Frontline workers – nurses etc.?
  - Greatest opportunity for future life? Favors young over old
  - Quantity of resources to be consumed? Lottery?
  - What do you think?
- Designing protocols for triage requires governments to engage in open and early consultation, and to take responsibility for need for triage

Summary – ACP entangled with resource allocation

- ACP is vital in a pandemic (interests of individual and community):
  - To ensure that time, energy and resources are not consumed on people who do not want them
  - To ensure that time, energy and resources are not consumed on people who will not benefit and may suffer harm
  - To ensure that people who do not want or would not benefit from life prolonging treatment continue to receive appropriate supportive and palliative care
- During a pandemic, when resources are stretched and PPE and quarantine become necessary, all services including palliative care, particularly psychosocial support, may be very difficult to deliver as normal
- ACP is best done early and before it become more difficult
- May be necessary for clinicians to be more direct