Health
South Eastern Sydney
Local Health District

UNSW
THE UNIVERSITY OF NEW SOUTH WALES

Advance Care Planning for patients with advanced illnesses attending hospital outpatient clinics study

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NSW GOVERNMENT Health

UNSW SYDNEY

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South Eastern Sydney Local Health District in partnership with Sydney Local Health District

NSW Ambulance

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Advance Care Planning

- Advance Care Planning (ACP) is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves.
- ACP could significantly improve the quality of care provided to patients with advanced illnesses. ACP allows patients to have a voice, to receive patient-centred care, in the setting of their choice, and avoid unwanted hospitalisations and inappropriate treatments.

Evidence for benefits of ACP

The literature shows that ACP can:

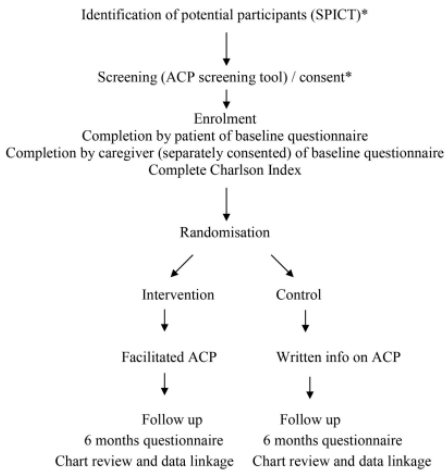
- Increase the chance of patient's wishes being known and followed (Detering et al, 2010)
- Improve emotional outcomes for the patient (Detering et al, 2010)
- Decrease caregiver burden and increase caregiver satisfaction (Detering et al, 2010)
- Reduce ambulance use and hospital admissions (Caplan et al, 2006; Molloy, 2000)
- Reduced patient mortality (Caplan et al, 2006)

Study aims

- Trial and evaluate a model of ACP, for patients attending NSW hospital clinics with advanced illnesses, that seeks to;
  - **increase the uptake of Advance Care Planning (ACP)** by patients
  - encourage NSW Healthcare professionals to **incorporate ACP into routine care**
- Determine if this model of ACP would;
  - **reduce acute health resources** utilisation
  - **improve the quality of care** provided to patients and caregivers
  - and result in an **improved understanding of ACP** by health professionals.

Study Design

- Pragmatic Randomised Controlled Trial (RCT) of patients and their carers across 5 sites in 2 LHDs.
  - POWH, STGH, TSH & WMH (SESLHD)
  - CRGH (SLHD)
- Intervention patients received facilitated ACP support from clinicians trained in ACP conversations.
- Controls received information package on Enduring Guardianship and Advance Care Directives.



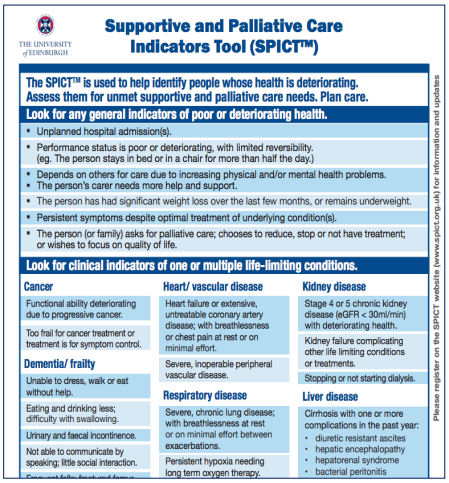
Protocol paper:
Rhee J, Meller A, et al Advance care planning for patients with advanced illnesses attending hospital outpatient clinics study: a study protocol for a randomised controlled trial. *BMJ Open 2019;9*:e023107. doi: 10.1136/bmjopen-2018-023107

Evaluation Measures

- Primary outcome:
  - Unplanned hospital admissions at 6 months
- Secondary outcomes:
  - Acute Health service utilisation
  - Ambulance calls
  - ED presentations
  - Hospital admissions
- Patient and caregiver outcomes:
  - Health-related quality of life (HRQOL)
  - Patient's experience of care
  - Primary Caregiver Burden
- Health professional outcomes:
  - Attitudes and knowledge of ACP
- Health care costs
- Evaluation the NSW Health ACD information book and template

Recruitment and training of HPs

- Health professionals from hospital sites were invited to participate in ACP training
- 118 clinical staff attended training
- Training included
  - ACP conversations
  - How to identify patients using SPICT (http://www.spict.org.uk/)

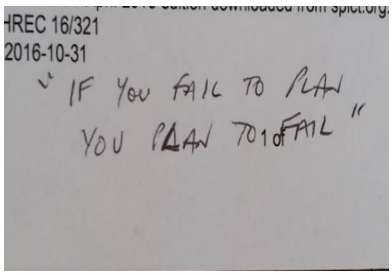


Educational Workshops

1. The workshop program developed and facilitated by Research Team
2. A site specific Geriatrician gave talk on patient capacity
3. CPD points were offered for staff attending workshops with catering supplied

Initial Screening of Participants

- **57%** of patients attending participating outpatient services were identified as eligible (using SPICT) for ACP conversations
- **49%** of the patients approached were interested in having an ACP conversation



Comment from conversation between consultant and patient

Initial Screening

When approached to participate in the project:

- Over one third (36%) of patients had spoken to their family or friends about their end-of-life wishes
- Only 13% had spoken to their doctor about their end-of-life wishes
- The majority (98%) had not written down their end-of-life values and wishes
- Only 20% had heard of ACP before
- 80% were comfortable with the initial conversation on ACP

Intervention is complete

- Clinicians, patients and carers recruited
- Intervention May – Nov 2017
- ACDs uploaded and alerts created
- Follow up January – June 2018
- Evaluation of NSW Ministry of Health ACD provided in Aug
- Data analysis/ linkages / outcome measures etc via CHeREL until June 2019

Participants at Baseline

- 197 patients randomised
  - 100 Control
  - 97 Intervention
- Mean age at recruitment was 80 years (Range 52-95)
- More than half of patients (58%) were male
- Over half (57%) were married or had a partner
- The majority (94%) were retired
- The majority were born in Australia (67%) and spoke English at home (84%)
- A small proportion (2%) identified as ATSI
- GP attendance 98.9% had seen a GP in the last 6 months
  - Mean no of visits 8.49 times (1-78)

6 month data collection

Quantitative data	Qualitative data	EMR Audit	Data linkage
• Questionnaires completed by: • 56% of health professionals (61/109) • 77% of patient participants (153/197) • 10 patients withdrew • 23 deceased • 71% of caregiver participants (89/125)	• Semi-structured interviews conducted with: • 10 patient participants • 10 caregiver participants • 10 health professionals • 7 focus groups conducted across 5 hospital sites	• Audit of 197 participants electronic medical records	• Conducted in collaboration with Centre for Health Record Linkage (CHeReL) • Findings due June 2019

Preliminary patient findings

- **Health related quality of life (SF-20):**
  - Intervention group had **worse health perception** compared to control group (p=0.002). But no differences in physical functioning, role functioning, social functioning, mental health or pain.
- **Perceived management of their chronic diseases (PACIC):**
  - Intervention group had better follow-up of their chronic disease compared to the control group (p=0.046)
  - There was a trend for intervention group having better goal setting and better overall chronic disease management compared to the control group (p=0.06)

Advance Care Documentation

	Intervention (N=99)	Control (N=98)
Advance Care Directive	39	4
Advance Care Plan	4	1
Total	43	5
% of total participants	44.3%	5.1%
% uploaded to EMR	42.2%	5.1%

Unplanned hospital admissions

	Pre-enrolment 6 months prior	Post enrolment 6-12 months
Intervention	51	42
Control	49	51

↓**18% reduction** in hospital admissions among intervention participants

↑**4% increase** in hospital admissions among control participants

Qualitative

- Semi-structured interviews were conducted at 6 months post intervention and follow up survey.
- Interviews participants included:
  - 10 patients
  - 10 carers
  - 27 clinical staff
  - 7 focus groups

Patient interviews

- N=10
  - 7 Intervention
  - 3 Controls
- Mean age 79.3 (66-91) years
- 60% born in Australia
- 80% retired
- 50% tertiary or vocational education
- Mean GP visits in last 6 months was 12.8 times

Themes

- Comfortable with the discussion (9)
- No concerns re being approached (9)
- ACP is relevant (8)
- Questions and concerns addressed (7)
- Timing appropriate (7)
- Length of discussion (5)
- Reduces family and friends distress; is beneficial to patient; No impact on relationship with HPs; No impact on relationship with family and friends; Interactive; High level of satisfaction (4)
- No effect on communication (3)

Initial expectations

- Clarify things (5)
- Personal Benefit (5)

"And that brought it out in the open, just about what was - just how serious all this was and to get it out in the open and to finalise it."

- Intervention, female, aged 75

Others involved?

- Family and friends (7)
- GP (6)
- Health Professional (6)
- Partner (3)
- Solicitor (1)

Suggestions for improvement

- Nothing (7)
- Complete each step slowly (1)
- Include funeral arrangements (1)
- HP too busy to assist (1)
- Too much information at once (1)

Would recommend to others?

- The majority (90%) of participants said they would recommend ACP to others

"Well, if it's planned out for you, I mean, there's that many things that happen in life, that's already planned, so that part is your life, it should be planned as well, to your liking, and not anybody else's liking."

- Intervention, male, aged 91

I'm really glad that it's happened. And so I'm very - overall, I'm just really pleased that advance care directive, which would never ever, have thought about. I'm very pleased that that's in place."

-Intervention, female, aged 89

Control participants

- Of the 3 interviewed, none had completed an ACD
- Reasons for not completing included:
  - Felt like they didn't need it
  - They weren't ready to complete the documents
  - Participant was interested, but when the nurses didn't call back they just dismissed the ACD.

Going Forward…

- NSW Health Document revised (Nov 2018)
- ACD Upload policy and guideline for LHD
- End of Life committee establishment
- In-services re policy to unit staff
- ACP workshops within LHDs for ongoing staff to incorporate into usual care
- Advance Care Planning Week
- Symposium – August to disseminate findings


We need to talk about a plan

ADVANCE CARE PLANNING WEEK

TRGS Round 3 Funding…

- To extend the follow up of current cohort to 18 months (same outcome measures)
  - Unplanned hospital admissions
  - Ambulance service calls
  - ED presentations
  - Deaths
  - Resuscitation attempts
  - Patient outcomes (HRQOL, Quality of Chronic Disease Care
  - Carer Outcomes (HRQOL, Caregiver burden)
- Health Economic evaluation
  - Cost comparison/ consequence analysis
- Post death file audit and carer survey
- June 2020

Summary of Findings

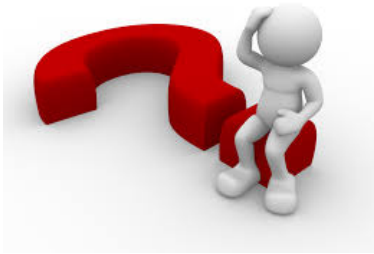
- Patients were **more likely to develop an ACD when supported by a health professional**
- The Information booklet and form from NSW Health "Making an Advance Care Directive" has been evaluated and **is available from the MOH website to download**
- The **majority of people who developed an ACD were happy for it to be uploaded to the health district's eMR.**

Further information

- http://www.planningaheadtools.com.au
- https://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf

Thanks to:
- Kate Marshall
- Joel Rhee
- Catherine Molihan

Questions?



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