Introduction

Advance care planning (ACP) has been shown to promote care that is coherent with patient wishes, however retaining decision making capacity (DMC) is a precondition for traditional ACP models. Alternative models of ACP are needed for use with and on behalf of people lacking and who no longer have DMC. We have developed a model of ACP by proxy (ACPbp) specifically for use with residential aged care facility residents (RACF) who no longer have DMC.

Aim

This study aimed to test the acceptability and feasibility of this ACPbp intervention through a pilot study, and to explore the impact on health care proxies’ decisional conflict and experience of the intervention.

Method

Data collection took place in four RACFs in French-speaking Switzerland. Health care proxies who participated in the intervention (n=14) participated in semi-structured interviews and completed the decisional conflict scale before and ACP-bp completion. Interviews were transcribed verbatim and analysed thematically.

Results

Participants in the research project represent around half of the participants invited to participate- reasons for decline included previous bad experience with research, emotional toll of the family situation and time constraints. Health care proxies reported that the intervention was an opportunity to establish or reinforce communication with the RACF personnel and physician. They appreciated the opportunity to discuss the resident’s life and values in order to give the RACF staff a better picture of the person. While some reported that discussions about the resident’s health status was difficult, they recognised the need for a timely and open discussion. Documentation of wishes was described as necessary but confronting to see the care that would not be administered in case of emergency.

Discussion

The intervention was generally well accepted by proxies and provides an important basis for advance care planning for people who no longer have decision making capacity.

Background

Tan Tock Seng Hospital’s (TTSH) Home Ventilation and Respiratory Support Service (HVRSS) has managed patients with chronic, progressive neurological diseases requiring home ventilation support since 2009. We examined patients’ healthcare utilisation [hospital admissions, cumulative length of stay (LOS), HVRSS home visits], 3 months prior-to-death; and investigated associations with having completed Advanced Care Plans (ACPs). We hypothesised that patients with and without ACPs potentially have differences in end-of-life healthcare utilisation outcomes.

Methods

This was a retrospective cohort study. Patients were deceased by 2019, had ≥1 HVRSS encounter and sufficient electronic medical documentation. Data was either recorded by TTSH HVRSS/ACP teams, or extracted by the research team. The factor of having completed ACPs (with and without) was incorporated into regression analysis of outcomes.

Results

Among 118 patients, 75 (63.6%) were male and mostly Chinese (84.7%). Mean HVRSS enrolment-age was 64.2 years (SD=16.1), and duration was 1.8 years (SD=1.8). Main diagnoses were Motor Neuron Disease (47.5%), Neurovascular Disease (12.7%) and Spinal Cord Injury (13.6%). Fifty-two (44.1%) had ACPs, with more being doctor-facilitated discussions (67.3%). Most discussions were conducted with patient and family (46.2%); followed by patient only (36.5%), then without patients (17.3%). Mean ACP-to-death duration was 1.6 years (SD=1.6).

Compared to patients without ACP, the cumulative hospital LOS in the 3 months prior-to-death was lower individuals with a completed ACP [ACP: mean=5.8, SD=11.0; No ACP: mean=14.9, SD=25.3; (IRR: 0.39–0.43; p<0.001)]. However, the number of home care visits were higher for those with completed ACPs [ACP: mean=5.3, SD=4.4; No ACP: mean=4.0; SD=4.2; (IRR=1.29–1.32; 0.001<p<0.004)]. No significant between-group differences in hospitalisation were detected (0.777<p<0.931).

Conclusions

HVRSS home visits appeared to have supported end-of-life care for those with completed ACP and therefore, may have reduced hospital LOS at end-of-life. ACPs can potentially be an important service-planning consideration for home ventilation patients.
workbook, GP training, ACP conversations, and a documentation template. Outcomes were the 15-item ACP Engagement Survey for patients and the ACP Self-Efficacy Scale for GPs. Linear mixed models evaluated differences at 3 months (T1, effectiveness evaluation) and 6 months (T2) post-baseline. Analysis was per intention-to-treat.

Results 35 GPs and 95 patients were randomized. Patient ACP engagement did not differ between the intervention and control group at T1 (baseline-adjusted mean difference, 0.34; 95% CI, -0.02 to 0.69; p=0.062) or T2 (baseline-adjusted mean difference, 0.20; 95% CI, -0.17 to 0.57; p=0.28). For GP ACP self-efficacy, there were no significant differences between groups at T1 (baseline-adjusted mean difference, 0.16; 95% CI, -0.04 to 0.35; p=0.11) or at T2 (baseline-adjusted mean difference, 0.11; 95% CI, -0.09 to 0.31; p=0.27).

Conclusion ACP-GP did not improve patient engagement and GP self-efficacy more than usual care. Both groups showed patterns of increase from baseline. Trial procedures and the COVID-19 pandemic that coincided with the trial may have increased awareness about ACP, which may have also stimulated the control group to conduct more ACP than expected. It may be necessary to also look further at what patients and surrogate decision makers want and need from the ACP process.

ADVANCE CARE PLANS: CREATION, CONTENT AND USE DURING WAVE 1 OF THE COVID-19 PANDEMIC


Background Mortality forecasts associated with COVID-19 stressed a need to prepare adults with advanced disease for possible severe illness and engage with Advance Care Planning (ACP). We aimed to examine ACP engagement and activity during the COVID-19 pandemic.

Methods A retrospective cohort study, comparing the creation, content and use of Coordinate My Care (CMC) records in London prior to and during the onset of COVID-19. Records for people aged 18+, created and published in pre-pandemic period (2018–2019) and ‘wave 1’ (W1) of COVID-19 (20/03/20–04/07/20) were extracted. Demographics, ACP-related content and the use of CMC records created were analysed and compared using descriptive statistics.

Results 56,343 records were included, 35,108 from the pre-pandemic period and 21,235 records from W1. The average records created each week rose by 296.9% (P<0.005) in W1. There were fewer records in W1 for those aged 80 years (60.8% vs 64.9% pre-pandemic, P<0.005) and who had WHO performance status 4 (34.8% vs 44.2% pre pandemic, P<0.005). More people who created records during W1 had an estimated prognosis of 1 year+ (73.3% vs 53.0% pre-pandemic, P<0.005), were ‘For Resuscitation’ (38.2% vs 29.8% pre-pandemic, P<0.005) and had a Treatment Ceiling of ‘Full Active Treatment’ (32.4% vs 25.7%, P<0.005). More people in W1 listed hospital as their preferred place of care (PPC) and preferred place of death (PPD) (PPC: 13.3% vs 5.8% pre-pandemic, P<0.005. PPD: 14.0% vs 7.9%, P<0.005). Average monthly non-urgent and urgent record views rose by 320.3% (P=0.02) and 154.3% (P=0.01) in W1.

Conclusions A large uptake in engagement with ACP is demonstrated during the 1st wave of the pandemic. An increase in use among younger, more independent patients with longer prognoses, with a higher preference for hospital care creating records in W1 compared to before the pandemic, suggests heightened awareness and provision of ACP at this time.