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Original Article

Equipping patients for a time of helplessness: An educational intervention

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Abstract

Objectives: *Quantify rates of awareness about, and ownership of, End-of-Life Planning (ELP) instruments. Examine whether this rate is increased by brief education during routine team care. Measure the time required by this exercise.*

Design: *Quality Improvement Activity.*

Setting: *General Practice on Mid-North Coast, New South Wales.*

Participants: *Forty-two consecutive, consenting elderly patients undertaking a Home Health Assessment.*

Main outcome measures: *This study assessed rates of ELP instruments at baseline, at 2 weeks, at 2 months and at 2 years following the provision and discussion of a fact sheet while measuring the clinicians' time required.*

Results: *This education exercise increased the number of patients with ELP instruments from one to ten (24%). On average it took 5.6 min of nursing time and 3.9 min for the GP.*

Conclusions: *Brief education during Home Health Assessments may empower patients to prepare for a scenario where they lost competency to make fully informed decisions. This may alleviate patient's fears about causing problems between those close to them and having treatments against their wishes.*

KEY WORDS: *Advance Care Directive*, *competency*, *consent*, *End-of-Life Planning*, *Enduring Guardianship*.

Introduction

In health, people have a right to make fully informed decisions about their care including the period between their loss of capacity to make decisions and their death.[1,2] People expect to participate in treatment decisions regardless of age or infirmity, and indeed fear losing this control if they have dementia or a stroke.[3] This is increasingly important given the aging of the population and the greater capacity of medicine to delay death regardless of quality of life.

People, while still competent to make decisions, may set up plans to protect their choices in treatment decisions where patient decision making competency is questioned. These plans may cover options such as 'no-cardiopulmonary resuscitation' orders, or the refusal of blood transfusions. In New South Wales (NSW), in the absence of a plan, a health care provider seeking consent or refusal decisions will look to someone identified in a legislated sequence of priority.[2] It is possible the person so selected would never have been approved of for this role by the patient. The presence of an End-of-Life Planning (ELP) instrument may alleviate fear, confusion and guilt for those nearest and reduce their risk of conflict.[1]

Each State of Australia has a different legislation for the legal status and functioning of ELP.[4,5] In NSW, a will or a Power of Attorney determines the division of assets but does not influence health and welfare decisions, though this varies between states. In NSW, an Advance Care Directive (ACD) or 'Living Will' is an informal document based on reflection and discussion about treatment preferences following a loss of competency to make decisions. An ACD is strongly persuasive to health care providers of patients' preferences but is not legally binding. A legally binding alternative is made by the appointment of an Enduring Guardianship (EG) under the terms of the NSW Guardianship Act 1987.[2] An EG requires preparation of specific documents signed by both the patient and the guardian with either a lawyer or a Local Court Registrar as witnesses. An ACD may be attached to the EG, setting out specific instructions that the enduring guardian is bound to observe.[2] The enduring guardian of a patient without decision-making capacity must be looked to by health care providers for decisions as they would to the competent patient.[4]

Public uptake of ACDs or EGs is poor. Only 2% patients in one Queensland general practice study had

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What is already known on this subject:

- People are unaware they can prepare for future loss of capacity to make competent health decisions.
- Families and health care providers may struggle when faced with making these decisions on behalf of another.
- GPs have not traditionally seen patient ELP as their responsibility.

What this study adds:

- Introducing ELP with a brief discussion and a fact sheet increases the prevalence rates of ELP instruments.
- Such education may be efficiently incorporated into routine Medicare-funded health checks.

a documented ACD.[6] In a NSW Residential Aged Care Facility study, 0.2% elderly had an ACD and 2.8% had an EG.[7] This low rate may reflect the infrequency that doctors inform their patients about ELP instruments. Such discussions are usually initiated by patients.[8]

A British study designed and evaluated the use of an education booklet to aid ELP in an acute hospital setting.[9] A valid ELP instrument was documented by 28 of 95 inpatients (30%). Patients rated the exercise as 'helpful, interesting, informative, and reassuring' but did not rate it as 'upsetting'. The authors called for assessment of both the utility and economic implications of the booklet in other settings and populations.[9]

In the general practice setting, the facilitation of ELP instruments has been described by the use of a fact sheet distributed during a Home Health Assessment (HHA),[10,11] without, however, any formal assessment. An HHA is an annual check-up at the homes of patients aged 75 and over (and Indigenous Australians aged 55 and over) funded by the Medical Benefits Schedule as Item 702.[12] This comprehensive assessment is designed, among other things, for the practice nurse to assess the patient's clinical condition and support structures; to enhance the capacity of the patient's carer to provide support; and to provide patients with information or interventions recommended by the GP.[12] The material gathered is then reviewed at the practice by the GP, for a total bulk-billed fee of $247.60. The facilitation of ELP instruments is now nominated to be a routine part of a Comprehensive Medical Assessment within a Residential Aged Care Facility (Medical Benefits Schedule item 712).[12]

Methods

The Australian Health Ethics Committee states a Quality Improvement Activity does not require formal approval from a Human Research Ethics Committee and so this was not sought.[13]

In 2006, the practice telephoned those patients aged 75 and over eligible for an HHA. At the conclusion of the HHA appointment, the nurse read a 1-min outline concerning ELP. Patients were invited to give signed consent to the collection of information about ELP. They were then asked if they had established a will, a Power of Attorney, an ACD or an EG or if they were aware of these instruments. Those who said they were not aware of ACDs or EGs were offered more information. Those who accepted the offer were given a brief overview of ELP with a fact sheet. The fact sheet had been prepared by the author in conjunction with health professionals and welfare groups. The nurse answered any questions generated, informally assessed whether there was any patient distress and timed the duration of the ELP dialogue.

A couple of weeks later the HHA was reviewed by the author or another GP. Following this patients were asked if they intended to establish, or had already established, an ACD or an EG. The GP answered any questions and discussed any issues raised. The GP then enquired whether the patient had felt comfortable about the practice raising these matters and requested consent to check up on their ACD/EG status in the future. The duration of this ELP dialogue was also timed. The presence or absence of an ACD and/or EG was assessed by either a nurse or the GP during routine consultations, HHAs or by phone after 2 months and again at 2 years later.

Results

Forty-four patients were invited to participate; however, two men declined consent, giving 42 data sets. There were 24 men and 18 women. Ages ranged from 75 to 93 with a median age of 79.

At the initial interview almost all (95%) had made arrangements concerning disposal of their assets. However, only nine patients (21%) were aware of ACDs and/or EGs. One of these nine, one with early dementia, already had an ACD and an EG, and an additional three patients were planning one. Excluding these four, 38 patients were offered the further information. Twenty-eight accepted the offer and 10 did not. None of the 42 patients described concern or appeared distressed to the nurse. The time taken by the nurse was recorded in 41 patients and ranged from 2 to 20 min at an average of 5.6 min.

TABLE 1: *ELP instrument prevalence* n = *42*

	ACD	EG	ACD and EG	ACD/EG cumulative prevalence	Will	Power of Attorney	Other
At initial HHA	–	1	–	2%	40	21	
2–3 weeks later (GP)	1	1	1	7%	No data	No data	
2 months later	2	4	3	21%	40	26	
2 years later	2	4	5	24%	No data	No data	Deceased: 3 Relocated: 3 Uncontactable: 1

ACD, Advance Care Directive; EG, Enduring Guardianship; ELP, End-of-Life Planning; HHA, Home Health Assessment.

At the review by the GP, two patients had subsequently established an ELP instrument. A further 12 patients intended to set up an ELP instrument. The rest were fairly evenly divided between being unsure of their intentions and not intending to set up an ELP instrument. Thirty-eight patients were asked by the doctor if they felt comfortable about our raising these matters, and all said they were. The doctor's time was recorded in 35 patients and ranged from 1 to 14 min at an average of 3.9 min.

The nurse followed up patients at 2 months post fact sheet. At this time, a total of nine patients had an ELP instrument. There also were an additional five patients who had established a Power of Attorney (62%). At the 2-year follow-up of those 33 patients hitherto without an ACD or EG, only one additional patient had since set up both an ACD and an EG giving a cumulative prevalence rate of 24%.

Since the ELP fact sheet was prepared (Table 1), it has been adopted for use by a Residential Aged Care Facility and by a local solicitor. The Hunter New England Health Service has also distributed it to regional GPs for their use.

Discussion

This datum demonstrates a high prevalence of instruments to direct the distribution of assets at death. It also shows an extremely low prevalence of instruments to direct patient preferences in the context of a loss of competency. This may reflect a traditional cultural emphasis on dealing with the financial aspects of death. The majority of patients were interested in accessing information about ELP. A far smaller number actually set up an ELP instrument, though there was an increase in coverage from 1/42 (2%) to 10/42 (24%), similar to that found in the British inpatient study.[9] Furthermore, the fact sheet and explanation resulted in many more patients discussing their ELP wishes with their families and health care providers. Given that the number with ACDs or EGs barely changed from the 2-month to the 2-year follow-up, it may be construed that the simple enquiry made at 2 months' stage was a poor motivator of change.

Some time-poor, disease-focused health care providers expect the breeching of the subject of ELP may lead to emotional outpourings of unacceptable duration. This was not shown here. The process was not laborious taking the nurse an average of 5.6 min and the GP 3.9 min. At no stage of the process was any patient perceived to be distressed. In fact, many patients seemed very glad to be able to address these issues and narrated stories of their own bereavements and how they were handled. They seemed pleased to discuss their thoughts about their own mortality and their plans for their own passing. There often seemed a sense of relief when people could express their fears about the future care of other aging family members. There was a general sense from the patients that this was a natural area of discussion with their GP. Very many patients, without documenting an ELP instrument, commented that they had discussed these eventualities with those close to them.

It may well be that some aspects of preparing for death, such as the establishment of a will or a Power of Attorney, should not be the primary responsibility of health care providers. However, this study has shown health care providers may efficiently and effectively play a role in education about ELP for health and welfare decisions. This may facilitate discussions about values and goals, and also about loss and grief between the patients, those close to them and their health care providers.

Conclusion

This paper described and evaluated an ELP educational intervention linked to Medicare-funded nurse-driven assessments within a NSW rural primary health care environment. Despite 95% patients having already established a will to plan their end of life disposal of assets, patients had rarely considered ELP for their health care. The provision of a brief synopsis and a fact sheet increased the prevalence of ELP instruments from 2% to 24%. Anecdotally, many other patients initiated significant discussions with those close to them which may assist with future decision making.

Many of our patients will become incompetent to make consent or refusal decisions at some time during their lifespan. With an ELP instrument, they can ease the burden of those close to them and their health care providers. This study has demonstrated within routine team care of the elderly in the community, GPs can effectively and efficiently decrease patients' fear of any future loss of control over health and welfare decisions and equip them with options for any future time of helplessness.

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