Interprofessional Learning Through Simulation Project

I just want to go home – Cultural and social considerations, chronic disease and end-of-life issues

Facilitators' Guide

Acknowledgements

Ms Rebecca Crellin, A/Coordinator, Clinical Simulation Support Unit, Western Australian Department of Health

Winthrop Professor Jeffrey Hamdorf, Director, Clinical Training and Evaluation Centre and Professor of Surgical Education, School of Surgery; University of Western Australia

Associate Professor Brian Nook, Dean for Chiropractic and Sports Sciences, Murdoch University

Ms Carol Watson, Assistant Superintendent Physiotherapist, Royal Perth Hospital

Dr Monica Gope, Director, Post Graduate Medical Education, Western Australian Country Health Service (WACHS) and Clinical Senior Lecturer, School of Primary, Aboriginal & Rural Health Care, University of Western Australia

Dr Martin Glick, Manager, Central Clinical and Support Services, Dental Health Services, Public Health and Ambulatory Care, North Metropolitan Health Service, Western Australian Department of Health

Ms Lisa Sorensen, Manager, Learning and Development, Western Australian Country Health Service (WACHS)

Ms Kendra Bell-Hayes, A/Program Manager, Clinical Workforce and Reform, Western Australian Country Health Service (WACHS)

Ms Margo Brewer, Director of Interprofessional Practice, Faculty of Health Sciences, Curtin University of Technology

Professor Cobie Rudd, Pro-Vice-Chancellor (Health Advancement) and Professor of Mental Health, Edith Cowan University

Professor Gavin Frost, Dean, School of Medicine (Fremantle), University of Notre Dame Australia

Professor Ian Rodgers, Professor of Emergency Medicine, St John of God Hospital, Murdoch

Associate Professor Erica Yates, School of Dentistry/Oral Health Centre of Western Australia, University of Western Australia

Disclaimers:

All information and content in this material is provided in good faith by the Western Australian Department of Health, and is based on sources believed to be reliable and accurate at the time of development. The State of Western Australia, the Western Australian Department of Health and their respective officers, employees and agents, do not accept legal liability or responsibility for the material, or any consequences arising from its use.

The filmed scenario has been developed from the experiences of the Interprofessional Learning in Simulation Project Steering Group. All due care has been taken to make the scenarios as realistic as possible. The characters in the filmed scenarios are fictitious and any resemblance to persons living or dead is purely coincidental.

Contents

How to use this resource

This resource (the Facilitators' Guide) provides the framework to support the development of communication and problem solving, together with problem-based learning scenarios that encompass some challenging (but quite typical) patients that clinicians could expect to encounter as part of their practice. The goal of this interprofessional learning experience is to help prepare all health professionals – be they students or beginning clinicians – for working together.

This resource is intended to develop your understanding of the principles of interprofessional practice and raise your awareness of opportunities for implementing interprofessional practice in your own environment. Throughout the resource are opportunities to consider how notions of interprofessional practice affect your current work practices and activities that enable you to reflect on these.

> **The goal of this interprofessional learning experience is to help prepare all health professionals – be they students or beginning clinicians – for working together.**

Interprofessional learning through simulation

This resource utilises simulation as a means to facilitate a learning experience; one that re-creates events that are closely linked to reality. Gaba[1] defined simulation as a technique, rather than a technology, to replace or amplify real life experiences with guided experiences, often immersive in nature, to evoke or replicate aspects of the real world, in a fully interactive pattern.

Simulation provides a safe learning environment for students to practice, where they are free to make mistakes, correct them and improve the processes of care.[2] Simulation is the bridge between classroom learning and the real life clinical experience, allowing students to put theory into practice.

Interprofessional learning through simulation provides learning opportunities to prepare future health care professionals for the collaborative models of health care being developed internationally[3] and can encompass a range of environments and resources that harness technologies, including multimedia and online applications.[4]

Resource contents

There are four sections within this resource. Information presented in Section One and Section Two is largely focussed on interprofessional learning and Section Two also contains an introductory section on end-of-life care.

- Sections One and Two of this resource contain questions that require users to reflect on the content they have covered.
- Scenarios included in Section Three require users to watch the associated audiovisual resource 'I just want to go home!' and complete the questions that relate to interprofessional learning and end-of-life care.
- Section Four provides a literature review about end-of-life care, which can be used as reference material.

Learning objectives

The key interprofessional learning message of this resource is:

End-of-life care

The learning objectives of this resource are based on **five competency domains** from the Australian audit of interprofessional education in health:

- Teamwork;

- Understanding roles and respecting other professions;

- Role clarification;

- Understanding of Interprofessional Education (IPE); and

- Reflection.[5]

Learning outcomes will be addressed through the consideration and discussion of material presented in Sections One and Two in relation to interprofessional practice generally, and the case study presented in Section Three which is focussed more specifically on end-of-life care.

Learning outcomes

On completion of this resource, participants should be able to:

- Identify the key elements of interprofessional practice;

- Differentiate between interprofessional practice and current ways of working;

- Understand the importance of 'human factors' and appreciate how non-technical factors impact patient care;

- Develop an awareness of tools to enhance successful communication with patients/clients and carers;

- Describe strategies to develop a deeper understanding of other professions' roles and responsibilities;

- Identify what changes are required to promote interprofessional practice;

- Distinguish between the roles of the health professionals involved in this case study, including areas of possible overlap;

- Identify the potential barriers to interprofessional communication and collaboration when caring for culturally diverse patient groups;

- Assess the impact of team communication and team relationships on patient care;

- Reflect on own and other health professionals' practice;

- Explain what an Advanced Health Directive (AHD) is and be aware of the challenges relating to AHDs;

- Discuss the topic of advance care planning (ACP) with patients and be familiar with common ACP templates;

- Be aware of the clinical practice guidelines for communicating prognosis at the end-of-life; and

- Reflect on personal goals and values that may be barriers to culturally sensitive, patient-centred care.

Section One: What is 'interprofessional'?

Why the need for interprofessional learning?

In today's health care setting, human service professions are facing problems so complex that no single discipline can possibly respond to them effectively.[6] The World Health Organization (WHO) has stated 'It is no longer enough for health workers to be professional. In the current global climate, health workers also need to be interprofessional'.[7]

What does the term interprofessional mean?

Interprofessional learning (IPL) is defined as:

- Learning arising from interaction between members (or students) of two or more professions. This may be a product of interprofessional education or happen spontaneously in the workplace or education settings.[8]

> **Encourages professions to learn with, from and about each other**

Interprofessional education (IPE) is defined as:

- Occasions where two or more professions learn from, with and about each other to improve collaboration and the quality of care.[8]

Interprofessional practice (IPP) is defined as:

- Two or more professions working together as a team with a common purpose, commitment and mutual respect.[8]

When interprofessional practice is working well it is thought to achieve the following six outcomes:[9]

1. **Works to improve the quality of care:**

   No one profession, working in isolation, has the expertise to respond adequately and effectively to the complexity of many users' needs and to ensure that care is safe, seamless and holistic to the highest possible standard.

2. **Focuses on the needs of service users and carers:**

   IPL puts the interests of service users and carers at the centre of learning and practice.

3. Encourages professions to learn with, from and about each other:

IPL is more than common learning, valuable though that is to introduce shared concepts, skills, language and perspectives that establish common ground for interprofessional practice. It is also comparative, collaborative and interactive, a test-bed for interprofessional practice, taking into account respective roles and responsibilities, skills and knowledge, powers and duties, value systems and codes of conduct, opportunities and constraints. This cultivates mutual trust and respect, acknowledging differences, dispelling prejudice and rivalry and confronting misconceptions and stereotypes.

4. Respects the integrity and contribution of each profession:

IPL is grounded in mutual respect. Participants, whatever the differences in their status in the workplace, are equal learners. They celebrate and utilise the distinctive experience and expertise that participants bring from their respective professional fields.

5. Enhances practice within professions:

Each profession gains a deeper understanding of its own practice and how it can complement and reinforce that of others. This is endorsed where the IPL carries credit towards professional awards and counts towards career profession.

6. Increases professional satisfaction:

IPL cultivates collaborative practice where mutual support eases occupational stress, either by setting limits on the demands made on any one profession or by ensuring that support and guidance are provided by other professionals if and when added responsibilities are shouldered.

How is interprofessional practice different to how people currently work?

The Australasian Interprofessional Practice and Education Network (AIPPEN) have identified a number of terms currently that convey a similar but different intent and meaning to the term interprofessional.[10]

Interdisciplinary

- Interdisciplinary has been used by researchers and practitioners when they attempt to analyse, synthesise and harmonise the connections between disciplines, to generate a coordinated and coherent health delivery system.[11] 'Interdisciplinary' is said to lack the inherent depth of collaboration implied by the term 'interprofessional'.

Multidisciplinary

- Health professionals represent a range of health and social care professions that may work closely with one another, but may not necessarily interact, collaborate or communicate effectively.[12]

Multiprofessional

- Work occurs when a range of professional practitioners work in parallel. Each discipline has clear role definitions and specified tasks and there are hierarchical lines of authority and high levels of professional autonomy within the team.

- Multiprofessional, as a term, may not imply optimal levels of collaboration.

- Practitioners consult individually with service users and use their own goals and treatment plans to deliver services.[13]

Collaboration

- Is 'an interprofessional process of communication and decision-making that enables the separate and shared knowledge and skills of providers to synergistically influence the ways patient/patient care and broader community health services are provided'.[14]

Do we need to focus on interprofessional collaborative practice – don't professionals already work interprofessionally?

Interprofessional practice is a way of practicing that is based on collaboration. Nurses, doctors and other health professionals have, for a long time worked, closely together and have developed successful long-term partnerships. However, as has been stated:

> We cannot assume that health professionals have either the skills or attributes required for interprofessional practice. They may need to learn how to collaborate. Developing interprofessional practice requires a commitment to engage in shared learning and dialogue. Dialogue has the potential to encourage collegial learning, change thinking, support new working relationships, and improve patient care.[15]

Although health professionals receive extensive professional development, most training emphasises specific disease processes, technology and treatment and has largely undervalued human factors. Human factors training is necessary to help individuals learn how to improve working relationships with colleagues and those from other disciplines.[15]

The end goal of interprofessional education is to create a health workforce with improved levels of teamwork, collaboration, knowledge-sharing and problem-solving, eventually leading to better patient and patient outcomes in health settings.[16] The WHO has recognised the importance of interprofessional education and collaborative practice in developing a health workforce that is able to meet the complex health challenges facing the world and assist in the achievement of the health-related Millennium Development Goals.[7]

ACTIVITY ONE

What would you expect to notice as indicators of interprofessional practice?

What range of factors might be different in an interprofessional practice environment?

ACTIVITY ONE: ANSWER AID

Anecdotes from clinicians with an increasing awareness of interprofessional thinking and behaviour in the clinical environment:

"I went to a placement and something clicked. It gelled and I suddenly got it…it's more than an awareness of others – you realise you are not an island and it's up to others as well. You can recognise opportunities for patients and refer them to other disciplines".

"I used to get frustrated at them not seeing through my discipline lens but then I saw how difficult it was for me to learn about their discipline".

"You begin to realise you are part of a bigger picture and because of that you need to be able to communicate with people in a way they understand…I was listening to nurses with all the jargon they use and it made me become more aware of the amount of jargon I use – I thought I was practising interprofessionally but didn't realise I was using so much jargon".

Section Two: Competency framework for interprofessional education

Although a range of competencies have been identified, there is no one overarching framework that provides a definitive set of interprofessional competencies. Initial findings from an Australian national audit of pre-registration interprofessional education in health identified five IPE domains to support the development of a national curriculum framework. The identified domains were:

- Teamwork;
- Understanding roles and respecting other professions;
- Role clarification;
- Understanding of IPE; and
- Reflection.[5]

> **Patients will increasingly demand physicians, nurses and other health professionals to communicate and work together effectively**

Teamwork

The identified domain 'teamwork' included the elements: communication, leadership, attitudes, team relationships and conflict resolution. We know that effective teamwork plays a key role in improving quality and safety in health care, and the need for increased collaboration and teamwork across the health professions is necessary in order to care for an ageing population with multiple chronic illnesses.[17] Patients will increasingly demand physicians, nurses and other health professionals to communicate and work together effectively. Teams bring their collective knowledge and experience to provide a more robust foundation for decision-making than any single clinician can offer.[17]

Team functioning and collaboration is thought to be enhanced when individuals:

- Participate in team activities;
- Foster positive team relationships;
- Appreciate differing personalities within teams; and
- Demonstrate respect.[17]

Lack of focus on human factors

The elements that make up teamwork are regarded as 'human factors' and are the non-technical factors that impact on patient care. Human factors can be defined as the interaction of equipment and individuals and the variables that can affect the outcome.[18,19] Bromily and Reid quote Catchpole in their article,[20] stating that more broadly the term clinical human factors can also encompass interactions with the environment that include an 'understanding of the effects of teamwork, tasks, equipment, workspace, culture and organisation on human behaviour and abilities, and the application of that knowledge in clinical settings'.

The contemporary focus of human factors in health care reportedly had its genesis in the work of James Reason in 1995 when he stated that, 'human rather than technical failures now represent the greatest threat to complex and potentially hazardous systems'.[18] More recent research highlights that rather than poor technical skill, human factors such as suboptimal communication and organisational system and culture inadequacies were implicated in up to 87% of the errors, adverse events and near misses that occur.[21-24]

Historically, health care has regarded technical skills and competence as key to patient safety. Technical excellence in, for example, nursing and medicine is important because health care professionals need to know what they are doing to maintain high standards of care and quality outcomes for patients. However, other safety-critical industries (such as defence and aviation) have learnt that even the most technically qualified and expert individuals can encounter difficulties when under stress. Such non-technical abilities – sometimes referred to as 'soft skills' – need to be valued equally.[25] Humans, when under pressure, have a capacity to become overly focused or fixated on technical problems.[26] Focus on human factors to improve the way teams work is important because:

- Opportunities to optimise the way teams work is becoming progressively more difficult with an increasing number of part-time workers, increasing patient loads and decreased staffing;

- The attitudes and behaviours of those who make up `teams' can be problematic at times and a lack of congruence in how teamwork itself is interpreted exacerbates underlying resentments, undermines professional esteem, and in some cases, creates outright conflict; and

- Working in teams, at times, can be fraught with difficulties and the `ideal' of effective team-working as defined in the prescriptive literature, is apparently rarely realised.[27]

ACTIVITY TWO

Think about your team (past or present) and how your team functions…what are the issues that make it challenging to focus on improving team performance?

What strategies have you found to be effective in improving team performance?

What do you feel could be done to improve team performance?

Communication

Appropriate interprofessional communication:

- Maintains patient confidentiality;

- Provides and delivers feedback;

- Promotes the role of other disciplines to patients/carers;

- Communicates in a clear and concise manner;

- Validates the knowledge of other disciplines; and

- Explains discipline-specific terminology.

Interprofessional practice also places an increased focus on the needs of service users and carers. Although communication among and between professionals is critical, to ensure the interests of service users and carers remains at the centre of learning and practice, strategies to enhance communication practices with service users and carers are essential. Patient-centred care:

- Places the service users and carers at the centre of practice;

- Establishes patient-centred goals;

- Facilitates decision-making with patient/family; and

- Recognises and responds to the patient's changing needs.[28]

The mnemonic LIPSERVICE will help ensure that you consider the many aspects of successful communication with clients and patients and will be utilised later in the resource.

L is for Language	• Does your patient speak English? • How well do they speak it? • Do you need to consider getting an interpreter to assist? • What is the person's education level and understanding – will you need to modify the language you use in order to help them understand what you are asking or telling them?
I is for Introduction	• Make sure you introduce yourself to the person, and give them your role – especially if what you do is something that is not commonly known. While most patients will understand the role of a 'doctor', they may not be familiar with what an 'occupational therapist' does. If in doubt, you should explain your role.
P is for Privacy, Dignity and Cultural issues	• Is this a person who is going to be embarrassed by being examined by someone of the opposite gender? • Should you ask before you address them by their first name? Many more elderly patients are of a generation who value the respect that being called 'Mr' or 'Mrs' gives them. Be aware of different cultural expectations that you may encounter.

S is for Subjective Questioning	•	This is where you take the person's history.
	•	A thorough history will be invaluable in helping to make a diagnosis.
	•	Be aware of the power of 'leading questions' though.
	•	Ask open-ended rather than closed questions to obtain your answers.
E is for Examination	•	Some considerations here include talking the person through what it is that you are doing, especially if this is an invasive or unusual procedure for them.
	•	Knowing what is happening and why, as well as what to expect, can help alleviate the person's concern about what it is you are doing to them.
R is for Review	•	Talk through what you have done as part of the examination – and what it added to your knowledge of their condition.
	•	For example, 'You were talking about how you get short of breath, and I could hear from listening to your chest that your lungs are quite congested.'
V is for Verdict	•	The diagnosis.
	•	What their history and your examination have led you to think is causing their symptoms and signs.
I is for Information	•	What does the diagnosis mean for the person?
	•	Having a diagnosis of a lump in the breast can mean many things.
	•	The person needs to know about these.
C is to remind you to Check Understanding	•	This is where you determine if what you have said has made sense to the person.
	•	People may only hear the diagnosis and then go into a state of shock – which means they don't process what you tell them next.
E is for End or Exit	•	What's going to happen next for the person?
	•	What about follow up?
	•	Referrals to other professionals?

Understanding roles and respecting other professions / role clarification

The need to address complex health and illness problems, in the context of complex care delivery systems and community factors, calls for recognising the limits of professional expertise and the need for cooperation, coordination and collaboration across the professions in order to promote health and treat illness. However, effective coordination and collaboration can occur only when each profession knows and uses the other's expertise and capabilities in a patient-centred way.[29]

The WHO report in 2005 argued that health care providers must work interdependently, demonstrating mutual respect, trust, support and appreciation of each discipline's unique contribution. Although it is changing, the traditional way in which health professional students are educated is uni-professional, and occurs within discipline- and profession-specific groups.[30] Within uni-professional environments students develop a solid grounding in the specific knowledge of their own profession, although many, if not most, students leave educational environments with a cursory understanding of other disciplines' roles and responsibilities.

> **Interprofessional practice is about developing professionals who are confident in their own core skills and expertise and who are also fully aware and confident in the skills and expertise of fellow health and care professionals.**

One educational approach which is thought to assist professionals to develop greater `team awareness' is to understand other professional perspectives through 'shared learning'.[27] Shared learning has the potential to deepen understanding of how professional roles and responsibilities complement each other[29] and engender a greater appreciation of 'common' or overlapping competencies.[31] An enhanced understanding of other professionals' roles and responsibilities possible through shared learning can alleviate some of the potential tensions that exist in relation to overlapping competencies between health practitioners.

Interprofessional practice is about developing professionals who are confident in their own core skills and expertise and who are also fully aware and confident in the skills and expertise of fellow health and care professionals.[32]

ACTIVITY THREE

Within your own discipline, how easy/difficult would it be to verbalise your concerns about a colleague's knowledge, skills or competencies?

Thinking outside your own discipline, how would you know what knowledge, skills and competencies other disciplines need/should have? Pick a discipline you have contact with and explain what it is they do, as if you were explaining it to a patient.

Would it be more or less difficult to flag concerns about a colleague from another discipline, than a colleague from your own discipline and why?

ACTIVITY THREE (continued)

Over your career, how have you learnt about other professionals' roles?

Given that optimal interprofessional practice requires you to have a deeper understanding of other professions' roles and responsibilities, identify two professions you would like (or need) to know more about and list strategies you could implement to attain a greater in-depth understanding of that profession's roles and responsibilities.

ACTIVITY THREE: ANSWER AID

Each profession's roles and responsibilities vary within legal boundaries; actual roles and responsibilities change depending on the specific care situation. Professionals may find it challenging to communicate their own role and responsibilities to others. For example, Lamb et al.[33] discovered that staff nurses had no language to describe the key care coordination activities they performed in hospitals. Being able to explain what other professionals' roles and responsibilities are and how they complement one's own is more difficult when individual roles cannot be clearly articulated. Safe and effective care demands crisply defined roles and responsibilities.

Specific Roles/Responsibilities Competencies:

RR1. Communicate one's roles and responsibilities clearly to patients, families, and other professionals.

RR2. Recognise one's limitations in skills, knowledge, and abilities.

RR3. Engage diverse health care professionals who complement one's own professional expertise, as well as associated resources, to develop strategies to meet specific patient care needs.

RR4. Explain the roles and responsibilities of other care providers and how the team works together to provide care.

RR5. Use the full scope of knowledge, skills, and abilities of available health professionals and health care workers to provide care that is safe, timely, efficient, effective, and equitable.

ACTIVITY THREE: ANSWER AID (continued)

RR6. Communicate with team members to clarify each member's responsibility in executing components of a treatment plan or public health intervention.

RR7. Forge interdependent relationships with other professions to improve care and advance learning.

RR8. Engage in continuous professional and interprofessional development to enhance team performance.

RR9. Use unique and complementary abilities of all members of the team to optimize patient care.

(Interprofessional Education Collaborative, 2011)

Reflection

The importance of personal reflection in interprofessional practice was highlighted in a national study designed to inform the further development of IPL in Australian health professional education and workforce development. The report identified the importance of reflection as interprofessional learning centred on:

> …the relational aspects of practice or practising, with a learning and reflective focus on the team, as well as the individual, and is responsive to a body of knowledge and ethical orientation that engages with teams and team functioning as well as individuals and individual functioning. [5]

Processes that facilitate both individual and team reflection are critical to increase awareness and understanding of intra and inter personal relationships. One such tool to assist in the process of personal or team-based reflection to generate well-considered steps to problem solving with team members, patients and clients, is the mnemonic ASPIRIN.

A	Acknowledge the problem	Basically, is there something that needs to be addressed?
S	Situational analysis	What is the cause of the situation?
		How did it come about and who is involved?
		What is likely to happen if you don't act?
		What are the risks if you do act?
P	Provide some solutions.	There is almost always more than one approach that could be used to try and solve this situation.
		Decide on which is the most suitable.
I	Implement	Your preferred solution.
R	Review the outcome	How did it help?
		Do you need to try something else?
I	Inform stakeholders	Let people know – communication is very important.
N	Next steps	Is this a temporary fix?
		Do you need to look at a different long term solution?
		Will the problem occur again and again unless steps are taken to resolve it in the longer term?

ACTIVITY FOUR

Consider a problem (past or present) and utilise ASPIRIN to assist you to generate new ways of thinking about that situation.

Reflect on how you consider interprofessional practice has the potential to impact upon patient outcomes.

Reflect on what you have covered in this resource thus far and consider what changes you need to make to ensure your own practice is interprofessionally-focussed.

End-of-life care

End-of-life care attends to the physical, psychosocial and spiritual concerns of patients and their families or carers, and extends into the bereavement period. Best practice in end-of-life care focuses on supporting both the patient and their family.[34] It requires very good communication and teamwork from health care professionals.

It is essential to identify patients who are dying, in order to allow them and their caregivers to reorient their priorities and achieve their goals so that appropriate end-of-life care can be provided. While there are situations in which it is possible to identify the terminal phase with some accuracy, many diseases have a natural history of progression and exacerbations which makes the transition to the terminal phase difficult to identify. This uncertainty can complicate timely planning for end-of-life care. To achieve real improvements in end-of-life care there must be a significant cultural change in the community and the health professions about dying as a normal part of living.

Advance care planning (ACP) is one means of improving end-of-life care. ACP is the process by which patients make decisions that can guide their future health care if they become unable to speak for themselves. It is based on the ethical principle of respect for patient autonomy. ACP reflects patients' own values and concerns, and requires patients to understand their medical condition as well as the benefits and burdens of possible treatments. ACP requires that patients are given:

- Accurate and sensitively-provided information about their illness and health care options and prognosis;

- Opportunities to discuss their wishes with their doctors and their chosen decision-maker/s; and

- Assurance that their wishes are accurately documented, regularly updated, and can be accessed as needed.

Ideally ACP should begin early in a patient's illness, and be a part of routine clinical care. There are many people who are completely healthy who wish to engage in ACP. Surrogate decision-makers can be appointed by the patient. This process should involve having discussions with the surrogate decision-maker to discuss their values and preferences with them. The surrogate decision-maker also requires support and information to fulfill this role.

ACP does not need to be complicated. It can be summarised in five steps:[35]

1. Identifying your future medical and personal care needs;
2. Planning your care;
3. Choosing your helper;
4. Putting your decisions in writing; and
5. Informing others.

Autonomy in medicine is not simply allowing patients to make their own decisions. Health professions have an obligation to ensure that respect for autonomy includes respecting an individual's right to self-determination as well as creating the conditions necessary for autonomous choice. 'Autonomy, described as "deliberate self-rule", recognises the right of a person to have an opinion, make choices, and take actions based on personal values and beliefs'.[36] Beauchamp and Childress[37] assert that two conditions are essential to autonomy: agency and liberty. To meet the condition of agency, a patient must possess the capacity for both understanding and intention. The condition of liberty requires that a patient has access to information about his or her condition and available options, and freedom from coercion.[38] Autonomy underpins privacy, confidentiality, and consent, and assumes that the individual has the capacity for deliberation.[36]

ACP can enhance patient autonomy by providing the opportunity to express and document desired treatment wishes.[39] It empowers patients to become partners with the health care team in the management of their own care, and assists to create a plan that respects preferences for their health care within the spectrum of reasonable clinical options. Similarly, Advanced Health Directives (AHDs)[1], the documents in which patients' wishes, values and goals of care may be recorded, are founded on respect for personal autonomy.

Given Australia's Indigenous heritage and increasingly multicultural population, it cannot be assumed that individual autonomy is the prevalent ethic in all communities or that Western values and decision-making norms will apply to all families. AHDs can provide a means for a person to appoint the culturally-appropriate decision-maker within his or her family or community context.

---

[1] The terms 'Advanced Health Directives' (AHDs) and 'Advanced Care Directives' (ACDs) are used by different Australian State and Commonwealth agencies to denote similar concepts. The term 'Advanced Health Directive' is in common use by the Western Australian Department of Health and is used in this Facilitators' Guide throughout, except where otherwise indicated.

In particular, culturally sensitive approaches to decision-making, breaking bad news and gathering information are needed when planning for end-of-life care. The beliefs about death and dying of Aboriginal and Torres Strait Islander peoples must be recognised and respected. However, it must also be recognised that AHDs are not necessarily appropriate for every person or every community, and that a person may choose not to complete an AHD.[40]

A more complete literature review about end-of-life care is available in Section Four.

Resource activities in relation to end-of-life care follow in Section Three.

The scenario in Section Three highlights the importance of cultural and social considerations, chronic disease and end-of-life issues.

Section Three: Scenario – I just want to go home!

Scenario

Mr Barry is a 55 year old Aboriginal man from the Pilbara, admitted to hospital with end-stage renal failure and requiring specialist care. Due to distance, he has no family present and he is unhappy, disengaged and confused. Mr Barry and the health care team also have conflicting opinions regarding his long-term medical management. The hospital's Aboriginal Liaison Officer is working with Mr Barry and the team to help them understand each other and help Mr Barry receive optimal care.

List of characters

Mr Barry (patient)

Nurse

Mick Williams (Aboriginal Liaison Officer)

Renal consultant

Physiotherapist

Dietitian

Renal consultant (Port Hedland)

What to do next

Section Three of the resource requires that you:

1. Watch each scene of the associated resource 'I just want to go home!':

    o Scene One – Renal ward/team consultation

    o Scene Two – Team consultation/renal ward

    o Scene Three – Back to country

2. After you have watched a scene, complete the activity questions relevant to that footage.

3. If necessary, refer to the answer aid boxes after the activity questions for hints relating to end-of-life care.

Scene One: Renal ward/team consultation

Please watch 'I just want to go home!': Scene One

Notes:

ACTIVITY FIVE

What might it have felt like being Mr Barry and why?

What would it have felt like being a member of the health care team and why?

How did individual team members show respect and cultural awareness to Mr Barry and what factors could have been improved?

ACTIVITY FIVE (continued)

What are some of the clinical indicators that Mr Barry presented with that suggest advance care planning may be helpful?

ACTIVITY FIVE: ANSWER AID

What might it have felt like being Mr Barry and why?

• Frustrated and annoyed that staff don't seem to be listening to him, not respecting his choice not to participate in their proposed treatments, and not taking "no" for an answer.

• Confused, as he may not have understood why he had been transferred to a city hospital away from his country and people.

• Worried that his family might not know where he is or how to contact him, or that he might die away from his country.

• Nervous about what the future may hold and not fully understanding about his health issues and the treatment options.

• Overwhelmed and helpless, confronted by the number of different people involved in his care and the treatments being pushed upon him, without having family support present.

• Disrespected by female staff showering or assisting him.

• Upset, because he believes "the connection you have to your county, that's your spirit. That's where you come from". Mr Barry says he wants to die in his "heart country". He is worried about his spirit and feels disconnected where he is.

What would it have felt like being the health care team and why?

• Helpless and frustrated by Mr Barry ignoring their advice and rejecting their efforts to improve his health.

ACTIVITY FIVE: ANSWER AID (continued)

- Confused about how best to work with Mr Barry to get him to engage with the team, and unsure if he is depressed or making an informed choice about his treatment.

- Exhausted by trying to offer a range of alternate solutions (e.g. nutritional supplements, tube-feeding, bush tucker, etc.).

How did the team show respect or cultural awareness to Mr Barry and what factors could have been improved?

Positive points:

- Asking the Aboriginal Liaison Officer to visit Mr Barry.

- Taking a team approach to the management of Mr Barry's care. The Aboriginal Liaison Officer was invited to the team meeting so he could offer insight into Mr Barry's mental and emotional state, and offer some culturally appropriate suggestions for his care.

- The health care team members were open to ideas about what may help Mr Barry – providing bush tucker, finding ways to treat him in or near his home country – and were respectful of Mr Barry's culture.

Opportunities to improve feelings of respect:

- Offering male nurses to shower Mr Barry.

- Clarifying Mr Barry's understanding of his illness and treatment options.

- Inviting Mr Barry and his family (via video link or telephone) to participate in the case conference about his care.

ACTIVITY FIVE: ANSWER AID (continued)

- Asking Mr Barry what his wishes are in relation to his care, particularly if his health declined, what the main factors are impacting on his mood, and how he feels the team could best help him.

What are some of the clinical indicators that Mr Barry presented with that suggest advance care planning may be helpful?

- Two or more admissions to hospital for a chronic or life-limiting illness within 12 months.[41]

- Unintentional weight loss greater than 10% over 6 months.

- Karnofsky Performance Status (KPS) ≤ to 50%.[42]

- Deliberate non-compliance with treatment.

- Refusing food or fluids.

- Frailty (patients who present with multiple co-morbidities with significant impairment in day to day living and deteriorating functional status).

Scene Two: Team consultation/renal ward

Please watch 'I just want to go home!': Scene Two

Notes:

ACTIVITY SIX

If you were writing the script that involved planning the meeting between the team and Mr Barry what points would you include?

Do you foresee any problems with the nursing staff relying on Mr Barry's information when completing his fluid balance chart?

What factors could be at play that are influencing Mr Barry's 'non-compliance' with the physiotherapist's plan for him to mobilise?

If you were writing the script that involved discussions around Advanced Health Directives (AHDs) what points would be important or what questions would you ask?

ACTIVITY SIX

Thinking about the statement "The core essence of cultural safety is that the health professional understands their own cultural identity, and is aware of the impact their culture can have on another",[43] what are your values when it comes to:

i) patient autonomy;

ii) informed choice;

iii) AHDs?

How could your opinions influence your practice?

What other strategies or techniques could the nurse have used to better communicate with the patient about dialysis? How could she check his understanding?

ACTIVITY SIX: ANSWER AID

If you were writing the script that involved planning the meeting between the team and Mr Barry what points would you include?

• Who the best person would be to invite Mr Barry to the meeting.

• When is a good time to discuss Mr Barry's care and who he would like present from the multi-disciplinary team, his family, or carers.

• Identify the goals of the meeting.

• Gain an understanding of how Mr Barry is finding hospital, his disease burden and the available treatment options in his community.

• Gain an understanding of what the implications are if treatment is ceased and a management plan.

• Ask Mr Barry about his family, what matters to him, and who the best person is to talk to about returning home to his country.

• Discuss a plan for the next few days and the longer-term outlook for his care.

• Identify any cultural issues the team may not have addressed already.

Do you foresee any problems with the nursing staff relying on Mr Barry's information when completing his fluid balance chart?

• There may be an issue of trust here between the patient and the health care team.

• The team are respecting and trusting Mr Barry's autonomy and veracity, although he may not agree with their opinion of what is in his best interests.

ACTIVITY SIX: ANSWER AID (continued)

• There is a potential conflict here for the team, as they are aware Mr Barry may not be complicit in his care plan.

• Would the staff be so willing to trust Mr Barry's account if he were able to mobilise more easily (and get water from the tap)?

Why do you think Mr Barry is 'non-compliant' with the physiotherapist's plan for him to mobilise?

• The idea of 'compliance' with a treatment plan is professional-centric.

• Providing the patient understands the reasons for a given treatment and is competent, they are entitled to make an autonomous decision to refuse to participate.

• Mr Barry's unwillingness to participate in his treatment may also be affected by his mood and the fact he is upset about being away from his country.

• The health care team are required to act beneficently, but what is in a patient's best interests does not pertain only to their physical health.

If you were writing the script that involved discussions around Advanced Health Directives what points would be important or what questions would you ask?

• Issues such as privacy and allowing sufficient time for discussion and reflection over one or more consultations should be promoted.

ACTIVITY SIX: ANSWER AID (continued)

- Identify the patient's goals and wishes by asking questions such as:

    - "Think about what is most important to you in your life. What makes life meaningful or good for you now?";[44]

    - "What is your understanding of your condition now and in the future? At this point, given your medical condition, how could we (the health professionals) help you live well?";[45]

    - "Are there any special events/activities that you are looking forward to?" (e.g. birthdays, weddings, holidays etc.);

    - "If you have to choose between living longer and quality of life, how would you approach this balance?";[45] and

    - "What, if any, religious or personal beliefs do you have about sickness, health care decision-making, or dying?".[44]

- Identify the goals, benefits and burdens of other treatments and/or interventions the patient/carer/family may wish to discuss, e.g. CPR, ventilation, dialysis, artificial nutrition and hydration, antibiotics, etc.

- Discuss the likely progression of the disease, potential future symptoms and other relevant medical issues.

- Discuss the risks and benefits of current treatment options.

- Discuss life goals, spiritual and religious values and beliefs, cultural values and how these should influence medical decision-making, existential and/or psycho-social issues.

ACTIVITY SIX: ANSWER AID (continued)

- Determine treatment goals, preferences and care wishes, including the process of dying and preferences for place of death (when appropriate); tasks that need action; financial and/or other practical issues; and instructions for families/carers.

- Avoid medical jargon and provide realistic information on prognosis and treatment options with an emphasis on how you expect their illness will impact daily living and function.

- Some patients or family members may not have heard of ACP or hold a false belief about what it means. It is important that the health care team explains what ACP is clearly and simply, and outlines some of the reasons patients/carers/families may want to have these discussions.

- Determine goals of care and identify any specific desires for how information should be shared with family members. Some opening questions may include: "You may be aware that in Western Australia new laws have been introduced allowing people to define who will make decisions for them and how this will happen if they are ever too unwell to be able to make their own decisions. Is that something you are interested in finding out about?"

- Check if the patient already has an AHD, Living Will, Enduring Power of Guardianship, Enduring Power of Attorney or similar. If so, do they need to be reviewed?

ACTIVITY SIX: ANSWER AID (continued)

What other strategies or techniques could the nurse have used to better communicate with the patient about dialysis? How could she check his understanding?

When the nurse is explaining dialysis to Mr Barry, she frequently touches his arm. This might be appropriate for Caucasian patients but is not necessarily culturally appropriate for Aboriginal elders or Aboriginal men.

English is likely to have been Mr Barry's second language. As such, the nurse might have been able to use pictures to better explain dialysis. New technologies such as iPads and tablets are a useful way of communicating to patients about complicated medical procedures in ways which they understand. This would also help minimise physical contact in situations where that might be culturally inappropriate or insensitive.

Checking for patient understanding is essential to avoiding miscommunications. The nurse should first ask Mr Barry what understands about his renal failure and dialysis. This allows for an understanding of the patient's perception of the situation. The nurse should check for understanding after her explanation with a question such as "So that I can make sure that I've done a good job of explaining things to you, can you tell me what you are taking away from this discussion?".[46]

Scene Three: Back to country

Please watch 'I just want to go home!': Scene Three

Notes:

ACTIVITY SEVEN

If you had to identify one point where a change in behaviour or action could have changed the outcome, where would it be?

What changes will you make in your personal (future) practice as a result of what you have learned after watching this resource?

ACTIVITY EIGHT

Watch Scenes One to Three again and complete LIPSERVICE (below) to determine how focused the individual characters were on the needs of service users and carers.

First letter	LIPSERVICE Questions	Your notes
L is for Language	• Does your patient speak English? • How well do they speak it? • Do you need to consider getting an interpreter to assist? • What is the person's education level and understanding – will you need to modify the language you use in order to help them understand what you are asking or telling them?	
I is for Introduction	• Make sure you introduce yourself to the person, and give them your role – especially if what you do is something that is not commonly known. While most patients will understand the role of a 'doctor', they may not be familiar with what an 'occupational therapist' does. If in doubt, you should explain your role.	
P is for Privacy, Dignity and Cultural issues	• Is this a person who is going to be embarrassed by being examined by someone of the opposite gender? • Should you ask before you address them by their first name (many more elderly patients are of a generation who value the respect that being called 'Mr' or 'Mrs' gives them). • Be aware of different cultural expectations that you may encounter.	
S is for Subjective Questioning	• This is where you take the person's history. • A thorough history will be invaluable in helping to make a diagnosis. • Be aware of the power of 'leading questions' though. • Ask open-ended rather than closed questions to obtain your answers.	

E is for Examination	• Some considerations here include talking the person through what it is that you are doing, especially if this is an invasive or unusual procedure for them. • Knowing what is happening and why, as well as what to expect, can help alleviate the person's concern about what it is you are doing to them.
R is for Review	• Talk through what you have done as part of the examination – and what it added to your knowledge of their condition. • For example, 'You were talking about how you get short of breath, and I could hear from listening to your chest that your lungs are quite congested.'
V is for Verdict	• The diagnosis. • What their history and your examination have led you to think is causing their symptoms and signs.
I is for Information	• What does the diagnosis mean for the person? • Having a diagnosis of a lump in the breast can mean many things. • The person needs to know about these.
C is to remind you to Check Understanding	• This is where you determine if what you have said has made sense to the person. • People may only hear the diagnosis and then go into a state of shock – which means they don't process what you tell them next.
E is for End or Exit	• What's going to happen next for the person? • What about follow up? • Referrals to other professionals?

Section Four: Literature review – End-of-life care

Over the past 50 years, medical decision-making has become increasingly complex. Life expectancy and the likelihood of living with chronic disease for a longer period in life have increased in Australia and Western societies in general.[47] While people are now surviving illnesses or traumatic injuries that would once have been fatal, survival may be accompanied by dependence, indignity and reduced function. This may not be considered an acceptable quality of life for some. A person may reach a point where they wish to forgo life-sustaining treatment.

It is essential to identify patients who are dying, in order to allow them and their caregivers to reorient their priorities and achieve their goals so that appropriate end-of-life care can be provided. While there are situations in which it is possible to identify the terminal phase with some accuracy, many diseases have a natural history of progression and exacerbations which makes the transition to the terminal phase difficult to identify.

Best practice in end-of-life care focuses on supporting both the patient and their family. End-of-life care attends not just to the physical but also the psychosocial and spiritual concerns of patients and their families, and extends into the bereavement period. It requires good communication and teamwork from health care professionals.

Advance care planning (ACP)

ACP is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. ACP is directed at improving quality of care, facilitating patient self-determination and reducing unwanted and unwarranted medical treatments and hospitalisations.[48] By respecting every person's right to autonomy, dignity and fully-informed consent, health professionals can assist individuals to reflect upon, choose and communicate their wishes regarding current and future health care.[48]

ACP can assist to ensure a patient's preferences are known when crucial health and other personal decisions are required after they have lost decision-making capacity. ACP is a consultative and ongoing process that enables patients to choose future health care options which align with their personal beliefs and/or goals. Health care providers, family members and other important people close to the patient can collaborate and facilitate this process.

ACP does not need to be complicated, and can be summarised in five steps:[35]

1. Identifying your future medical and personal care needs;

2. Planning your care;

3. Choosing your helper;

4. Putting your decisions in writing; and

5. Informing others.

Advanced Health Directives (AHDs)

An AHD is a legally binding document that is completed using a prescribed form which contains a person's decisions about future treatment in anticipation of a time when they may be unable to make reasonable judgments for themselves.[39] A valid AHD documents treatment decisions in which a person consents or refuses consent to future treatments according to specific circumstances.[39]

AHDs are focused on the future care of a person, not on the management of his or her assets. They can also appoint substitute decision-makers to make decisions about health care and personal life management. Enduring Powers of Guardianship and Enduring Powers of Attorney that include health decision-making are the most commonly used AHDs.

AHDs have been referred to as life management documents which can be completed in home, community, hospital, institutional and aged care settings. AHDs are not meant to be involved in controlling medical treatment decisions, rather the aim is that people will live well and die with dignity in accordance with their personal beliefs.

What can an AHD do?

An AHD is legally binding and allows the maker to consent or refuse consent to treatment.[47] An AHD **cannot** be used to:

- Require unlawful medical interventions such as euthanasia. An AHD cannot require or authorise a health professional to take active steps to unnaturally end life;[47]

- Require specific interventions if they are not clinically indicated;[47] and

- Record wishes about organ and tissue donation. An AHD is ineffective after death. If a patient would like to donate their organs and tissues, they can register their wishes on

the Australian Organ Donation Register by contacting their local Medicare Australia office or visiting www.medicareaustralia.com.au for further information.[47]

Who can prepare an AHD?

It is possible to make an AHD if someone is at least 18 years of age and has full legal capacity. The maker must prepare their own AHD; it is not possible for one person to make an AHD on behalf of someone else without their knowledge or consent. However, if a patient is physically incapable of writing and signing their AHD (due to a disability or physical impairment, for example), they may direct another person to write and sign the AHD on their behalf and in accordance with their wishes. The person writing and signing the AHD on behalf of the maker and at their direction cannot then be a witness to the AHD as well, and other witnesses to the act of writing and signing must be found.[47]

Witnessing

An AHD must be signed in the presence of two witnesses. The witnesses must sign in the patient's presence and in the presence of each other. The witnesses must each be at least 18 years of age. One of the witnesses must also be a person who is authorised to witness statutory declarations. All registered health professionals are able to witness the document.[39]

Medical and legal advice

Whilst patients are not required to seek medical or legal advice to make an AHD they should be encouraged to do so. Health professionals can also advise patients that it may be useful for them to seek assistance to reassure themselves and their families that all possible options have been considered in their best interests. Additionally, in the event that there is later uncertainty about their AHD, the person/s whom provided advice may be able to provide assistance to ensure that the patient's treatment decisions are respected.

Record-keeping

Currently there are no national or State-based registers for AHDs. Copies of AHD forms should be kept with other legal documents and copies provided to the relevant health care providers, families/carers and legal representatives (where required).

Substitute decision-maker (SDM)

A substitute decision-maker (SDM) may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker by the relevant State/Territory-based Guardianship Acts. A document that appoints an SDM to make health, medical, residential and other personal decisions (but not financial or legal decisions) is considered to be an AHD.[40] More than one SDM can be appointed under an AHD.[39]

There are three main categories of SDMs:

1. SDMs chosen by the person (e.g. one or more Enduring Guardians appointed under a statutory AHD or a nominated SDM in a common law AHD);
2. SDMs assigned to the person by the law in the absence of an appointed SDM (e.g. family member, carer or 'person responsible'); and
3. SDMs appointed for the person (e.g. a guardian appointed by a guardianship tribunal).

A *substitute decision* is one made on behalf of a person who lacks capacity to make his or her own decision. A substitute decision seeks to replicate the decision it is thought the person would have made, whereas a *surrogate decision* reflects the view of the decision-maker and may not necessarily accord with the decision the person might have made.[39] A *contemporaneous substitute decision* is one that reflects or takes account of the current or contemporary circumstances, while still seeking to make the decision it is thought the person would have made if he or she had had access to contemporary information and advice.

History of AHDs

As an unintended consequence of rapid change in medicine over the last 40-50 years in Western nations, life-extending medical advances were occasionally putting patients in unacceptable circumstances when they were unable to communicate. As a response, some States of the US legislated 'living wills' which allowed people to record their preferences for medical treatment in advance, in case they became unable to communicate at a later stage.[40] By the end of the 1970s, most States in the US had '...ratified pieces of legislation that enabled patients to document end-of-life treatment decisions in the form of Living Wills, do not resuscitate (DNR) orders, or do not hospitalise (DNH) order'.[40]

In Britain, similar support for respecting patient's autonomy in decision-making with the right of an individual to refuse treatments was being accepted as part of palliative care services for the

terminally-ill.[40] Britain relied on common law until the passage of the *Mental Capacity Act* in 2005 which largely reproduced the common law.[40]

In Australia, early proponents for respecting an individual's right of treatment choice were mainly associated with the delivery of palliative care and the establishment of palliative care units.[40] Other researchers and ethicists were actively publishing in favour of autonomy and self-determination for the community at large.[40,49,50] AHDs became a conversation prior to 1998 through the pioneering work of Colleen Cartwright.[50,51]

International experience now informs policy and regulation addressing impaired decision-making capacity and its impact in health and care settings in Australia. One of the difficulties faced by the States has been the lack of case law in Australia to provide direction on the legality of an AHD.[40] It was not until August 2009 that an Australian court delivered a decision that affirmed the legality of instructions in AHDs and provided a summary of principles for practitioners to follow when provided with an AHD in an emergency situation.

Uptake of ACP and AHDs

Experience in the USA shows completion rates of AHDs of 10%-45%, but these rates vary dramatically among patient populations and health care settings.[39] Even when AHDs are completed, most health professionals are not aware of them and care is inconsistent with specific directives written in medical records at least half the time.[39]

In contrast to AHDs, the ACP process has proven far more successful in other parts of the world. In Australia, it has been estimated that less than 1% of residential aged care facility residents had an advance care plan in 2000, in contrast with more than 70% in nursing homes and up to 94% in hospices in the US in the same period.[39] Currently, acutely ill individuals complete AHDs only slightly more often than the healthy population. Only one in three chronically ill individuals in the community have completed AHDs (e.g. 35% in dialysis patients, 32% in COPD patients), and the comprehensiveness and applicability of AHDs vary substantially.[39]

National Framework for Advanced Care Directives[2]

In 2011 the Australian Health Ministers Advisory Council (AHMAC) developed the National

---

[2] The term 'Advanced Care Directive' has been adopted for use at the national level. The Western Australian health and legal system tends towards use of the term 'Advanced Health Directive' and that terminology has been used throughout this Facilitators' Guide. The National Framework includes a useful discussion on terminology.

[Framework for Advanced Care Directives](#) (the "National Framework"). It is intended as an aspirational document which describes the goals for which policy and practice should aim, rather than reflecting current law and practice across Australia.[40] The National Framework includes a Code for Ethical Practice for Advanced Care Directives and a set of Best Practice Standards for Advanced Care Directives which address issues including:

- AHDs may record personal values and life goals, describe circumstances the person would find unacceptable, identify specific medical interventions, appoint an SDM, or a combination of these;
- AHDs are relevant to adults at all stages of life – they can be completed by competent adults whether they are healthy and active, have recently had a disease diagnosed, are chronically ill, or at the end of their lives;
- AHDs can relate to any future time of impaired decision-making capacity, not just at the end-of-life – they can be activated during temporary periods of impaired or lost capacity such as an episode of mental illness or transient unconsciousness; and
- AHDs may cover health and personal care, not just medical treatment – they recognise that health has emotional and spiritual as well as physical dimensions – and can also address residential and other personal matters.

Code for Ethical Practice for Advanced Care Directives

The Code for Ethical Practice for Advanced Care Directives is intended to provide a set of principles to guide practice in health, institutional and aged care settings where AHDs are used for health, medical, residential and other personal decisions:[40]

1. *Advanced Care Directives are founded on respect for a person's autonomy and are focused on the person.*

   An ACD reflects personal views and is intended to ensure that a person's preferences and directions are known so they can be respected and honoured beyond loss of decision-making capacity.

2. *Competent adults are autonomous individuals and are entitled to make their own decisions about personal and health matters.*

   A competent adult can complete an ACD to guide future decision-making; a person's ACD will be valid regardless of whether the person's written directions were informed by, or are consistent with, medical advice.

3. *Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs.*

   Autonomy can be exercised by self- determined decisions, delegating decisions to others, making collaborative decisions within a family or community context, or a combination of these approaches.

4. *Adults are presumed competent.*

   An adult should be presumed competent at the time of completing an ACD unless there is good reason to question his or her competence at that time.

5. *Directions in Advanced Care Directives may reflect a broad concept of health.*

   Directions are not limited to medical treatment decisions, but may include directions about unacceptable circumstances, and preferred care and residential arrangements.

6. *Directions in Advanced Care Directives can relate to any future time.*

   Directions can be written to apply to any period of impaired decision-making capacity, and are not limited to the end-of-life.

7. *The person decides what constitutes quality of life.*

   The person determines his or her own preferred outcomes of care and desired levels of personal functional ability, and decides what circumstances are intolerable or unacceptable and which interventions are overly burdensome or intrusive; the person can communicate this information in the ACD or through discussion with a substitute decision-maker.

8. *The substitute decision-maker has the same authority as the person when competent.*

   The decision of a substitute decision- maker validly appointed under an ACD expresses the wishes and directions of the person; health care professionals provide advice to the substitute decision-maker about appropriate, beneficial and available treatment options.

9. *The substitute decision-maker must honour residual decision-making capacity.*

   The substitute decision-maker must consider each decision as the need arises and only make a substitute decision if the person is unable to make that particular decision.

10. *The primary decision-making standard for substitute decision-makers is substituted judgment.*

The substitute decision-maker has an obligation to make the decision the person would have made in the current circumstances had decision-making capacity not been impaired; substitute decision-makers should base their decision on what they know or can surmise about the person's life-goals, views, values and beliefs, taking into account information, including medical advice, that the decision-maker believes the person would have considered relevant.

11. *A substitute decision-maker should only base his or her decision on best interests when there is no evidence of the person's preferences on which to base substituted judgment.*

   The best interests of a person are personal in nature and not limited to medical interests or biological factors. If a person is unable to indicate what his or her best interests are, they are then defined by the chosen or legally assigned substitute decision-maker.

12. *An Advanced Care Directive can be relied upon if it appears valid.*

   A health care professional is entitled to assume that an ACD was completed by a competent adult without undue influence or coercion and is therefore valid, unless there are reasons to question that assumption.

13. *A refusal of a health-related intervention in a valid Advanced Care Directive must be followed, if intended by the person to apply to the situation.*

   A person can indicate in an ACD his or her advance refusal of health care, medical treatment, life-sustaining measures or hospital transfer through either written directions or appointing a substitute decision-maker. If intended to apply to the situation, such refusals in an ACD must be respected regardless of whether they may lead to serious deterioration in health or death, even where they differ from the views of a legally recognised substitute decision-maker, family members or health and aged care professionals caring for the person.

14. *A person, or their legally recognised substitute decision-maker, can consent to treatment offered, refuse treatment offered, but cannot demand treatment.*

   A person cannot use an ACD to demand particular medical interventions or treatment or to request something illegal. Health care professionals are not required to offer treatment options that they consider neither medically beneficial nor clinically appropriate, nor to accede to demands for such treatment written in an ACD. Health care professionals should discuss and explain all appropriate treatment options with legally recognised

substitute decision-makers.

15. *A valid Advanced Care Directive that expresses preferences or refusals relevant and specific to the situation at hand must be followed.*

When the terms of an ACD do not apply directly in the circumstances, the person's expressed values and preferred outcomes of care should guide decisions made by health and aged care professionals and substitute decision-makers.[40]

The Code for Ethical Practice underpins the Best Practice Standards. It is acknowledged that local laws will override this Code where they differ, but it is intended that over time State and Commonwealth legislation will align with the Code.

Best Practice Standards for Advanced Care Directives

The Best Practice Standards are founded on best practice evidence. The Standards are organised under six subheadings:

- Two sets of core standards designed to guide initial development of law and policy and of forms and guidelines;
- Three sets of specific standards designed to address the detail of law, policy, forms and guidelines that follow the ACDs journey from completing, through activating ACDs to making decisions under ACDs; and
- A final set of standards specifically related to problem-solving.

The Best Practice Standards apply to Advanced Care Directives that provide for substitute decision-making about health and medical care, residential arrangements and other personal matters, but do not apply to or affect the operation of Enduring Powers that appoint a SDM to manage a person's financial and legal affairs.

Challenges

Australian and international research indicates the uptake of AHDs has been low and that they are neither well-known nor widely understood outside of specific ACP programs.[35] However, recent studies indicate AHDs can lead to treatment decisions that respect patient preferences and reduce hospitalisation rates at the end-of-life, especially for nursing home residents. While it is thought that AHDs work well most of the time, they cannot resolve all conflicts in families nor can they guarantee a smooth decision-making pathway in every instance.[48]

A number of difficulties have arisen in relation to working with AHDs, for example when healthy people write specific medical directions in advance of any diagnosis of disease or injury. At times decision-makers try to interpret written medical directions that are uninformed, too specific to account for new treatments, or too non-specific to guide medical decisions.[39] Some people have changed their stated medical treatment preferences over time but fail to update their AHD. Health professionals can experience difficulties when interpreting directions recorded in AHDs, when they do not follow written directions in an AHD, or do not understand the rights of SDMs to make decisions.[48]

Validity of treatment decisions

A treatment decision contained in an AHD will be invalid (void) if:

- It was not made voluntarily. For example, if a patient was pressured by another person to make the treatment decision and the patient felt they had no choice but to do so;

- It was made as a result of inducement. For example, if a patient was told that a person close to them would receive some financial benefit if the patient agreed to make the treatment decision, and the patient made the treatment decision for this reason;

- It was made as a result of coercion. For example, if the patient was told that their family would only continue to care for them if they agreed to make a treatment decision, and the patient made the treatment decision for this reason;

- At the time that the patient made the AHD, they did not understand the treatment decision. For example, if the patient made a treatment decision which provided consent to receive a particular type of treatment, and the patient did not know what this treatment was, what it involved or what the risks of the treatment were; and

- At the time that the patient made the AHD, they did not understand the consequences of making the treatment decision. For example, if the patient did not understand that the treatment they refused consent for was necessary to save their own life.

If there is any doubt about the validity of an AHD, an application can be made to the relevant State Administrative Tribunal (SAT)[40] for clarification. Whether or not an AHD will be valid in another State or Territory of Australia will depend on the laws applying in that jurisdiction.

Impact of delayed planning for end-of-life care

Delayed end-of-life decision-making has led to a number of adverse outcomes including:

- Continued aggressive, unwanted and/or unwarranted life-sustaining measures instigated for those approaching end-of-life, including those who are imminently dying;

- Poor experiences for families where distraught family members are called on at a time of grieving to engage in end-of-life decisions, and who often experience distress observing life-sustaining measures in their dying loved one;

- Potentially avoidable conflicts between families and the health care team, or within the health care team, about the best course of treatment and care for the dying patient;

- Care being delivered in acute settings when better patient outcomes could be delivered in supported community or home environments; and

- Stress for health professionals balancing their obligation to act in the best interests of dying patients, sometimes differing views amongst treating clinicians and families about what that entails, and good stewardship of health resources.

Autonomy and cultural appropriateness

Modern bioethics has been tremendously influenced, both in theory and in practice, by the four principles approach:

1. Autonomy;
2. Nonmaleficence;
3. Beneficence; and
4. Justice.

Respect for autonomy dictates that patients who have decision-making capacity have a right to voice their medical treatment preferences, and the health care team has the duty to respect those preferences.[52] Nonmaleficence directs practitioners to maximize the benefit to patients while minimizing the harm.[52] Beneficence promotes the welfare and best interest of patients.[52] Finally, justice demands fair, equitable, and appropriate treatment for all patients.[52] These ethical principles are commonly referred to in professional ethical guidelines and applied in clinical decision-making.[52] See 'Section Four: Literature review – Duty of care' in *Interprofessional Learning Through Simulation Project: It's just a fracture! – Acute episode with underlying chronic conditions and social considerations* for a discussion on the four principles.

There is an argument that each of the principles are equal in their importance or without

hierarchical ranking.[53] A contrasting school of thought postulates that respect for autonomy should have priority over the other three principles.[54,55] Respect for autonomy has been widely accepted and applied in clinical and research settings over many decades with the advent of informed consent. Gaining informed consent for medical intervention and from human subjects in research has become the norm under the law. Failure to secure adequately informed consent can lead to serious ethical and legal consequences.[53] In other words, while the best interests of the patient (i.e. nonmaleficence and beneficence) remain at the core of health care, it is the values, preferences, wishes, and self-determination (i.e. autonomy) of the patient that distinguishes what is beneficial from what is harmful in the Western approach to bioethics.[53]

In this context, the heterogeneity of Aboriginal and Torres Strait Islander cultures means models of care need to be flexible to respect the autonomy and address their specific needs. Aboriginal and Torres Strait Islander people can be ambivalent toward Western health care and are under-represented in the palliative and end-of-life care patient population.[57] Contemporary models of palliative and end-of-life care in Australia, which are dominated by Western traditions and the biomedical paradigm, should integrate Aboriginal and Torres Strait Islander traditions, values and cultural practice relating to palliation and end-of-life transitions.[56] This may assist patients to feel they have autonomy in the health care setting.

The concept of cultural safety is acknowledgment of cultural assumptions, lived experiences, Aboriginal and Torres Strait Islander holistic concepts of health, and the historical context of ill-health, dispossession and racism.[56] This concept needs to underpin improvements in Aboriginal and Torres Strait Islander palliative and end-of-life care. Health professionals must be aware of these factors, their own prejudices and the historical power disparities that they reproduce in health service delivery. 'The core essence of cultural safety is that the health professional understands their own cultural identity, and is aware of the impact their culture can have on another'.[43]

Patients rely on health professionals for information when they do not have the necessary background or information for making informed choices.[35] Quality care at the end-of-life is realised when it is culturally appropriate to the particular needs of patients and groups that includes families, kinships and carers.[56] The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for Aboriginal and Torres Strait Islander patients, their families and carers.[56]

The place of dying and death is culturally and spiritually significant for many Aboriginal and

Torres Strait Islander peoples.[58] The principle of dying in the place of choice and the need to return to country has a particular meaning at the end of their lives. While logistically it may be challenging, returning to country has the potential to realise the greatest gain for patients, their families and communities at the end-of-life.[59] Understanding and respecting this aspect of Aboriginal and Torres Strait Islander culture ensures the promotion and facilitation of autonomous behaviour in health settings.

AHDs and cultural appropriateness

Autonomy is valued differently by different people depending upon their cultural, spiritual and religious beliefs or background. Laws and policies should allow for autonomy to be exercised in a range of ways, including using an AHD to exercise self-determination, to formally delegate decisions to others, to ensure decisions are made collaboratively with or by the family, and a combination of these approaches.[40]

Given Australia's Indigenous heritage and increasingly multicultural population, it cannot be assumed that individual autonomy is the prevalent ethic in all communities or that Western values and decision-making norms will apply to all families. AHDs can provide a means for a person to appoint the culturally-appropriate decision-maker within his or her family or community context. However it must be recognised that AHDs are not appropriate for every person or every community, and that a person may choose not to complete an AHD.[40]

Conclusion

Australian and international research indicates the uptake of AHDs has been low and that they are neither well-known nor widely understood outside of specific ACP programs. However, recent studies indicate that AHDs can lead to treatment decisions which respect patient preferences and which can help reduce hospitalisation rates at the end-of-life. The National Framework for Advanced Care Directives, including the Code for Ethical Practice for Advanced Care Directives and a set of Best Practice Standards for Advanced Care Directives, is a particularly useful starting point for a discussion on AHDs in Australia.

Regulatory, legislative and policy instruments must emphasise that completing an AHD is optional; a person must not feel coerced to write an AHD or be led to believe (intentionally or unintentionally) that it is mandatory to complete one. An AHD will be void where it has not been made voluntarily or made as a result of inducement or coercion. Although there is no legal requirement to seek medical advice, when a person consults a medical practitioner or nurse for professional advice about completing an AHD, especially about whether his or her directions will be understood and interpreted as and when intended, it is the responsibility of the health professional to be assured that the person:

- Understands what an AHD is for and how it would be used in the future;
- Has had adequate opportunity to receive advice on various health care options relevant to any current diagnosis and understands the advice provided; and
- Comprehends the likely outcomes of the decisions he or she has made and the preferences he or she has recorded.

Although challenging for health professionals, families and caregivers, delaying end-of-life conversations and decision-making can lead to adverse outcomes for patients and create unnecessary trauma for all involved. Health professionals are required to balance their obligation to act in the best interests of dying patients, the sometimes differing views amongst treating clinicians and families about what that entails, and good stewardship of health resources.

The principle of autonomy underpins end-of-life care, ACP and AHDs. It is the values, preferences, wishes, and self-determination (i.e. autonomy) of the patient that distinguishes what is beneficial from what is harmful in the Western approach to bioethics.[53] This is particularly pertinent in respect to Australia for Aboriginal and Torres Strait Islander peoples.

Models of care need to be flexible enough to respect the autonomy and address the specific cultural needs of Aboriginal and Torres Strait Islander peoples. Contemporary models of palliative and end-of-life care in Australia should integrate Aboriginal and Torres Strait Islander traditions, values and cultural practice relating to palliation and end-of-life transitions. This will avoid creating unnecessary and additional distress for patients, families/carers and communities at a difficult time.

Further resources:

Advance Health Directives, available at:

http//:www.health.wa.gov.au/advancehealthdirective

Indigenous Australians and end-of-life care, The Clinical Ethics Resource, available at:

http://clinicalethics.info/indigenous-australians/end-of-life-care

Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource kit, Department of Health, available at:

http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm

---

Acronyms

ACP	Advance care planning
ACD	Advanced Care Directive
AHD	Advanced Health Directive
AHMAC	Australian Health Ministers Advisory Council
AIPPEN	Australasian Interprofessional Practice and Education Network
ASPIRIN	Acknowledge the problem; Situational analysis; Provide some solutions; Implement; Review the outcome; Inform stakeholders; Next steps
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardiopulmonary resuscitation
IPE	Interprofessional education
IPL	Interprofessional learning
IPP	Interprofessional practice
LIPSERVICE	Language; Introduction; Privacy dignity and cultural issues; Subjective questioning; Examination; Review; Verdict; Information; Check understanding; End or exit
WHO	World Health Organization

Glossary

Advance Care Planning (ACP)	Advance care planning is an ongoing discussion between an individual, their carers/ family and their health care team about their values, beliefs, treatment and care options; in particular, their wishes for future care should they no longer be able to do so at the time decisions are needed. Ideally these decisions should be documented in an Advance Health Directive.
Advance Health Directive (AHD)	An Advance Health Directive is a legal document that is completed using a form which contains a person's decisions about future treatment in anticipation of a time when they may be unable to make reasonable judgments for him/herself. A valid AHD is legally binding and documents treatment decisions in which a person consents or refuses consent to future treatment according to specific circumstances. A valid AHD must be in the form or substantially in the form prescribed by the regulations.
Beneficence	A group of norms for providing benefits and balancing benefits against risks and costs.[60]
Capacity	Capacity is the cognitive ability to understand and appreciate the context, choices and consequences of our decisions. It is also a person's performance on measures of decision-making ability. On the other hand, competency is determined by courts and tribunals and is the judgement that a person's capacity is adequate to make the decision in question. Competency is a legal construct and capacity is a clinical one.
Duty of care	Where a health care provider has undertaken to provide care, supervision or control of a patient/patient or where it has assumed responsibility for the management of the patient/client's safety.[61]
End-of-life care	Patients are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

advanced, progressive, incurable conditions;

general frailty and co-existing conditions that mean they are expected to die within 12 months;

existing conditions if they are at risk of dying from a sudden acute crisis in their condition; and

life-threatening acute conditions caused by sudden catastrophic events.

Enduring Power of Attorney	An Enduring Power of Attorney is a legal agreement that enables a person to appoint a trusted person – or people – to make financial and property decisions on their behalf. An enduring power of attorney is an agreement made by choice that can be executed by anyone over the age of 18, with capacity.
Enduring Power of Guardianship	An Enduring Power of Guardianship is a document in which a person nominates an Enduring Guardian to make personal, lifestyle and treatment decisions on their behalf in the event that they are unable to make reasonable judgments about these matters in the future. An EPG is different from an Enduring Power of Attorney (EPA), which relates to financial and property matters.
Informed consent	An individual's autonomous authorisation of a medical intervention or participation in research.[60]
Interprofessional education	Occasions when two or more professions learn from, with and about each other to improve collaboration and the quality of care.[8]
Interprofessional learning	Learning arising from interaction between members (or students) of two professions. This may be a product of interprofessional education or happen spontaneously in the workplace or in education settings.[8]
Interprofessional practice	Two or more professions working together as a team with a common purpose, commitment and mutual respect.[8]
Mnemonic	Any learning technique that aids information retention, e.g. acronyms and memorable phrases.
Nonmaleficence	An obligation not to inflict harm on others.[60]
Palliative care	Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of the early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.
Paternalism	Literally means 'behaving like a father'.[36]
Proxy or substitute	The individual the person nominates to assist in decision-making on his/her behalf in the future, should the person be unable to participate in the decision-making process themselves. The individual proxy or substitute does not have to be next-of-kin or a family member.

Simulated learning environment	A technique, not a technology, to replace or amplify real experiences with guided experiences, often immersive in nature, that evoke or replicate substantial aspects of the real world in a fully interactive fashion.[1]
Statutory Advance Health Directive	A statutory AHD is one that is enshrined in legislation. This term is intended to include, for example, an Enduring Power of Guardianship, an Enduring Power of Attorney for health or personal decisions, an Advance Health Directive, a Medical Power of Attorney, a Refusal of Treatment Certificate, a Health Direction and any other similar AHD in legislation. It does not include, for example, the Respecting Patient Choices Program's Statement of Choices form which is not established under legislation but is recognised under common law.

References

1.   Gaba, D. (2004). The future vision of simulation in healthcare. *Quality in Health Care*, 13(1): p. 2-10.

2.   Kenaszchuk, C., K. MacMillan, M. van Soeren, and S. Reeves (2011). Interprofessional simulated learning: short-term associations between simulation and interprofessional collaboration. *BMC Medicine*, 9(29).

3.   Baker, C., C. Pulling, R. McGraw, J.D. Dagnone, D. Hopkins-Rosseel, and J. Medves (2008). Simulation in interprofessional education for patient-centred collaborative care. *Journal of Advanced Nursing*, 64(4): p. 372-379.

4.   Health Workforce Australia (2010). *Use of Simulated Learning Environments (SLE) in Professional Entry Level Curricula of Selected Professions in Australia*.

5.   The Interprofessional Curriculum Renewal Consortium Australia (2013). *Interprofessional Education: a national audit.* Report to Health Workforce Australia.

6.   McCallin, A. (2005) Interprofessional practice: learning how to collaborate. *Contemp Nurse*, 20(1): p. 28-37.

7.   World Health Organization (2010). *Framework for action on interprofessional education and collaborative practice.* Geneva: World Health Organization.

8.   Freeth, D., M. Hammick, S. Reeves, I. Koppel, and H. Barr (2005). *Effective interprofessional education: development, delivery and evaluation.* Oxford: Blackwell Publishing.

9.   Centre for the Advancement of Interprofessional Education (2006). CAIPE reissues it's statement on the definition and principles of effective interprofessional education. *CAIPE Bulletin*, 26: p. 3.

10.   Australasian Interprofessional Practice and Education Network (2013). "What is IPE/IPL/IPP?" Retrieved March 2013, from http://www.aippen.net/what-is-ipe-ipl-ipp.

11.   Choi, B.C. and A.W. Pak (2008). Multidisciplinarity, interdisciplinarity, and transdisciplinarity in health research, services, education and policy: 3. Discipline, inter-discipline distance, and selection of discipline. *Clinical and Investigative Medicine*, 31(1): p. E41-E48.

12.   Atwal, A. and K. Caldwell (2006). Nurses' perceptions of multidisciplinary team work in acute health-care. *International Journal of Nursing Practice*, 12(6): p. 359-65.
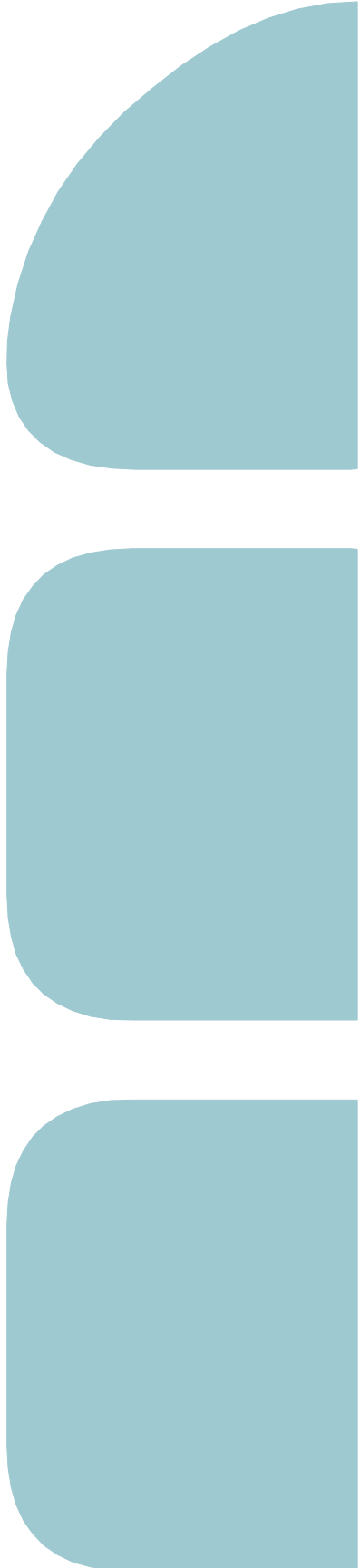
13. Griffin, S. (1996). Occupational therapists as health care team members: A review of the literature. *Australian Occupational Therapy Journal*, 43(1): p. 83-94.

14. Way, D., N. Busing, and L. Jones (2002). *Implementing Strategies: collaboration in primary care – family doctors and nurse practitioners delivering shared care*. Toronto: Ontario College of Family Physicians.

15. Newton, C., V. Wood, and L. Nasmith (2012). Building capacity for interprofessional practice. *The Clinical Teacher*, 9(2): p. 94-98.

16. Braithwaite, J., J. Westbrook, A. Foxwell, R. Boyce, T. Devinney, M. Budge, K. Murphy, M. Ryall, J. Beutel, R. Vanderheide, E. Renton, J. Travaglia, J. Stone, A. Barnard, D. Greenfield, A. Corbett, P. Nugus, and R. Clay-Williams (2007). An action research protocol to strengthen system-wide inter-professional learning and practice [LP0775514]. *BMC Health Services Research*, 13(7): p. 144.

17. Interprofessional Education Collaborative (2011). *Team-based competencies: building a shared foundation for education and clinical practice, conference proceedings*. USA: Interprofessional Education Collaborative.

18. Reason, J. (1995). Understanding adverse events: human factors. *Quality in Health Care*, 4(2): p. 80-89.

19. Ross, J. (2009). Considering the human factors in patient safety. *Journal of PeriAnesthesia Nursing*, 24(1): p. 55-56.

20. Bromiley, M. and J. Reid (2012) Clinical human factors: The need to speak up to improve patient safety *Nursing Standard*, 26(35): p. 35.

21. Mercer, S.J, C.L Whittle, and P.F Mahoney (2010) Lessons from the battlefield: human factors in defence anaesthesia. *British Journal of Anaesthesia*, 105: p. 9–20.

22. Bion, J.F., T. Abrusci, and P. Hibbert (2010). Human factors in the management of critically ill patient. *British Journal of Anaesthesia* 105: p. 26–33.

23. Toff, N.J. (2010). Human factors in anaesthesia: lessons from aviation. *British Journal of Anaesthesia*, 105: p. 21-5.

24. Leonard, M., S. Graham, and D. Bonacum (2004). The human factor: the critical importance of effective teamwork and communication in providing safe care. *Quality and Safety in Health Care*, 13(Suppl 1): p. i85–i90.

25.   Flin, R. and N. Matan (2004). Identifying and training non-technical skills for teams in acute medicine. *Quality and Safety in Health Care*, 13(Suppl 1): p. i80-i84.

26.   Dirkin, G.R. (1983). Cognitive tunneling: use of visual information under stress. *Perceptual and Motor Skills*, 56(1): p. 191-198.

27.   Freeman, M., C. Miller, and N. Ross (2000). The impact of individual philosophies of teamwork on multi-professional practice and the implications for education. *Journal of Interprofessional Care*, 14(3): p. 237-247.

28.   Interprofessional Ambulatory Care (IpAC) Program (2012). "IpAC Program Assessment Tool". Retrieved 8 April 2013, from http://www.ecu.edu.au/__data/assets/pdf_file/0011/297416/IPL-assessment-tool-for-5-Days-and-longer-v4.pdf.

29.   Interprofessional Education Collaborative Expert Panel (2011). *Core Competencies for Interprofessional Collaborative Practice*. Washington, D.C.: Interprofessional Education Collaborative.

30.   World Health Organization (2005). *Preparing a health care workforce for the 21st century: the challenge of chronic conditions*. Geneva: World Health Organization.

31.   Barr, H. (1998). Competent to collaborate: towards a competency-based model for interprofessional education. *Journal of Interprofessional Care*, 12(2): p. 181-187.

32.   McGrath, M. (1991). *Multidisciplinary Teamwork*. Aldershot: Avebury.

33.   Lamb, G., M. Schmitt, P. Edwards, F. Sainfort, I. Duva, and M. Higgins (2008 October 2-4). *Measuring staff nurse care coordination in the hospital*, in *National State of the Science Congress on Nursing Research*: Washington DC.

34.   Andershed, B. (2006). Relatives in end-of-life care--part 1: a systematic review of the literature the five last years, January 1999-February 2004. *J Clin Nurs*, 15(9): p. 1159-69.

35.   New South Wales Government (2013). *Advance Planning for Quality Care at End-of-Life - Action Plan 2013–2018 New South Wales Industry of Health Sydney*, Office of the Chief Health Officer, Editor.

36.   Freegard, H., ed. (2007). *Ethical practice for health professionals*. Melbourne, Australia: Thomson.

37.   Beauchamp, T.L. and J.F. Childress (1994). *Principles of biomedical ethics.* 4th ed. NY, New York: Oxford University Press.

38.   Cummings, S.M. and C. Cockerham (1997). Ethical Dilemmas in Discharge Planning for Patients with Alzheimer's Disease. *Health and Social Work*, 22(2): p. 101-8.

39.   Department of Health, WA (2012). *Advance Care Planning. A step-by-step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life.* WA Cancer and Palliative Care Network, WA Department of Health.

40.   Australian Health Minister's Advisory Council (2011). *A National Framework for Advance Care Directives.* Australian Health Minister's Advisory Council.

41.   Fischer, S., W. Gozansky, A. Sauaia, S. Min, J. Kutner, and A. Kramer (2006). A practical tool to identify patients who may benefit from a palliative approach: the CARING criteria. *J Pain Symptom Manage*, 31(4): p. 285-92.

42.   Stuart, B., L. Herbst, and B. Kinzbrunner (1996). Medical guidelines for determining prognosis in selected non-cancer diseases: the National Hospice Organization. *Hosp J*, 11(2): p. 47-63.

43.   Fenwick, C.E. (2001). *Pain management strategies for health professionals caring for Central Australian Aboriginal people.* Canberra: Commonwealth Department of Health and Aged Care.

44.   Karel, M.J., J. Powell, and M.D. Cantor (2004). Using a values discussion guide to facilitate communication in advance care planning. *Patient Educ Couns*, 55(1): p. 22-31.

45.   Austin Health (2006). *Respecting patient choices: an Australian Advance Care Planning Program: consultant's manual*. Western Australian Edition. Melbourne: Austin Health.

46.   West, H.F. (2010). "Tell me what you understand": the importance of checking for patient understanding. *The Journal of Supportive Oncology*, 8(5).

47.   Department of Health, Western Australia (2008). *A Guide For Health Professionals to the* Acts Amendments (Consent to Medical Treatment) Act 2008*. Office of the Chief Medical Officer: Western Australia Department of Health.

48.   Smith, M., N. Rousseau, J. Lecouturier, B. Gregson, J. Bond, and H. Rodgers (1997). Are older people satisfied with discharge information? *Nursing Times*, 93(43): p. 52-53.

49.   Steinberg, M.A., C. Cartwright, S.M. MacDonald, J.M. Najman, and G. Williams (1997). Self-determination in terminal care: a comparison of GP and community members' responses. *Australian Family Physician*, 26(6): p. 703-709.

50.   Steinberg, M., C. Cartwright, G. Williams, G. Robinson, and W. Tyler (1997). Survey of approval of Australia's Northern Territory *Rights of the Terminally Ill Act (1995). The Lancet*, 349(9051): p. 577.

51.   Cartwright, C. and M. Steinberg (1995). Decision-Making in Terminal Care: older people seek more involvement. *Social Alternatives*, 14(2): p. 7-10.

52.   Gillon, R. (1994). Medical ethics: four principles plus attention to scope. *BMJ*, 309(6948): p. 184-188.

53.   Fu-Chang Tasai, D. (2008). Personhood and Autonomy in Multicultural Health Care Settings. *Virtual Mentor*, 10(3): p. 171-176.

54.   Engelhardt Jr, H.T. (1986). *The Foundation of Bioethics*. 2 ed. New York, NY: Oxford University Press.

55.   Locke, J. (1964). *An Essay Concerning Human Understanding*. Vol. 2. London: Oxford University Press.

56.   Palliative Care Australia. "Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians: Position Statement". Retrieved from http://www.palliativecare.org.au/Portals/46/PCA%20-%20Palliative%20care%20and%20Indigenous%20Australians%20-%20position%20statement%20updated%2016-8-11.pdf.

57.   Sullivan, K., L. Johnston, C. Colyer, J. Beale, J. Willis, J. Harrison, and K. Welsh (2003). *National Indigenous palliative care needs study: final report.* Canberra: Department of Health and Ageing.

58.   Prior, D. (2009). The meaning of cancer for Australian Aboriginal women: changing the focus of cancer nursing. *European Journal of Oncology Nursing*, 13: p. 280-286.

59.   Stevenson, F.A., C.A. Barry, N. Britten, N. Barber, and C.P. Bradley (2000). Doctor-patient communication about drugs: the evidence for shared decision-making. *Soc Sci Med*, 50(6): p. 829-840.

60.   Beauchamp, T.L. and J.F. Childress (2001). *Principles of biomedical ethics.* 5th ed. NY, New York: Oxford University Press.

61.   Savage, P. (2007). *Legal issues for nursing students: Applied principles.* Frenchs Forest, NSW: Pearson Education Australia.

This document can be made available in alternative formats on request for a person with a disability.

Delivering a **Healthy WA**