



**Family Mechanisms and Readiness for Advance Care Planning
Engagement among Elderly Patients with Cancer in
Songkhla Province, Thailand**

Supakorn Sripaew

**A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Philosophy in Epidemiology (International Program)**

Prince of Songkla University

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ชื่อวิทยานิพนธ์	กลไกของครอบครัวและความพร้อมในการวางแผนการดูแลล่วงหน้าใน ผู้สูงอายุที่ป่วยเป็นโรคมะเร็งในจังหวัดสงขลา ประเทศไทย
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บทคัดย่อ

ความเป็นมาและความสำคัญของปัญหา

การเปลี่ยนแปลงตามวัยและการมีโรคร่วมหลายอย่างทำให้ผู้สูงอายุมีความเสี่ยงต่อสุขภาพ โดยเฉพาะอย่างยิ่งในผู้สูงอายุที่มีโรคมะเร็ง การรักษาเช่นการให้ยาเคมีบำบัดหรือรังสีรักษาอาจแสดงผลข้างเคียงที่รุนแรงขึ้น และบางครั้งการตอบสนองต่อการรักษาในผู้สูงอายุอาจไม่ดี การตัดสินใจเกี่ยวกับการรักษาร่วมกับผู้ป่วยมะเร็งในขณะที่สุขภาพของผู้ป่วยแย่ลงแล้วนั้นเป็นไปได้ยากเนื่องจากผู้ป่วยมักมีระดับความสามารถในการตัดสินใจที่จำกัด การวางแผนการดูแลล่วงหน้า (Advance Care Planning หรือ ACP) ได้ถูกบูรณาการเป็นส่วนหนึ่งในกระบวนการดูแลผู้ป่วยมะเร็ง โดย ACP เป็นกระบวนการสื่อสารระหว่างแพทย์ ผู้ป่วย และสมาชิกในครอบครัว เพื่อให้มั่นใจว่าความต้องการของผู้ป่วยได้รับการปฏิบัติตาม อย่างไรก็ตามในบริบทประเทศไทยนั้นคนไทยมักให้ความสำคัญกับการตัดสินใจของครอบครัว และในบางครั้งกระบวนการมีส่วนร่วมใน ACP อาจถูกขัดขวางด้วยกลไกในครอบครัวบางอย่าง เช่น การเก็บงำความจริง (conspiracy of silence) เป็นต้น การศึกษานี้จึงมีวัตถุประสงค์เพื่อทำความเข้าใจการรับรู้ของผู้ป่วยสูงอายุที่มีโรคมะเร็งและผู้ดูแลเกี่ยวกับ ACP ตรวจสอบว่ามุมมองของผู้ป่วยและครอบครัวมีความสอดคล้องกันหรือไม่ อธิบายลักษณะความพร้อมของผู้สูงอายุในการมีส่วนร่วมใน ACP และ ศึกษาความสัมพันธ์ระหว่างปัจจัยส่วนบุคคลและปัจจัยของครอบครัวต่อการมีส่วนร่วมใน ACP ในผู้สูงอายุที่มีโรคมะเร็ง

วิธีดำเนินการวิจัย

การศึกษาระยะที่ 1 มีเป้าหมายเพื่อสำรวจการรับรู้เกี่ยวกับ ACP ในผู้สูงอายุที่มีโรคมะเร็งและผู้ดูแล การศึกษานี้คัดเลือกผู้เข้าร่วมการศึกษาจากผู้ป่วยที่ได้รับการรักษาที่คลินิกรังสีรักษาและมะเร็งวิทยาของโรงพยาบาลสงขลาณครินทร์ เกณฑ์คัดเข้าของผู้ป่วยในการศึกษาช่วงนี้ได้แก่ ผู้ป่วยที่มีอายุ 60 ปีขึ้นไป ได้รับการวินิจฉัยว่าเป็นมะเร็งชนิดที่ไม่ใช่มะเร็งเม็ดเลือด

และสามารถสื่อสารด้วยภาษาไทยได้ ในขณะที่ผู้ดูแลต้องเป็นผู้ดูแลหลักที่สื่อสารด้วยภาษาไทยได้และเป็นผู้ดูแลที่ไม่ได้รับคำตอบแทน ผู้วิจัยคัดผู้ป่วยที่มีภาวะบกพร่องทางจิตหรือร่างกายที่รุนแรงหรือมีเนื้องอกในสมองออกจากการศึกษา หลังจากได้รับการอนุมัติจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ ผู้วิจัยเข้าถึงกลุ่มเป้าหมายโดยผ่านเจ้าหน้าที่ลงทะเบียนผู้ป่วย ซึ่งเป็นผู้แจ้งข้อมูลเกี่ยวกับการศึกษาเบื้องต้นแก่ผู้ป่วย การศึกษานี้ใช้การสุ่มตัวอย่างแบบหลากหลาย (Maximum Variation Sampling) เพื่อให้ได้กลุ่มตัวอย่างที่หลากหลาย

การเก็บข้อมูลดำเนินการผ่านการสัมภาษณ์แบบกึ่งโครงสร้าง ครอบคลุมหัวข้อต่าง ๆ เช่น การรับรู้เกี่ยวกับโรคข้อดีและอุปสรรคของ ACP และมุมมองที่เกี่ยวข้อง ผู้สัมภาษณ์จะสัมภาษณ์ผู้ดูแลก่อนผู้ป่วยเพื่อป้องกันความขัดแย้งระหว่างผู้วิจัยและผู้สูงอายุอันเกิดจากกระบวนการการสัมภาษณ์ การสัมภาษณ์ใช้เวลาประมาณ 45 นาที โดยได้รับอนุญาตให้บันทึกเสียงและจดบันทึกภาษาทราบดีถึงรายละเอียดต่างๆ การวิเคราะห์ข้อมูลใช้วิธีการวิเคราะห์แก่นสาระ (Thematic Analysis) โดยอ้างอิงแนวคิดจาก Health Beliefs Model เพื่อทำความเข้าใจการรับรู้ที่ส่งผลต่อความพร้อมในการมีส่วนร่วมใน ACP ผู้วิจัยใช้หลายมาตรการเพื่อยืนยันความน่าเชื่อถือของผลการศึกษา เช่น การตรวจสอบจากนักวิจัยหลายคน (investigator triangulation) และการอธิบายข้อมูลที่ละเอียด (thick descriptions) รวมถึงใช้การตรวจสอบผลการวิเคราะห์ร่วมกับผู้เชี่ยวชาญด้านระเบียบวิธีและการดูแลแบบประคับประคองเป็นต้นการจัดการและวิเคราะห์ข้อมูลในช่วงนี้ดำเนินการผ่านโปรแกรม Microsoft Excel และ R

การศึกษาในระยะที่ 2 เป็นการศึกษาระบบภาคตัดขวาง (cross-sectional study) ที่มีเป้าหมายเพื่อตอบวัตถุประสงค์ในข้อที่ 2 ถึงข้อที่ 4 ผู้วิจัยเกณฑ์อาสาสมัครที่มีคุณสมบัติเหมือนกับในระยะการศึกษาเชิงคุณภาพ ผู้วิจัยวิเคราะห์ข้อมูลความพร้อมในการมีส่วนร่วมใน ACP ของผู้ป่วยสูงอายุ โดยใช้สถิติและการสร้างแบบจำลองหลายวิธี ข้อมูลประชากรและความพร้อมต่อ ACP ถูกอธิบายโดยใช้สถิติเชิงพรรณนา การเปรียบเทียบมุมมองเกี่ยวกับ ACP ระหว่างผู้ป่วยและผู้ดูแลดำเนินการผ่านการวิเคราะห์สหสัมพันธ์ (Intraclass correlation) เพื่อประเมินความสอดคล้อง ผู้วิจัยใช้การวิเคราะห์ปัจจัยเชิงยืนยัน (Confirmatory Factor Analysis หรือ CFA) ด้วยแพ็คเกจ *lavaan* เพื่อยืนยันความน่าเชื่อถือของแบบสอบถามข้อดี-ข้อเสีย (pros-cons questionnaire) สำหรับการวิเคราะห์อื่น ๆ โมเดล CFA ใช้โครงสร้างที่มีความสัมพันธ์กัน (correlated structure) และการประเมินความเหมาะสมของโมเดลใช้ดัชนี เช่น Root Mean-Squared Error of Approximation (RMSEA) standardized root-mean-square residual (SRMR) และ Comparative Fit Index (CFI) โดยมีการตรวจสอบความถูกต้องของเกณฑ์การพิจารณาเกณฑ์ดังกล่าวด้วย dynamic fit indices หลังจากนั้นจึงใช้คะแนนมาตรฐาน (standardized score) ของแต่ละปัจจัยในการคำนวณคะแนนของแต่ละโครงสร้าง เพื่อให้สอดคล้องกับการศึกษาก่อนหน้านี้

การศึกษานี้ใช้การวิเคราะห์โดยตัวแบบเครือข่ายของเบย์ (Bayesian Network หรือ BN) เพื่ออธิบายกลไกของครอบครัวและการมีส่วนร่วมใน ACP ของผู้ป่วยสูงอายุที่มีโรคเรื้อรัง โดยนำข้อมูลเชิงคุณภาพในการศึกษาช่วงแรก มาใช้เพื่อเลือกตัวแปรสำหรับตัวแบบดังกล่าวเพื่อช่วยลดปัญหาการปรับแต่งที่มากเกินไป (overfitting) และเพื่อเพิ่มความสามารถในการตีความตัว

แบบ BN โดยตัวแปรของครอบครัว เช่น ลักษณะครอบครัวเดี่ยวหรือขยายและความสัมพันธ์ระหว่างผู้ดูแลกับผู้ป่วย ได้ถูกจัดกลุ่มโดยใช้การวิเคราะห์กลุ่มแฝง (Latent Class Analysis) โครงสร้าง BN ในการศึกษาถูกสร้างขึ้นโดยใช้ score-based algorithms และได้ปรึกษาผู้เชี่ยวชาญเพื่อประเมินความสัมพันธ์ที่แสดงอยู่ในตัวแบบ BN นอกจากนั้นผู้วิจัยได้ใช้ sensitivity analysis เพื่อระบุความไวของตัวแบบต่อการเปลี่ยนแปลงค่าพารามิเตอร์ความน่าจะเป็น นอกจากนั้นผู้วิจัยได้วิเคราะห์การแทรกแซงและจำลองการแทรกแซงโดยใช้ "do-operator" เพื่อช่วยจัดลำดับความสำคัญของตัวแปรเป้าหมายเพื่อออกแบบกลยุทธ์ในการเพิ่มความพร้อมสำหรับ ACP ในการศึกษาช่วงนี้ผู้วิจัยได้ใช้ GeNIe Modeler และแพ็คเกจต่างๆ ใน R software (*bnlearn*, *igraph*, และ *caret*) ในการจัดการและวิเคราะห์ข้อมูล

ผลการศึกษา

ในการศึกษาเชิงคุณภาพ ผู้วิจัยได้สัมภาษณ์ผู้ป่วยสูงอายุที่เป็นมะเร็งจำนวน 16 คน และผู้ดูแลของผู้ป่วยเหล่านั้น 16 คน พบแก่นสาระ 3 ประเด็นเกี่ยวกับการรับรู้ของผู้ป่วยและครอบครัวเกี่ยวกับ ACP แก่นสาระที่หนึ่ง คือ โอกาสอันเป็นประโยชน์ ซึ่งประกอบด้วยแก่นสาระย่อย ได้แก่ การเข้าใจคุณค่าชีวิตของตนเอง และการมั่นใจว่าความต้องการของผู้ป่วยจะได้รับการตอบสนอง แก่นสาระที่สอง คือ การใคร่ครวญและอุปสรรคต่อ ACP ซึ่งประกอบด้วยแก่นสาระย่อย ได้แก่ ACP เป็นเรื่องที่ไม่คุ้นเคยและอาจไม่มีความจำเป็น ACP มีประโยชน์น้อย ACP อาจทำให้ผู้ป่วยและครอบครัวกังวล ACP บั่นทอนความหวังในการรักษา และ ACP ไม่เหมาะสมกับสถานการณ์สุขภาพในปัจจุบัน และแก่นสาระที่สาม คือ สัญญาณสำหรับการเริ่มต้น ACP ซึ่งประกอบด้วย การรับรู้ถึงความสอดคล้องกับหลักศาสนาของตนเอง ความตระหนักถึงสถานะของสุขภาพ/มะเร็ง การมีโรคร่วมหลายโรค ประสบการณ์ความทุกข์ที่เกี่ยวข้องกับการรักษาทางการแพทย์ ความปรารถนาที่จะไม่เป็นภาระต่อครอบครัว การมีสมาชิกในครอบครัวที่ใกล้ชิดและความไว้วางใจในแพทย์

ในระยะที่สองของการศึกษา ผู้วิจัยได้เกณฑ์อาสาสมัครผู้ป่วยสูงอายุที่เป็นมะเร็งจำนวน 279 คนและผู้ดูแลของผู้ป่วย รวมทั้งหมด 558 คน ผลการศึกษพบว่าร้อยละ 54.8 และร้อยละ 58.3 ของผู้ป่วยมีความพร้อมแต่ไม่เคยมีส่วนร่วมในการพูดคุยเกี่ยวกับเป้าหมายการรักษาและการใช้การรักษาเพื่อชีวิตกับแพทย์ผู้ดูแล ตามลำดับ อย่างไรก็ตามการสนทนาลักษณะดังกล่าวกับครอบครัวมีอัตราที่สูงกว่า (ร้อยละ 29.1 และร้อยละ 23.1 ได้พูดคุยเกี่ยวกับเป้าหมายการรักษาและการใช้การรักษาเพื่อชีวิตกับครอบครัวในช่วง 6 เดือนที่ผ่านมาตามลำดับ) นอกจากนั้น ผู้วิจัยพบว่าผู้ป่วยสูงอายุน้อยกว่าร้อยละ 5 ได้บันทึก ACP เป็นลายลักษณ์อักษร เช่น การมอบหมายผู้ตัดสินใจแทนด้านสุขภาพ (Durable Power of Attorney for Healthcare หรือ DPAHC) และ พินัยกรรมชีวิต (Living Will) และมีอาสาสมัครเพียงส่วนน้อยที่รู้จัก ACP (ประมาณร้อยละ 4 ของผู้ป่วยที่ทราบถึงการมีอยู่ของ DPAHC และ Living Will) อีกด้านหนึ่งมุมมองเกี่ยวกับ ACP และค่านิยมทางสุขภาพระหว่างผู้สูงอายุและผู้ดูแลในประเด็นส่วนใหญ่ไม่สอดคล้อง

กัน กระนั้นการศึกษานี้พบว่าครอบครัวมีความเห็นพ้องกันระดับเล็กน้อยว่า ACP สามารถช่วยให้ผู้ป่วยสามารถควบคุมการดูแลที่จะเกิดขึ้นในอนาคต และช่วงเวลาปัจจุบันอาจเป็นช่วงเวลาที่เหมาะสมสำหรับ ACP

จากการวิเคราะห์โดยตัวแบบเครือข่ายของเบย์ ผู้วิจัยพบว่าปัจจัยส่วนบุคคลและครอบครัวมีปฏิสัมพันธ์กัน และได้แสดงออกมาในรูปแบบ Directed Acyclic Graph ซึ่งประกอบด้วยตัวแปร 18 ตัวและเส้นความสัมพันธ์ 53 เส้น แสดงให้เห็นผลโดยตรงของการที่ผู้ป่วยรับรู้ประโยชน์และโทษของ ACP ต่อการตัดสินใจเกี่ยวกับการรักษาเพื่อการยืดชีวิตกับครอบครัวหรือแพทย์ รวมถึงการทำ DPAHC นอกจากนี้ BN สะท้อนความน่าจะเป็นโดยรวม (marginal probability) ว่าผู้ป่วยมอง ACP เป็นประโยชน์ในขณะที่ผู้ดูแลมีความเห็นที่ไม่ชัดเจนเกี่ยวกับ ACP เมื่อผู้วิจัยได้วิเคราะห์การแทรกแซงเชิงสมมติที่เกี่ยวข้องกับข้อดีและข้อเสียของ ACP พบว่าวิธีดังกล่าวดังกล่าวมีความเป็นไปได้เชิงสาเหตุ (Bayes factor >10) หากแต่การปรับเปลี่ยนมุมมองของผู้ป่วยมีผลมากกว่าการปรับเปลี่ยนมุมมองของผู้ดูแลอย่างมาก (การจัดการความกังวลของผู้ป่วยเพิ่มความน่าจะเป็นในการทำพินัยกรรมชีวิตร้อยละ 14.9 และการตัดสินใจเกี่ยวกับการรักษาเพื่อยืดชีวิตร้อยละ 43.8) นอกจากนี้กราฟเชิงสาเหตุแสดงให้เห็นว่าการทำงานของครอบครัวโดยรวมมีได้นำไปสู่การมีส่วนร่วมใน ACP

สรุปผลการศึกษา

ครอบครัวของผู้ป่วยสูงอายุที่มีโรคมะเร็งมักมองว่า ACP เป็นเรื่องที่ไม่คุ้นเคยและไม่จำเป็น อาจทำให้เกิดความกังวลและบั่นทอนความหวัง อย่างไรก็ตาม ครอบครัวอาจยังมองว่า ACP มีคุณค่าเนื่องจากจะช่วยให้ผู้ป่วยและครอบครัวมั่นใจว่าความต้องการของผู้ป่วยจะได้รับการตอบสนองหากผู้ป่วยไม่สามารถสื่อสารกับทีมผู้รักษาได้ การศึกษานี้พบผู้ป่วยจำนวนมากที่มีความพร้อมที่จะพูดคุย ACP กับครอบครัวและแพทย์แต่ยังไม่เคยได้พูดคุยจริงจึงเป็นโอกาสอันดีที่จะแนะนำและส่งเสริมการทำ ACP อย่างไรก็ตามยังมียุทธศาสตร์จำนวนมากที่ไม่พร้อมที่จะทำ ACP เป็นลายลักษณ์อักษร นอกจากนี้มุมมองของผู้ป่วยและครอบครัวต่อ ACP มักไม่ตรงกัน การปรับการรับรู้ของผู้ป่วยอาจกระตุ้นให้เกิดการมีส่วนร่วมใน ACP ได้อย่างมาก โดยการแนะนำประโยชน์อาจให้ผลที่ชัดเจนสำหรับ DPAHC ในขณะที่การลดความกังวลต่อ ACP ส่งเสริมการมีส่วนร่วมกับ ACP ประเภทอื่นๆได้โดดเด่น ทั้งนี้การปรับเปลี่ยนมุมมองของสมาชิกในครอบครัวหรือการทำงานของครอบครัวอาจไม่ส่งเสริมการมีส่วนร่วมใน ACP ในกลุ่มผู้ป่วยสูงอายุที่มีโรคมะเร็ง

คำสำคัญ: ผู้สูงอายุ, โรคมะเร็ง, การทำงานของครอบครัว, การวางแผนการดูแลล่วงหน้า, ประเทศไทย, Translational model,

Bayesian Network

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ABSTRACT

Background

Aging and multiple comorbidities make the elderly vulnerable to poor health outcomes. In elderly people with cancer, treatment such as chemotherapy or radiotherapy can cause more adverse effects, and sometimes the elderly's response to such treatment can also be limited. Decision-making with elderly cancer patients when such undesirable effects arise might not be possible due to a lack of mental capacity. Advance care planning (ACP) is integrated into cancer care as a process of communication among clinicians, patients, and family members to ensure respect for patients' preferences. However, Thai people prioritize family and sometimes their planning is hindered by family mechanisms, including a conspiracy of silence. The current study aims to: 1) understand perceptions of elderly with cancer and their caregivers pertaining to advance care planning, 2) examine whether their perspectives were congruent, 3) describe the elderly's readiness for advance care planning engagements, and 4) examine the relationships between individual and family factors in advance care planning engagements of the elderly.

Methods

Phase 1 study (January – April 2023) aimed to explore perceptions of advance care planning among elderly cancer patients and their caregivers. Participants were recruited from the oncology radiotherapy clinic at Songklanagarind Hospital. Inclusion criteria for patients included being aged 60 years or more, diagnosed with non-hematological cancer, and able to communicate in Thai, while their primary caregivers needed to be adult Thai speakers who provided unpaid care. Those with

severe mental or physical conditions, brain tumors, or communication barriers were excluded. After obtaining ethics approval, we approached potential informants through registration staff informing participants about the study. The study employed maximum variation sampling to ensure a diverse participant pool.

Data collection involved semi-structured interviews using an interview guide, covering topics such as illness perceptions, benefits and barriers to advance care planning, and related values. Caregivers were interviewed before patients to safeguard elderly participants from sensitive issues potentially introduced during the interviews. The interviews lasted approximately 45 minutes, with permission for audio recording and note-taking. Thematic analysis was applied, guided by the Health Beliefs Model, to identify perceptions influencing readiness for advance care planning engagement. Trustworthiness and transferability were ensured through measures such as investigator triangulation and thick data descriptions. Coding and theme development were conducted collaboratively and audited, with findings reviewed by oncology and palliative care experts.

The second phase (August 2023 – October 2024) involved a cross-sectional study in which the remaining objectives were addressed. We recruited the elderly and their caregivers using the same eligibility criteria as was applied in the qualitative study. Demographic and readiness data were described using descriptive statistics. Comparisons of advance care planning perceptions between patients and caregivers utilized intraclass correlation for consistency, and confirmatory factor analysis was conducted using the lavaan package to validate a pros and cons questionnaire. These models assumed a correlated structure and applied fit indices such as root mean square error of approximation, standardized root-mean-square residual, and comparative fit index, with dynamic fit indices enhancing robustness. Factor scores were computed to standardize results, ensuring alignment with prior studies.

Bayesian network learning was applied to explore potential causal relationships between family mechanisms and advance care planning engagement. The qualitative findings informed variable selection, aiming to reduce overfitting and ensure interpretability. Family background variables were grouped using latent class analysis. The Bayesian network structures were built through score-based algorithms. Expert input and mandatory arc specifications strengthened the model's conceptual validity.

Sensitivity and intervention analyses were conducted to identify nodes that were sensitive to parameter alterations (due to a change in context) and simulate interventions using a "do-operator". Tools such as GeNIe Modeller and R packages (bnlearn, igraph, and caret) facilitated structure and parameter learning, sensitivity analysis, and intervention analysis.

Results

In the qualitative study, we interviewed 16 elderly with cancer and 16 caregivers. Three themes regarding perceptions of advance care planning were found: 1) Advantageous opportunity: the patients believed the planning would help them realize their life values, and ensure that their preference would be respected; 2) contemplations and barriers to advance care planning: unfamiliarity and thoughts of it being unnecessary might cause low utility, worry among patients and family members, take away optimism, and would not be a proper activity for the patient at the current health situation; and 3) cues for initiation: perceived conformity with one's religion, awareness of the current cancer state, having multiple comorbidities or experience with suffering related with medical care, wishing not to burden the family, having close family members, and trust in physicians.

In the second phase, we recruited 279 elderly patients with cancer and their caregivers, resulting in 558 participants. Totally, 54.8% and 58.3% of participants were prepared, but never participated in any advance care planning discussions pertaining goals of care and life-sustaining treatment with their physicians. On the other hand, discussions with the family regarding the two types of planning was relatively higher (29.1% and 23.1% had maintained discussions pertaining goals of care and life-sustaining treatment with the families, respectively, for more than 6 months). We also found that less than 5% of the elderly had a durable power of attorney for health care and a living will. The prior awareness of any types of advance care planning were low; approximately 4% of the participants were knowledgeable of legalized advance care planning—durable power of attorney for health care, and living will. Perceptions towards advance care planning and general health values between the elderly and their caregivers were commonly incongruent, although small agreements were found on the ideas that advance care planning can help one control the future care and the present

could be a good timing. From the Bayesian network analysis and the directed acyclic graph, the marginal probability suggest a trend of perceiving advance care planning as advantageous among the elderly patients. However, the caregivers were equivocal about the advantages but generally perceived that the disadvantages were low. The Bayesian network learning produced a directed acyclic (causal) graph in which the older persons' pros and cons are directly linked to readiness for certain types of ACP engagement (discussing life-sustaining treatment use with family or clinician, discussing goals of care with clinician, and appointing a durable powever of attorney for healthcare). The effects of the elderly's perceptions demonstrated dominant effects on ACP engagement than the caregiver's perceptions. Hypothetical interventions on the patients' and caregivers' perceived pros and cons of advance care planning to promote engagement were found to be possible (Bayes factor >10). The patient's cons showed large causal effects on the motivations for advance care planning (14.9% and 43.8% had an increased probability of documenting advance directives and discussing cardiopulmonary resuscitation with physicians, respectively). Finally, the causal graph also shows a lack of causal relationship between family functioning and advance care planning engagement in older patients with cancer.

Conclusions

Families of older Thai cancer patients often viewed advance care planning discussions as unfamiliar, unnecessary, and potentially distressing, fearing they might cause worry, diminish optimism, or seem inappropriate. However, they recognized its value in ensuring that patient preferences are respected. While many older patients were prepared to engage in discussions about advance care planning with family and care providers, a significant number remained in the precontemplation or contemplation stages regarding formal documents like advance directives or living wills. Favorable attitudes were observed, but disagreements between patients and caregivers were notable. Advance care planning was seen as a way to maintain mindfulness and control over future medical care, suggesting that now might be an opportune time to encourage such discussions.

Patients who were motivated for certain advance care planning behaviors were more likely to be ready for others. However, formal documentation

was less likely to be adopted. Interventions targeting pros and cons had varying effects, with promoting pros being relatively effective for durable power of attorney for health care, while reducing cons had a stronger impact on other advance care planning behaviors. In time-limited oncology settings, prioritizing cons may be more efficient. Designing personalized interventions based on pros and cons could support patient engagement, but care professionals should remain mindful of differing perspectives between patients and caregivers to ensure patient autonomy is respected.

Keywords: Elderly, Cancer, Family functioning, Advance care planning, Thailand, Transtheoretical model, Bayesian network

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LIST OF ABBREVIATIONS

ACP	Advance care planning
AD	Advance directive
BN	Bayesian network
CE	Causal effect
CFA	Confirmatory factor analysis
CFI	Comparative fit index
DFI	Dynamic fit index
DPAHC	Durable power of attorney for health care
ECOG	Eastern Cooperative Group
EM	Expectation maximization
MA	Model averaging
LCA	Latent Class Analysis
LST	Life-sustaining treatment
RMSEA	Root mean square error of approximation
SRMR	Standardized root mean squared residual
TTM	Transtheoretical model
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

1. Background

This section provides an overview of the background knowledge of the study topic. The contents encompass aging and cancer, advance care planning (ACP) in elderly patients with cancer, ACP engagement and influences from family mechanisms, stakeholders of ACP in Thailand, and the context of the study setting.

1.1 Aging and cancer

The number of elderly people has been growing and is a leading global health topic. With this pace, the population of elderly was predicted to double (12% to 22%) from 2015 to 2020.^{1,2} This becomes a concern as aging is associated with a gradual decrease of physical (e.g., cardiac capacity and muscular strength) and mental capacity (e.g., dementia and other emotional issues).¹ While the majority of elderly are living in good health, some of them are fragile and require help from others.³

Cancer is a limiting and life-threatening disease and is a leading cause of death worldwide, and can be found in all age groups with the incidence peaking in older age (75-90 years).⁴ Age is the most significant risk factor for cancer. It also plays an important risk in several types of cancers. According to the US National Cancer Institute, in 2021, the incidence of cancer among those aged under 20, 45-49 and 60 years or older were 25, 350, and more than 1,000 cases per 100,000 people, respectively, and the median age at diagnosis was 66 years.⁵ The incidence of cancer varies greatly by type, age, sex, period, race, and geographical area.^{4,6} Cancer also ranks in the top two cause of premature deaths worldwide, and is predicted to increase from 18.1 million cases in 2018 to 29.4 million cases in 2040.⁷ Globally, lung cancer ranked in the top 10 leading causes of age-specific disability-adjusted life years in 2015 with a considerable burden in 2005.⁸ In Thailand, liver cancer main contributor to the national cancer burden while lung, breast, colorectal, cervix, and uterus cancers also have a high incidence.^{8,9} With a population of approximately 70 million, Thailand had 183,541 new cancer cases in 2022, and the cumulative incidence for developing cancer

overall (before age 75) was approximately 16%.⁹ Although most cancer types are life-threatening, some cancer types such as prostate, testicular, breast, and melanoma have approximately 90% 5-year survival rates.⁹

Apart from the burden of cancer itself, cancer treatment in elderly is an important concern.¹⁰ With aging, the elderly can face both changes from aging, as well as experiencing multiple chronic diseases which contribute to additional expected side effects of cancer treatment; for example, diabetes, heart, and lung diseases can make the elderly prone to drug interaction when chemotherapy is introduced.¹¹ Lichtman and colleagues¹² found that the risk of severe neutropenia after treatment increased from 22% in age group 55-64, to 35% and 49% in elderly aged 65-74 and 75 years or more, respectively. Langer and colleagues also found that the elderly had both a higher risk of neutropenia (42% in elderly versus 17% in younger age group) and neuropsychiatric toxicity (17% in the elderly versus 7% in younger age group). In the elderly with vascular comorbidities, the tolerability of radiotherapy may be decreased.¹³ Aging was found to be related to chronic radiotherapy side effects such as long-term dysphagia, which has a great impact on a patient's quality of life. A previous study¹⁴ found that chronic toxicity was more common among elderly than in those aged less than 50 (56% versus 31%, respectively).

1.2 Advance care planning in elderly patients with cancer

Advance care planning (ACP) has terminological variations with regards to local and international definitions. Until now, there has been two consensus pertaining to its definition.^{15,16} Rietjens and colleagues, conducted a mixed method, Delphi consensus process,¹⁵ to identify the definition with multidisciplinary and multinational participation. The key definition was “*a process that includes the identification of values and defining goals and preferences for future medical treatment and care and discussion of these factors with the patient's family and health-care providers*”. A more recent definition in Asia¹⁶ was similar to the first European consensus, but additional recommendations stress the importance of family assessment in its introduction.

Apart from the consensus definition, Chikada and colleagues¹⁷ argued that Asian people, whose culture is more family-oriented than their Western counterparts, have a different definition. Based on 32 published sources in their

reviews, they defined ACP as “*a process in which adult patients (individuals) repeatedly discuss future medical care with family and/or other closely related people and their healthcare team, so they can identify future medical care based on their values and preferences, should they, at some point, be unable to make their own decisions. ACP helps make decisions that ensure patients' dignity at the end of life*”. A few years after the publication of this definition, another consensus supported the previous consensus for application in Asian countries; however, there were several additional points pertaining to the inclusive role of family in the patient.¹⁷ In Thailand, according to the Notification of the National Health Commission on the Operational Definitions of Terms Pertaining to Palliative Care for Thailand, B.E. 2563 (A.D. 2020), ACP was defined as “*A care planning made before a patient loses his/her capacity to make decisions or enters into the end-of-life stage*”.¹⁸

ACP plays an important role in cancer care. In general, cancer is a chronic disease in which patients will experience declining health at the terminal phase.¹⁹ Compared with other chronic diseases, cancer may manifest steady progression before approaching the terminal phase, during which a predictable decline of functional capacity can be expected. This nature of cancer highlights the importance of ACP.^{19,20} Previous guidelines also suggest that participating in ACP can help individuals and their family member make informed decisions in advance.^{20,21} However, there have been mixed preferences from cancer patients and their families on the proper circumstances for ACP initiation; terminal cancer patients and their families agreed that ACP can be initiated at any stage in the cancer trajectory, while some (60%) patients thought that the late stage was too early.²² Furthermore, some cancer patients preferred to engage in ACP only when the cancer had become advanced.²³ This might complicate the situation in hematological cancer settings, where the disease can manifest as an acute severe disease or as a chronic stable one.²⁴

1.3 Engagement in ACP and influences from family mechanisms

Engagement in ACP can vary across individuals, time, and health conditions. In Korea, the proportions of individuals who were aware of ACP were 16.1%, 33.8%, 33.2%, and 61.4% among the general population, cancer patients, caregivers of the cancer patients, and physicians, respectively.²⁵ In addition, 7.3% and 20.3% of community-dwelling adults in the USA²⁶ and China,²⁷ respectively, were

aware of ACP. According to Zhu et al.,²⁷ 79.3% of the elderly who were additionally informed about ACP had positive feelings were willing to engage in ACP. In Thailand, 70.2% of terminally ill patients and their families who were informed about ACP later engaged in ACP practices.²⁸ Some patients may engage in ACP discussion without any documentation while keeping the discussion limited between them and their loved ones; therefore, it may not be recognized by healthcare providers. A study showed that 59%, 12%, and 11% of cancer patients were willing to discuss ACP with family only, clinician only, and both clinician and family, respectively.²⁹ In an acute care setting, Knight and colleagues³⁰ found that 3.5%, 23.3%, and 7.1% of patients who had been residing in the community, admitted to an institutional care setting, and previously admitted to a hospital, respectively, engaged in ACP when they were admitted. In Thailand, 60.6% and 35.7% of cancer and non-cancer patients, respectively, had documented ACP in the inpatient system.³¹

Family is a social unit in which internal mechanisms play several roles in shaping elderly patient's physical and mental health.³² It is very common that the patient's nominated proxy decision-maker is a family member. In addition, approximately 40% of cancer patients were willing to include their families in decision-making regarding future medical care.²³ According to a systematic review, mechanisms in the family can increase the likelihood of ACP engagement, or instead, hinder it.²¹ Criticisms from an elderly's spouse and children in the family were both associated with a decreased likelihood of accepting durable power of attorney for health care (DPAHC); however, the association was not statistically significant.³³ On the other hand, general family functioning was found to be associated with engagement of ACP (odds ratio 4.34, 95% CI = 1.09 – 17.30).³³ In Asian countries, the family often involves medical decisions with clinicians but does not involve the patients because they thought the patient may not be ready.³⁴ However, 39% - 90% of patients were willing to engage in it.²⁹ Therefore, a family unit consisting of the elderly and other significant members can play roles as communicators, belief-modifiers, different-thinkers, or surrogate decision-makers. Thus, a family's mechanisms can drive or hinder the readiness for ACP engagement through their influence on the elderly's perceptions of it.

1.4 Advance care planning stakeholders in the Thai National Health System

According to Pilch et al, stakeholders in advance care planning for the elderly ranged from the older individuals, their significant others, healthcare professionals, non-healthcare professionals, service managers, and policymakers.³⁵ The elderly are direct users of the planning while the trusted individual (potentially nominated proxy decision-maker) and healthcare professionals take relational stakes.²³ Implementation of ACP could yield several benefits for the stakeholders. ACP can enable the care team to understand and respect the patient's wishes and preferences,³⁶ allowing patients to manage individual affairs,³⁷ reducing psychological distress among surviving family members,³⁸ and improving patient satisfaction and quality of life.³⁹ For the health care system, ACP can lead to less hospitalization and more hospice use, reducing medical care costs.^{40–42} From the patient's perspective, ACP may also help them have peace of mind, and keep peace within the family.³⁷ However, it has been recognized that participation in ACP for Asian families could be emotionally distressing for older individuals and/or their families, leading to negative reactions such as showing signs of discomfort or leaving the counseling room.⁴³ Therefore, international experts suggest that, in Asian countries, a tailored explanation and assessment of readiness for ACP engagement should be endorsed, and be particularly attuned to the emotions of the whole family.^{15,16}

In Thailand, concepts of palliative care and ACP became more in the spotlight in 1997, when some cancer centers started to advocate palliative care. In 2007, ACP was recognized by the Thai government and was legalized in the constitution (the National Health Act 2007, section 12 – Living will). From 2014 to 2017, palliative care and ACP were further advocated in the National Health System and supported by the National Health Security Office Fund. Since 2017, ACP has become one of the medical service requirements according to the Ministry of Public Health standard. Legal definitions regarding palliative care and ACP were drafted in 2021 by government organizations, including the National Health Commission Office (NHCO) and various medical and nursing staff in several health institutes and non-government organizations. In January 2022, the NHCO launched the standard of ACP and determined supporting structures, including a steering committee and several policies and provisions driving ACP engagement in both government (i.e. the National Health

Security Office, the Health Promotion Foundation, and the Department of Medical Service) and non-government sectors (i.e., Peaceful Death group).^{18,44} As a result, several health promotion campaigns were implemented after 2021, and the National Health Service Administration has included ACP as a part of the palliative care performance indicator for service reimbursement and action-based performance tracking. However, Thailand has focused on training healthcare facilitators whose work is related to palliative care, leaving some focused populations, including elderly and cancer patients, to depend on trained healthcare volunteers. This situation can be complicated when the facilitator lacks information or evidence-based strategy on how ACP can be implemented in the context of family-centered health care, in which collectivism has a strong influence on ACP engagement, leading to negative experiences among facilitators, patients, and families.⁴⁵

1.5 Study setting background

1.5.1 Study area

Songkhla province is a major economically contributing province in Southern Thailand. It has an area of approximately 7.4 million km² and a population of approximately 1.4 million. Most of the population are Buddhists (64.7%).⁴⁶ In Southern Thailand, there are nine cancer referral centers, including 2 university hospitals, six tertiary hospitals and one private hospital. The cancer centers have been serving cancer patients under the Universal Health Coverage Scheme which facilitates cancer patients to receive cancer care without traditional requirements at any hospital in Thailand (Cancer Anywhere Health Scheme).⁴⁷ According to the overall cancer incidence based on the Southern Thailand (Suratthani) registry,⁴⁸ age-standardized rate of cancer in this region is the lowest in both males and females, compared with all the other regions in Thailand. Lung, liver, and colorectal cancers were the top three leading cancers in this area.⁴⁸

1.5.2 Study site

Songklanagarind Hospital is located in Songkhla province, Southern Thailand. The hospital was established in 1982. The hospital is a medical university

and referral care center for cancer and other major diseases in Southern Thailand. Songklanagarind Hospital serves approximately 4,000 outpatients per day and has 800 inpatient beds.⁴⁹ It is one of the two centers responsible for the National Cancer Registry in Southern Thailand. The hospital also provides medical training, including medical teaching residency training. It has more than 18 programs among 22 medical specialties and 16 sub-specialties. Cancer patients can be followed by almost all the specialties in the hospital, based on the site and the current treatment they have. Among more than 10 specialty clinics in the hospital, the radiotherapy and oncology clinics provide radiotherapy and chemotherapy to the majority of patients. Moreover, cancer services contributed approximately 29% of the outpatient services each day.

2. Literature review

To study the family mechanisms that influence ACP engagement, detailed information pertaining to the family and its mechanisms towards ACP, as well as multidimensional determinants that influence ACP engagement were reviewed. In our reviews, we searched for advance care planning and related terms (e.g., advance directive and living will), elderly, cancer, and family influence, in academic databases such as Pubmed and Scopus. Firstly, we overviewed the literature by examining existing systematic reviews and their reference lists. Subsequently, we conducted a manual search to gather relevant information including all types of publications. Finally, our review used narrative synthesis to provide a broad scope of contents including ACP in elderly patients with cancer, theoretical concepts of ACP engagement, and family mechanisms and ACP engagement. The following sections will discuss the existing evidence and suggestions and propose potential gaps in this field.

2.1 ACP for elderly patients with cancer

This section outlines concepts and the importance of ACP in elderly cancer patients, providing relevant definitions, available standards, and historical and contextual information in the study field. Regarding the terminology, there are various standard definitions of elderly. The UN defines an elderly as an individual who is 65+ years old.⁵⁰ The World Health Organization (WHO) defines aging separately for men and women due to gender-specific biological process. However, in general, elderly are individuals aged 60+ years.⁵¹ Some studies define elderly as 55+ years pertaining to the clinical significance in health outcomes.^{33,52} Thus, different settings might define terms related to “older persons” differently based on the objective. According to the Thai 2003 Elderly Act, Article 3, an elderly was defined as an individual aged 60+ years.⁵³ In Thai healthcare, however, this definition is often used to determine retirement, health benefit packages, and inclusions for certain health campaigns.⁵⁴ Therefore, the following parts in this study consider the elderly as adults whose age is 60+ years.

When ACP is considered for elderly patients, a previous study suggested the following steps,⁵⁵ 1) assessing the patient readiness (according to the

transtheoretical model, or TTM) and identifying the barriers, 2) identifying surrogate decision-makers, 3) asking for values related to quality of life and serious illnesses, 4) documenting advance directive preferences, and 5) translating advance directives to an individual care plan. This recommendation conformed with the previous consensus and systematic reviews (summarized in Table 1).^{15,17} The following subsections will, therefore, discuss each step in the context of the elderly and cancer.

Table 1 Recommended elements in ACP

ACP elements	Consensus ^{15,16}	Systematic reviews ¹⁷
1. Readiness to participate	Adapt to individual ‘readiness’ to participate	Be tailored to the patient’s ‘willingness’ to participate
2. Patient’s understanding	Ensure understanding of patient by sufficient explanation from providers	Ensure understanding of patient by sufficient explanation from providers
3. Clarify preferences	Clarify goals and preferences for future medical treatment or care	Sufficiently eliciting patient’s values and preferences
4. Personal representative	Discuss the role of a personal representative	This should include selecting a personal representative
5. Documentation	This might include completion of advance directives, encouraging patient to provide a copy of advance directives to family or care providers	Ensure respect for a patient’s will through documents such as advance directives or living wills

2.1.1 Assessing readiness for ACP

Although ACP has several benefits, it comes with potential distressing content for patients and families, especially those living in Asian countries, who are not willing or ready to discuss issues pertaining to death and dying.⁵⁶ Several international recommendations suggest that initiating ACP requires careful assessment of individual readiness to avoid negative reactions.^{15–17} Commonly, ACP can be initiated by oncologists in outpatient settings,⁵⁷ or with support from nurses through several health transitions (pre-admission to hospital).^{23,57,58} However, inconsistent findings were reported in previous studies, where although the patient was willing to discuss ACP,

and some saw ACP as beneficial, many cancer patients had not done so or were not ready before hospitalization.²³ The gap between perceived benefits and actual health circumstances is further supported by a low readiness for ACP engagement (more than 90% of the older persons had neither participated in ACP nor were willing to do so in the next 6 months), especially in the context of Asian oncology settings and elderly populations.^{59,60}

2.1.2 Eliciting understanding and preferences of the elderly

Integrating ACP into elderly care can be challenging because of the prevalent cognitive limitation: around 0.1% of individuals aged 40-65 years have dementia while the incidence is 20% among individuals aged 80+ years.^{2,61} However if the elderly have cancer, their capacity to understand and make decisions can be further limited through cancer progression at the late stage,¹⁹ thus respecting the wishes could be challenging in the late stage or when the elderly has a critical illness.^{56,62} This highlights a notable trade-off in the optimal introduction of ACP. This issue particularly concerns the stakeholders when the elderly's decision-making capacity is still intact but possibly making unrealistic plans (ACP is introduced early) and lack of mental incapacity (ACP initiation is made when an individual is critically ill).^{56,63} Fried and colleagues conceptualized that this clarification step encompasses two important areas: goals of care (weighing quality of life versus living as long as possible) and the use of life-sustaining treatment (LST).⁶⁴ Challenges arise in Asian oncology settings despite the availability of standard ACP recommendations.¹⁵⁻¹⁷ Clinicians reported great difficulties in dealing with patients and families together in early discussions on the use of LST, while eliciting individual understanding regarding LST in actual ACP sessions (usually at the time when a critical illness develops) was also equivocal.⁶⁵ Some (32%) patients deferred their decisions to their families, more (62%) preferred to ensure a CPR attempt as much as the law allowed, while only a few (6%) were against CPR being attempted at the end of life.⁶⁵ In Thailand, limited ACP knowledge and health literacy regarding LST were reported.^{45,66} These may have influenced Thai people's understanding of ACP and their readiness to engage in it,⁶⁷ potentially leading to a low

willingness, or decision-making, to sustain life for as long as possible as their default beliefs in modern medicine.⁶⁸

2.1.3 ACP documentation

To ensure that individual preferences and decisions will be respected if they become unable to speak for themselves, formalizing the conversations in terms of documentation can play important roles.^{15–17} This type of documentation was originally proposed in 1967. The Euthanasia Society of America proposed a concept of “advance directives” to protect the patient’s right.⁶⁹ A few years later, advance directives were premised by Kutner.⁷⁰ He stated “the law provides that a patient may not be subjected to treatment without his or her consent”, and “individuals should indicate in writing ahead of time the extent to which he or she would consent to treatment” and referred “a declaration determining the termination of life” as a “living will”.⁶⁹ Later formalization by Silveira and colleagues⁷¹ stated that an advance directive is a document that includes patients' wishes with respect to life-sustaining treatment (i.e., living will), choice of surrogate decision-maker (in a DPAHC), or both.

In Thailand, *advance directives* and *living will* are almost the same concept. According to the Notification of the National Health Commission on the Operational Definitions of Terms Pertaining to Palliative Care for Thailand, B.E. 2563 (A.D. 2020),¹⁸ the definition of advance directives and living will were given as follows; “*A letter in which an individual states his/her wishes to refuse public health services that are merely for life sustaining or to cease a severe suffering from his/her illness in advance*”

In the advance directives and living will, LST is mentioned. The National Health Commission defines LST as medical treatments that are artificial supports of vital organ functions, for instance, cardiopulmonary resuscitation (CPR), endotracheal intubation, inotropic drugs, parenteral nutrition administration, blood transfusion, and renal replacement therapy.¹⁸ Apart from these directives, DPAHC refers to “*A legal document or any other means recognized by law that authorizes a person to make decisions on behalf of a patient (surrogate decision-maker) when the patient enters his/her terminal stage and is not capable of making decisions. This may*

*be specified in the Advance Directive or Living Will to refuse public health services in accordance with Section 12 of the National Health Act, B.E. 2550 (A.D. 2007)”*¹⁸

In Thailand, several educational bodies, including the Peaceful Death group, designed and distributed user-friendly versions of living will, namely, “Bao Jai” (or Comfort Heart Book), and provide online training for interested practitioners from healthcare and non-healthcare sectors.⁷² In recent years, the Ministry of Health, Singapore,⁷³ further conceptualized ACP into three distinct uses, but connected chronologically, based on the patient’s condition: general ACP, disease-specific ACP, and preferred plan of care. Growing interest in ACP is noted in Hong Kong, Taiwan, and Korea.⁷⁴ However, development and evaluations regarding ACP engagement in Thailand, particularly among cancer patients, are lacking.

2.2 Family and family mechanisms

This section provides an overview of definitions relating to family and family mechanisms, and scope potential family factors which demonstrate potential influences to ACP engagement. However, the effects of family mechanisms on ACP have not been studied or explicitly reported. Thus, potential applications and their appraisals are additionally conceptualized.

2.2.1 Definition of family

“Family” is a word that has evolved from the Latin words “familus” and “familia”. Generally, family is defined as a social group of parents, children, and sometimes grandparents, uncles, aunts, and others who are related (Cambridge Academic Dictionary).⁷⁵

In the field of family medicine, family is defined as “any group of intimates with a history and a future”.⁷⁶ Another definition is “a group of people related either biologically, emotionally, or legally”.⁷⁷ This definition includes, but is not limited to, a group of people that has a significant contribution to a patient’s well-being. Freeman says that a family is a “particular kinship group” whose structure can vary over time and culture while its function reasonably remains unchanged, also supported that a family shares biological, psychological, social, and spiritual basis of individuals’ living.⁷⁸ Smilkstein (1978) conceptualized family as a psychosocial group of the patient

and one or more persons, children or adults, in which there is a commitment for members to nurture each other.⁷⁹ Pasley says that family structure reflects relationships at the juncture of biological relatedness, marital and partnership status, and living arrangements.⁸⁰

2.2.2 Family structure

For the past few decades, family structures have been illustrated by several national-scale censuses.⁸⁰ A household refers to a unit of one or more people living in the same housing unit, and a family household refers to a group such that at least two members are related by birth, marriage, or adoption, one of whom owns the house; including a family which a man or a woman owns a house and lives with relatives (with or without children). Regarding the size of the household, the number of people, including children, adults, and elderly, were considered for household size. Additionally, family can also be grouped by marital status, child adoption status, parent-to-child pattern, and type of marriage.^{78,80,81}

2.2.3 Family types

Types of family are also defined. Pasley⁸⁰ summarized four types of family: nuclear, cohabiting, same-sex cohabiting, and step/blended. A nuclear family is a family consisting of a child living with two married biological parents, with or without siblings. A cohabiting family is one in which a child's parent lives with one or more non-related adults; this additional adult can be biologically related or non-related. A same-sex cohabiting/married family is one in which a child's parent lives with at least one same-sex adult, and this additional adult can be either biologically related or non-related with the child. Lastly, a step-family or blended family is one containing a step-parent, step-sibling, or half-sibling.

As Thailand has been transforming, issues of work and living opportunities, aging, and its declining birth rate, its family structure has changed.⁵⁴ Upon the additional classification of family structure provided by the United Nations Population Fund Thailand Country Office,⁵⁴ nuclear families cover family units of husband and wife without children; parents and child (or children). Extended family, the other majority type of the Thai family, is defined as a three-generation family (grandparent, working age children, and grandchildren) or skipped-generation family

(grandparents and grandchildren). Apart from these two types, there is also another minority, for example, a subnuclear family, which includes single parent and one-person structure. However, despite such modernizing transformation, the two most common family structures were still nuclear (approximately 50%) or extended families (approximately 30%).⁸²

2.2.4 Family dynamics and family functioning

Family members share an emotional, physical, and socioeconomic environment. Interaction among the members, roles, relationships are considered as patterns in family dynamics which influences individual's health, both physically and mentally.⁸³

There are several proposed models to explain these dynamics, for example the McMaster Model of Family Functioning,⁸⁴ Beaver's system model for family functioning,⁸⁵ and the Circumplex model of Family Functioning.⁸⁶ Although these models have different base concepts, some constructs are considered to be equivalent, for example, family cohesiveness in the Circumplex model and affective involvement in the McMaster model are considered equivalent. A variety of ways are proposed to assess family functioning, for example structured interviews, semi-structured interviews, and direct observations. However, structured interview is less time-consuming and more practical⁸⁷ and several instruments are proposed to help in measurements of family functioning in clinical settings.⁸⁸⁻⁹⁰

In Thailand, McMaster's model is one of the well-known family functioning models that were applied as a ground theory for family functioning assessment and intervention. According to this model,⁸⁴ family functioning is conceptualized based on the three areas of family tasks: basic tasks (e.g., providing food or shelter), developmental tasks (the journey that a family goes through individual development amongst life cycle and family life cycle), and hazardous task (experience crises, such as illness, accident, or loss of income). In summary, the model includes 'Problem-solving', 'Communication', 'Role', 'Affective responsiveness', 'Affective Involvement', and 'Behavioral control'.

2.2.5 Family involvement in ACP

Frechman and colleagues⁹¹ suggested that family plays several roles in the engagement of ACP. Family dynamics, family involvement, and the role of the family members: caregiver, or surrogate decision-maker, were consistently mentioned in the literature. Family involvement is important in ACP engagement due to several reasons. First, ACP involves communication that pertains to issues regarding future illness and death. A previous study demonstrated that it was very common that discussions regarding life-sustaining treatment and CPR were held between clinicians and family members.⁹² Family members who are caregivers or surrogates can be stressed or burdened by the duty of decision-making for the patient, and can sometimes result in overtreatment.⁹³ There are many factors that individuals weigh to make decisions. In Western countries, the two main factors influencing discussions between family and clinicians about life-sustaining treatment are quality of life and preferences.⁹⁴ In non-Western countries, the focus might be shifted as the decision might be based on the caregiver's perspectives, including one's needs, burden, spiritual or religion beliefs, or family needs.⁹⁵

In Asia, family plays central roles in ACP engagement. A previous study found that Asian families rarely engage the person in the process as family members and their doctor perceived that the patient might not be ready for ACP.²⁹ A cross sectional study found that most cancer patients and their caregivers (72%) were willing to engage in ACP when there was an aggravating symptom or were in the terminal phase of life.⁹⁶ Patients and families also think that ACP may take away hope and positivity, especially in Asian countries wherein people can consider ACP as a taboo.⁵⁶ Different countries can also have different family perspectives. Hammami and colleagues⁹⁵ found that culture can affect the way that healthcare surrogates make decisions. In Thailand, talking about death and dying within a family can also be difficult. Thai people often perceive discussing topics such as death as taboo,⁹⁷ and sometimes family members and clinicians separate the patients from ACP due to concerns about the patient's distress (i.e., conspiracy of silence).⁴⁵

Family authority can also play a critical role in this circumstance, for example when there is a problem in decision-making, the authority system in the family influences the dynamic,⁹⁸ leading to normative consideration.⁹⁹ In the ACP process, the tendency of the head of the family to perceive high benefits of ACP may nudge the

whole family dynamics towards seeing it as beneficial, and if the patient is the head, he/she might influence the norm of the family and influence the family member's perception of ACP. Moreover, gaps between conveying wishes and the authority of the nominated family member to make formal decisions exist. According to McCarthy et al., 91% of the elderly who had preferences discussed their wishes with their family members, while 66% of such elderly defined their families as a health proxy.¹⁰⁰

Among these complexities, the elderly with a serious illness (i.e., cancer) who live in different family backgrounds experience different family mechanisms, including family structure, functioning, authority, relationships, and perceptions of each member (i.e., older individual and the caregiving member).^{33,34,60,91,99,100} These interplays as well as their own beliefs (perceptions) can be seen as modifying factors when elderly patients with cancer would contemplate on planning for future medical care (ACP) according to the concepts of the Health Belief Model, the Decisional Balance model, and the Stage of Change.^{101,102}

2.3 Theoretical concepts of ACP engagement

2.3.1 ACP engagement as a behavior

Behavior refers to an action (or reaction) of humans and animals which are observable (overt behavior) and unobservable (covert behavior). Overt behaviors are grouped into two minor categories: molar and molecular behaviors. Molar behaviors are observable without applying any instruments, for example, laughing, jumping, and crying. Molecular behaviors require instruments to facilitate the observation, for example, heart sounds and blood pressure. Covert behavior is an internal mechanism that is noticeable if one expresses their internal thoughts, memories, fantasies, or emotions. Researchers can apply a certain instrument (e.g., questionnaires) for detecting covert behaviors or inferring from certain overt behaviors. Covert behaviors can be conscious processes (e.g., pain, hunger, tiredness, and admiration) or unconscious processes (e.g., fear, thoughts, yearnings, and happiness).¹⁰³

We propose that ACP is neither deliberative nor expectation-led, unlike general decision-making processes, decisions about euthanasia, or discussions about end-of-life matters, consistent with the argument proposed by Scherren and

colleagues.¹⁰⁴ According to Fried and colleagues,⁶⁴ ACP engagement is an overt behavior which falls into a spectrum of progressing motivation (readiness), including not being ready, to being prepared, and ultimately taking action. Fried posited six domains of engagement: 1) Discussions about the use of LST with family members, 2) Discussions about the use of LST with clinicians, 3) Discussions about health care preferences with family members, 4) Discussions about health care preferences with clinicians, 5) Completion of a living will, and 6) Completion of a health care proxy. While all the aforementioned behaviors are overt behaviors that researchers can assess using an instruments, additional few constructs about the underpinning covert behaviors are also proposed: Stages of change, Processes of ACP engagement, Decisional balance of perceived pros and cons, and Values and Beliefs.⁶⁴

2.3.2 Readiness for ACP engagement

According to Prochaska: “No single theory can be accountable for the complexities of behavior change”.¹⁰¹ ‘Transtheoretical’ means that this model has integrated concepts from a comparative analysis of various theories of behavioral change intervention. It contains temporal dimensions: stage, process, and principle of change. One can be stuck at any stages in this model if the planned intervention is lacking. Thus, based on this model, a stage-based paradigm was suggested as an alternative for traditional action-based intervention. Regarding ACP, some clinicians experience initiation of ACP when patients and /or their caregivers are not ready and can result in non-participating and may stimulate negative reactions.¹⁰⁵ Fried and colleagues³⁷ proposed that ACP is a component behavior, consisting of the abovementioned six domains, in which their changes are based on the Transtheoretical Model (TTM) and Stages of Change. The readiness is conceptualized based on the TTM and the study’s concept to four levels in which an individual is in the: 1) Precontemplation, 2) Contemplation, 3) Preparation, or 4) Action or Maintenance stage. The concept that ACP behaviors follow the TTM was also supported by Schickedanz and colleagues, but further incorporated ‘Knowledge’ and ‘Self-efficacy’ into their measurement.¹⁰⁶

2.3.2.1 Stage of change

Change' implies phenomena happening over time, and ranges from stage 1 to 6. These 6 stages of change are: precontemplation, contemplation, preparation, action, maintenance, relapse, and termination.¹⁰¹ The first two stages, precontemplation and contemplation, are stages where the target's overt behavior has not yet been established. The likelihood of changing a behavior depends on the motivation of the person who is in the stage. Pre-contemplated persons usually lack the intention to engage in a behavior within the next six months, while contemplated persons could have some actions in the next six months. Possible underlying mechanisms for precontemplations are lacking knowledge or having large gaps between perceived (highly) cons and (lowly) pros of a behavior (Decisional Balance), while the explanation for contemplation is one's ambivalence in the Decisional Balance. Preparation, on the other hand, reflects a strong intention to change the behavior. A person who is in this stage commonly has an action plan and performs a real action within approximately one month. Action is the stage where a person takes significant action within the past six months, and maintenance is where such action is maintained over six months.

Previously, the TTM has been widely used to explain the change mechanisms of a person's pertaining to a desirable or healthy behavior (e.g., exercise or smoking cessation) which progress through motivations.¹⁰⁷ In some persons who successfully change their behaviors, lacking motivation and/or an increase in temptation (from the past behaviors) could make them return to the earlier stages of the target behaviors, such as precontemplation or contemplation. On the other hand, strong self-efficacy and zero temptation can also lead to complete change (and no relapse) or "Termination".

In ACP, the two conceptualizations are majorly a unidirectional progression of the stage of change from precontemplation to maintenance.^{37,106} An example of individuals in maintenance was provided in Fried and colleagues; "We review our [advance directives] every couple of years", said an informant. Nevertheless, it is possible that a person stops maintaining ACP behaviors, and becomes less motivated to engage in ACP at any time. We argue that the existing concepts explaining ACP behaviors as a motivation process only focus on the motivation towards engagement than the bidirectional dynamics of ACP readiness.

However, this approach can benefit statistical modeling of the relationships between variables from data inquired from a cross-sectional study design (common design).⁶⁷

2.3.2.2 Processes of change

Across the stage of change, the motivation progresses through the mechanisms of decisional balance and process of change. The more the person engages in any motivation-raising process, the higher the likelihood of them being in the higher stage in the continuum. The process encompasses both overt and covert processes. For instance, looking for information regarding the target behavior (consciousness raising), feeling relieved after watching a campaign video (dramatic relief), and evaluating perceptions and emotions of others (environmental reevaluation). For ACP,⁶⁴ these processes may cover a broad range of activities, including, seeking information regarding ACP, asking or evaluating a family member's perceptions of ACP, or feeling relieved when thinking about having planned for the future. Table 2 illustrates the relationship between stage and process of change regarding TTM. Although the application of this process has not been frequently used or clearly described in the literature,¹⁰⁴ Levo and colleagues have found that several ACP intervention studies have potentially used the principle of Process of change in their intervention designs.¹⁰⁸

Table 2 Stages of change and change processes¹⁰¹

Stages of change					
Precontemplation	Contemplation	Preparation	Action	Maintenance	
Consciousness raising					
Dramatic relief					
Environmental reevaluation					
	Self-reevaluation	Self-liberation			
					Contingency management
					Helping relationship
					Counterconditioning
Stimulus control					

2.3.2.3 Decisional balance

Prochaska mentioned the original decision-making concept of Janis and Mann (1997) regarding four categories of pros and four categories of cons:¹⁰¹

Instrumental benefits to self and others, Instrumental costs for self and others, Approval for self and others, and Disapproval for self and others. With factor analysis, Prochaska simplified them into only pros and cons. In Prochaska's study, 12 prior studies¹⁰⁷ including 12 health behavior change assessments were analyzed. The score of the experience that the participants reported in each behavioral change study was converted to a standard score. The additional analysis revealed interventions decreasing perceived cons had a two-fold higher impact ("Strong principle") compared to interventions increasing perceived pros ("Weak Principle") of behavior change, in terms of directing an individual from precontemplation to contemplation.¹⁰¹

2.3.3 Health Belief Model

In the 1950s, the Health Belief Model (HBM) was developed in order to understand people and enhance the effectiveness of health education programs and compliance with preventive behaviors. In later years, it has been applied in various health problems.¹⁰⁹ It conceptualizes that an individual's beliefs can shape behavior through primary socialization. This model also assumed that beliefs are modifiable and related to behavioral change. Rosenstock conceptualized three components in the HBM: perceived benefits (and barriers), perceived severity, and perceived susceptibility.¹¹⁰ The HBM has since been modified, with some components being added, including cues to action and self-efficacy, which play through sociodemographic variables (e.g., age, gender, and class) as well as psychological barriers (e.g., poor understanding) and motivation to change.¹⁰⁹ The HBM can be used to provide understanding for the uptake of actions that reduce negative impacts to health while individuals have certain health risk as well as the actions that promote good behaviors when individuals are relatively healthy.¹¹¹ The main HBM constructs are explained as follows (Figure 1 shows the HBM construct and the relationship within).

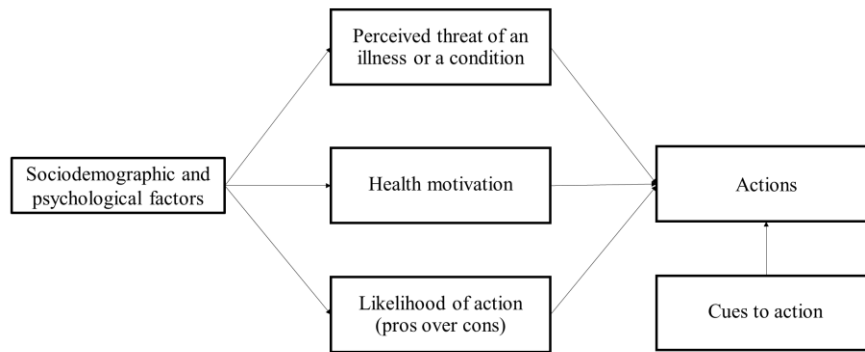


Figure 1 Health Belief Model

The HBM has also been applied to explain why individuals engage in ACP. According to Scherrens and colleagues, both the HBM and TTM were the only two models applied in ACP engagement evaluation studies.¹⁰⁴ These two models share one equivalent outcome, likelihood of action (HBM)¹⁰⁹ and stage of behavior change (TTM).³⁷ The HBM is also a flexible concept explaining individual behavior based on the behavior-related beliefs, taking into account possible cues (e.g., physician counselling, awareness, and health status) and modifying factors (e.g., family issues).¹¹²

2.3.4 Instrument for measurements of readiness for ACP engagement

In the literature, there are two instruments specifically assessing readiness for ACP engagement. Fried and colleagues proposed a TTM-based instrument⁶⁴ which conceptualized ACP behaviors to six distinct domains. Sudore and colleagues proposed an ACP engagement questionnaire¹¹³, which also incorporated TTM, including Stages of Change and Process of Change. However, it included “Social Cognitive Theory”¹¹⁴ and separated the ACP behavior into “Process”, which included “Knowledge”, “Contemplation”, “Self-efficacy”, and “Readiness”.

2.3.4.1 Stage of change for ACP questionnaire

The ACP questionnaire is a set of interview-guided questions. There are 22 questions in total. The respondents will be asked questions that are delivered algorithmically. The first question will be the same for every respondent. The remaining

questions will be asked based on the prior responses, thus will vary across individuals. The maximum number of questions for any participant is 16, and the minimum is 5 (if the respondent answers “no” to all questions). The results of this assessment will be either Pre-contemplation, Contemplation, Preparation, and Action or Maintenance (i.e., 1 from the 4 categories). The questionnaire was validated by mapping the stage with the change in pros and cons, showing a consistent pattern of decisional balance dynamics and questionnaire-assessed stage of change.⁶⁴

2.3.4.2 Advance Care Planning Engagement Survey

The instrument is a self-rated questionnaire using a 5-point Likert scale, which has several versions based on its length, including 82, 55, 49, 34, 15, 9, and 4 items.¹⁰⁶ The instrument was subsequently validated for the 49-item version in which there are two constructs: Process and Action domain.¹¹⁵ Process is divided to 4 subscales: Knowledge, Contemplation, Self-efficacy, and Readiness, while Action is subdivided into 4 domains: surrogate decision maker, discussion about quality of life, flexibility, and question asking. All the versions had a reliability (Cronbach’s alpha) of more than 0.70. The scores ranged from 0 to 410. The higher the score means the better the quality in each domain.

Both the Stage of Change for ACP^{116–119} and the Advance Care Planning Engagement Survey^{120,121} were subsequently translated and applied in several studies. The former tool was often used to describe readiness patterns in clinical settings to guide intervention implementations,^{116–119} while the latter tool was mostly used in clinical trials to evaluate the intervention effects.¹²² Among these applications, the Stage of Change questionnaire, which applies algorithmic querying, is more widely used.^{116–119} This question resulted in stage-based classification, which could provide guidelines for stage-based interventions, and is user-friendly in terms of relatively small number of questions delivered by the interviewer.

2.5 Relevant studies

ACP engagement varies upon cultural contexts, and several studies highlighted the collectivist culture and family-centered decision making in Asian countries.^{74,123,124} However, research specifically examining readiness for ACP engagement in elderly cancer patients was limited.⁶⁰ With this consideration, this

section focuses on describing factors influencing ACP engagement of elderly cancer patients (with a small inclusion of studies in mixed patients who had cancer and/or conditions related to organ failure) in various contexts potentially relevant or applicable to elderly cancer patients in Asia. Associated factors will be conceptualized based on the HBM and Decisional Balance in the TTM. In addition, we partly extend our review to qualitative studies conducted in other similar elderly populations to help conceptualize potential factors associated with the readiness. Table 3 summarizes relevant studies which help conceptualize the study.

2.5.1 Factors associated with readiness for ACP engagement

The readiness for ACP engagement (i.e., likelihood of action in the HBM) is an internal (covert) behavior process through individual beliefs towards benefits and barriers of ACP.^{102,104} Different aspect of beliefs (i.e., perceptions) and psychosocial factors can manifest by means of cues to actions and modifying factors.^{102,104} To elaborate sociodemographic variations, gender, education, marital status, monthly income, health insurance and religious beliefs are associated with likelihood of ACP adoption in the elderly.^{26,100,125–127} Additionally, perceived health status, trust in physician, family issues, and experienced families or friends having had life-sustaining treatment are also the significant cues.^{26,112,125–128} ACP can be hindered from thoughts such as perceived barriers, which encompasses thoughts such as family issues, ACP document length and complexity, seeing ACP as talking about death and dying, and authority of a god to control life;^{37,112} while perceived ACP benefits, for example, ensuring person-centered care, increasing sense of control, and reduced stress of oneself and family^{64,112} can motivate engagement. Perceived severity constructs were also assessed in a study by Ko and colleagues.¹²⁹ The authors showed that negative consequences from family conflict, receiving unwanted treatment, and costs, as a part of health beliefs which take into account perceived benefits, barriers, and severity from not engaging in ACP, were associated with engagement among white older adults. Regarding family factors, Boerner³³ showed that general family functioning was significantly associated with ACP discussions (adjusted odds ratio 2.79, 95% CI 1.2 – 6.3), but not with two-pronged ACP (discussion and documentation). In addition, they also demonstrated a relationship between spouse support and ACP discussions

(adjusted OR 4.3, 95% CI 1.1 – 17.3). McCarthy found that support from family, including having someone to listen, and someone to provide support and make difficult decisions were associated factors. Elderly who always had someone to listen to them were 7 times more likely to have advance directives than those who did not.¹⁰⁰ There were also several qualitative studies describing interactions between family mechanisms and ACP in the elderly in several aspects, including relational autonomy, intention to protect the elderly from distress, and potential discordance in views towards ACP.^{21,23,29,130}

Associated factors or perceptions examined in different cultures might not be readily applicable in other cultures as different people might perceive ACP quality in different aspects, for example, religiosity was conceptualized as a facilitator for ACP documentation,¹²⁹ while another study conceptualized god's authority as a barrier for ACP.³⁷ Apart from that, lack of knowledge regarding ACP were conceptualized differently as modifying factor¹²⁹ and barriers.³⁷ Moreover, cultural context plays a significant role in ACP engagement. Lin and colleagues commented on collectivism in Asian culture, in which factors associated with ACP engagement are stressed on relational autonomy and family member's views about ACP.⁵⁶ This culture is also relevant in Thailand as the elderly attitude can shift towards the same side of the family members.¹³¹ These variations in factors potentially associated with readiness for ACP engagement of elderly cancer patients across cultural settings stress the importance of mixed-method methodology in developing a better understanding of the ACP engagement in the Thai context prior to administering research instruments.¹³²

2.5.2 Readiness for ACP engagement in elderly cancer patients

There is limited research quantifying the readiness of elderly cancer patients to engage in ACP as well as assessing influences from their families. We identified only two studies specifically assessing readiness for ACP engagement in older cancer patients and family influences: one in Korea (n = 1,001, 67% age $\geq$ 50 years)⁵⁹ and one in Taiwan (n = 9, 100% age $\geq$ 70 years).⁶⁰ The former study⁵⁹ surveyed willingness of cancer patients and their families to engage in ACP based on different simulated scenarios. They found that willingness to engage increased with deteriorating health and peaked near the end of life and 74% and 77% of cancer patients and their

caregiver were willing to engage in ACP, respectively. The level of willingness of the caregivers was always higher than that of the patients. This supported the discordance in views towards ACP between elderly patients and their caregivers mentioned previously.¹³⁰ The study from Taiwan⁶⁰ reported that almost all the elderly cancer patients (n = 9) were not ready for ACP engagement, reflecting a substantial gap in clarifying the readiness for ACP more comprehensively.

2.5.3 Understanding complex relationships using Bayesian networks

In certain studies, researchers may want to test whether their concept or proposed model works or fits well in their study population. However, such analyses require a prior understanding of the relationships between variables. In some situations, it is not always possible or sensible for the researcher to understand the relationships. A Bayesian network (BN) is a member of a probabilistic graphical model that applies probabilistic representations of relationships in the form of directed acyclic graphs (DAGs). After developing an acceptable DAG that can explain the observed data well (i.e., having a high likelihood or network score), the researcher may also be interested in making inferences on the network, so-called network querying, to see what a certain outcome would be when some conditions happened, or were observed. A BN encompasses three tasks, 1) finding the network skeleton (possible DAGs) and the probability parameters within the network, 2) representing probabilistic independence of the variables as a DAG, and 3) making inferences^{133,134} (see Appendix 10 for more details).

BN has valuable applications in learning complex hierarchical relationships among psychosocial variables, as well as facilitating understanding of medical diagnoses and genetic studies.^{133,134} Having a BN can benefit from improving understanding of causal relationships between variables. Additionally, a causal BN allows simulations of intervention effects (intervention analysis), applying “do-operator”, to identify potential variables that have causal links with the desirable outcomes and answer “What would the effect be if the intervention successfully changed the target outcome?”.^{135,136}

Interplays among readiness for ACP engagement, family mechanisms, and other associated variables in the domain can be guided by BN learning. DAGs can

provide potential relationships explaining the domain of associations between relevant factors and readiness for ACP. Understanding cause-effect relationships in the domain is crucial. It helps explain the behaviors and thoughts of the elderly patient and the family member in a clinical encounter or ACP session. Applying BN in this context, therefore, allows us to objectively formulate an understanding of the relevant variables identified in the literature. Furthermore, the causal BN also helps prioritize target variables in the domain to promote motivations (readiness) for ACP in the elderly.

Table 3 Summary of relevant studies

No.	Author	Research question	Setting	Participant	Methods	Results	Appraisal
1	Li, et al. (2021) ¹³⁷	How are ACP awareness and intention to engage in advance directives in indigenous Taiwanese older cancer patients?	3 indigenous oncology clinics in Eastern Taiwan	9 older indigenous Taiwan who resided in a remote area	Mixed method study: multiple case study method and questionnaire survey to quantify the number of individuals who were in each stage of readiness	All nine participants were in the pre-contemplation stage for ACP engagement. Extremely low understanding and awareness of ACP were reported.	Complex context, elderly cancer patients in a remote area in a highly developed palliative care country. Limitation in the strength of conclusion on nine participants
2	Park, et al. (2019) ⁹⁶	How are attitudes and awareness towards advance directives in 1) the general population 2) cancer patients and family caregivers 3) physicians?	12 general hospitals were involved in the inclusion of cancer patients and caregivers The general population and physicians were recruited by telephone	1,001 adult cancer patients and 1,006 family caregivers	Cross-sectional study using a structured questionnaire to interview cancer patients and caregivers	Willingness to engage in ACP gradually increased from 58.0 to more than 70% when cancer patients and families were aware that there was a worsening condition of a serious disease	Using simulated scenarios to measure willingness Dichotomous assessment method of willingness for ACP (yes/ no) Nonspecific age group elderly patients with cancer

3	Dobbs, et al. (2015) ²⁶	Is acculturation associated with awareness of end-of-life decision-making and advance directive (AD) documentation?	Korean migrant community institutes (such as senior centers or churches)	675 elderly (age >60) Korean immigrants with at least 1 chronic condition	Community-based telephone survey	20.3% were aware of AD 18.6% had AD Gender, marital status, education, higher morbidity, health insurance, and acculturation were significant factors. Age was an insignificant factor.	Asian community in a Western country (acculturation as the main exposure) in which statistical modeling did not include beliefs or perceptions related to ACP.
4	Fried, et al. (2009) ³⁷	Is ACP a process of behavior and what are range of ACP behavior constructs?	Affiliated senior clinics in a government hospital network	63 elderly (aged ≥65) with at least 1 chronic condition and caregivers of the elderly	Qualitative study (grounded theory) using focus groups	ACP demonstrates stage-based patterns associated with perceived benefits and barriers of ACP (TTM), and experience of healthcare decision-making for loved ones influences the engagement	The qualitative study purposively recruited mixed elderly outpatients in a Western country, limiting generalizability to Asian countries.

5	Fried and O'Leary (2008) ¹³⁰	How are the end-of-life care experiences of older patients and their caregivers and how are they associated with ACP?	Outpatient practices affiliated with three network hospitals	64 caregivers of the deceased elderly who had had cancer, chronic lung or heart disease	Qualitative study (grounded theory) using in-depth interviews	There were patient-caregiver variations of agreement in prognostic information preference. Patient-caregiver communication issues were stressed including differing hopes and avoidance.	Assessing ACP-related preferences and attitudes in a different cultural context, limiting generalizability to Asian countries.
6	Boerner, et al. (2013) ³³	What are the effects of family relations, general family functioning, support, and criticism from children and spouses on both overall ACP and specific POA designation?	2 University hospitals and 1 comprehensive cancer care center	305 OPD patients (aged >55, with colorectal cancer, type II diabetes, or congestive heart failure; or any medical condition with some symptoms that affect quality of life)	Cross-sectional study, face-to-face interviews Use computer-assisted structured face-to-face interviews	The high family function had higher odds of ACP discussion only: OR 2.79 (95% CI 1.24-6.27) Higher functional limitations had higher odds of AD and discussion: OR 2.73 (95% CI 1.23-6.05)	Assessing an impact of general family functioning in unspecific elderly patients. Lacking information on the causal relationship of family factors to ACP behaviors

7	McCarthy, et al. (2008) ¹⁰⁰	To what extent do the elderly have ACP? What are the elderly's ACP preferences? How do ACP and preferences relate to social support, illness burden, physical functioning, and other domains?	Community setting at the recruitment of the health examination site in Framingham, Massachusetts	220 community-dwelling and cognitively intact elderly	Cross-sectional study at a biennial examination of the population in Framingham Heart Study from 2004 – 2005	Had social support (had someone to listen) had 6.93 times higher odds of having AD Had emotional support had 2.83 times higher odds of having AD	There was no definition of the elderly's age. Only showing descriptive family statistics Lack of clear measurement for roles of family in ACP
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3. Rationale

3.1 Gap of knowledge

Advance care planning benefits a wide range of people, including general patients and the elderly living with cancer.^{15,55,73} Previous studies showed a diversity in the number of elderly who were aware of^{26,125,128} and engaged in^{33,100,138} ACP. However, the majority of these studies focused on this action-based outcome (ever or never engaging in certain types of ACP) in non-elderly cancer patients; only one study investigated the spectrum of motivation in ACP engagement in elderly cancer patients.¹³⁷ The lack of context-specific information leaves a significant gap of knowledge on how elderly cancer patients can proceed to engage in ACP and how they should be supported based on their readiness. Although implementation of ACP in general can be influenced by factors from multiple layers of the medical ecology¹³⁹ including patients, care professionals, and the health system,¹⁴⁰ individual motivation to engage in ACP mainly proceeds through factors from those who are close in proximity such as assessing family member's behaviors or thinking about what the clinician has advised.³⁷ Several studies highlighted the importance of family mechanisms in ACP engagement among elderly patients, especially in Asian settings where ACP is greatly influenced by collectivism and relational autonomy.^{23,56,74,131} Some studies quantified the impact of family mechanisms (e.g., family structure, general family functioning, emotional support, and criticism)^{33,100,126,141} on ACP action-based outcomes. However, there was a significant gap in understanding the impacts of many other family factors, for example, family type, authority, and perceptions of caregiving family members on ACP readiness. In addition, conceptualizing the complex relationships among the readiness and sociodemographic and family factors has never been objectively done.

3.2 Rationale for the study

Elderly persons who have cancer face uncertainty in health from aging, cancer, and treatment.^{4,12,142} ACP helps families and clinicians understand elderly cancer patients' wishes and preferences, leading to better care and health system outcomes.¹⁴³ However, ACP engagement among Asian people is relatively low and

unique due to particular beliefs and collectivist culture.^{56,74} Additionally, there is a lack of information on how elderly cancer patients are motivated to engage in ACP (only one study from Taiwan). Many studies focused on action-based outcomes, leading to a lack of guiding information for stakeholders in Thailand on strategies to improve motivation on ACP engagement in elderly cancer patients.

ACP proceeds mainly through perceptions and evaluations of context close in proximity, especially the family.³⁷ Thus, clinicians whose practice is involved in ACP should incorporate family dynamics in the care, or “practice family”.¹⁴⁴ However, counseling sessions involving unmotivated elderly cancer patients and/or their families and caregivers require targeted interventions for patients and/or their families in order to promote ACP engagement. Choosing an effective intervention requires conceptual understanding in terms of causal relationships among interrelated variables,¹³⁵ which are indirectly implied in the previous studies. However, this information is limited. The knowledge regarding how readiness for ACP engagement varies in elderly cancer patients and what factors play causal roles in the readiness can help clinicians and those who are involved in ACP fully understand the extent to which elderly cancer patients are unmotivated, and how family mechanisms, which is the focus in the ACP process in a collectivist culture, might lead to a better readiness for ACP. Lack of a causal conceptualization among these variables stresses the importance of using a Bayesian network to identify the probable intervenable pathways. Thus, family members, clinicians, and policy makers in the Thai health system can devise and prioritize appropriate strategies for ACP initiation and promotion based on a rigorous reasoning.

4. Research questions

1. What are the perceptions of elderly patients and caregivers towards ACP?
2. What are the stages of readiness for ACP engagement among the elderly with cancer?
3. How do family mechanisms account for other sociodemographic factors influence readiness for ACP engagement of the elderly with cancer?

4. How do stages of ACP engagement of the elderly vary with different family mechanisms?
5. How do stages of ACP engagement of the elderly vary with different clinical and sociodemographic factors?
6. To what extent are family members' and the elderly's perceptions towards ACP congruent?

5. Objectives

5.1 Objectives of the study (phase 1)

Primary objective

1. To understand the perceptions of elderly patients and caregivers towards ACP

5.2 Objectives of the study (phase 2)

Primary objectives

1. To examine stages of readiness for ACP engagement among elderly with cancer,
2. To develop and examine structural relationships between family mechanisms and readiness for ACP engagement, taking into account clinical and sociodemographic factors of the elderly with cancer and their families

Secondary objectives

1. To compare readiness for ACP engagement between the elderly with different family mechanisms accounting for clinical and sociodemographic factors,
2. To assess the congruence in perceptions towards ACP between the elderly and their family members.

CHAPTER 2

METHODS

6. Conceptual Framework

The family mechanisms and readiness for ACP engagement are conceptualized based on 1) the Health Belief Model and 2) the Transtheoretical model's stage of change. However, as one of the main objectives of this study is to define the relationships between variables, this section represents a preliminary conceptual framework of how the variables interact. In general, individual perceptions are influenced by personal factors. Patient factors include sociodemographic factors and clinical factors playing as cues to ACP. Caregiver factors encompass roles and relationships with the patient, as well as their social characteristics. The elderly's decisional balance on ACP is associated with such balance of the caregiving family member (caregiver), but working through family mechanisms. This interplay can lead to readiness for ACP engagement. Hypothetically, more favorable perceptions and family mechanisms means the patient is more likely to be in a higher stage of readiness for ACP. These relationships are outlined in Figure 2.

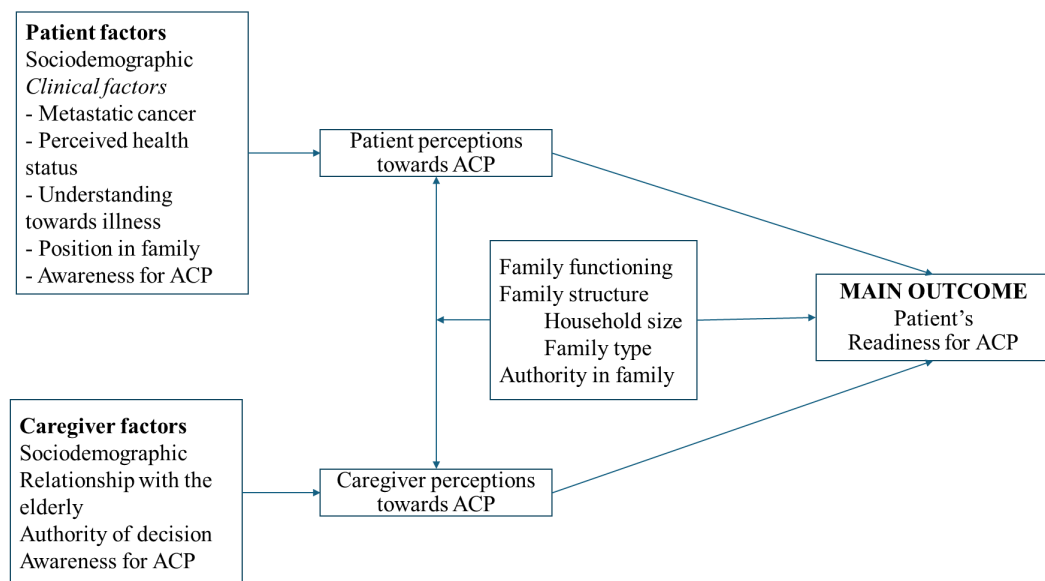


Figure 2 Conceptual framework

7. Methodologies

A sequential exploratory mixed-methods design was applied. In phase 1, a qualitative study was conducted to pretest the usability of a cross-culturally adapted questionnaire (developed by Fried and colleagues)⁶⁴ that was used to measure the stage of change, and explore the mechanisms among family members that influence the readiness for ACP. The findings were then used to supplement the pre-constructed questionnaire based on the literature review. Then, a quantitative cross-sectional study was conducted. Figure 3 summarizes the study procedure stages.

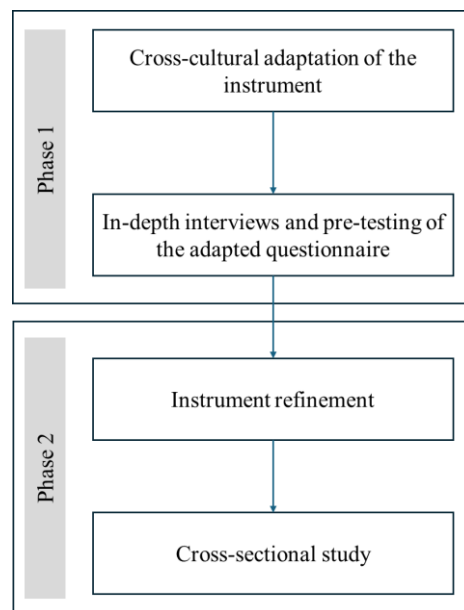


Figure 3 Study procedure stages

7.1 Study Phase 1: Descriptive Qualitative phase

Before conducting the cross-sectional study, in-depth interviews of elderly patients and their caregivers were conducted. We applied an interpretivist approach in the qualitative study to identify potential culturally sensitive or perspective factors associated with ACP engagement in elderly Thai cancer patients,¹³² and examined possible cultural adaptations of the original questionnaire item texts to make the questionnaire contextually applicable in the second phase.¹⁴⁵

7.1.1 Target population

Elderly with cancer and their families in Southern Thailand

7.1.2 Study population

Elderly with cancer and their primary caregiver visiting oncology and radiotherapy clinics in Songklanagarind Hospital, Songkhla Province, Thailand, between January 2023 and April 2023.

7.1.3 Inclusion criteria (for indexed elderly)

1. Thai adults aged 60 years old or older
2. Diagnosed with a non-hematological cancer
3. Able to understand and communicate in Thai

7.1.4 Exclusion criteria (for indexed elderly)

1. Diagnosed with schizophrenia, major depressive disorder, dementia, or mental retardation
2. No primary caregiver
3. Not physically and mentally well enough
4. In moderate to severe pain
5. Head and neck cancer (limited verbal communication)
6. Brain tumor
7. Currently participating in two or more research projects

7.1.5 Inclusion criteria (for the primary caregiver of the indexed elderly)

1. Thai adult 18 years old or older
2. Having spent the highest number of hours in taking care of the elderly (in case there are more than one caregiver)
3. Literate in the Thai language
4. Not employed to take care of the indexed elderly

7.1.6 Exclusion criteria (for the primary caregiver of the indexed elderly)

Not applicable

7.1.7 Study procedure

7.1.7.1 Preparatory phase

After the Institutional Review Board (IRB) approved the study protocol, the investigators informed the clinics about the study protocol and acquired permission to perform this research study, including participant recruitment and data collection.

7.1.7.2 Cross-cultural adaptation of the study instruments

The permission to adapt the original questionnaire, including 1) Stage of Change Questionnaire, 2) Pros and Cons, and 3) Values and Beliefs Questionnaire, was given by the corresponding author of a previous study.¹⁴⁶ The adaptation process follows the WHO Cross-cultural Adaptation of the Instrument, which includes forward translation, expert panel discussions, backward translation, and pretesting.¹⁴⁷ The pretesting step is also included in this phase. The aim of this step is to develop an instrument that is suitable for the Thai context.

7.1.7.2 Data collection

Purposive sampling was used. The registration staff of the eligible services cooperated and was the gatekeeper (a registration nurse). Thus, they were aware of the study subject eligibility criteria and protocol. At the radiotherapy clinic, the participants were informed about the existence of the research project at the registration counter by the registration staff and finished their registration for services. The investigator approached the eligible participants only if they gave verbal permission for further interviews. The investigators approached the eligible participants upon their convenience (e.g., after finishing the service procedure), and invited them to a predetermined private area for the informed consent process. After giving the information about the study, potential participants were given time to decide and choose the place of interviews as well as written consent. After determining the place of interviews, an appointment was made based on the convenience of patients and their caregivers.

7.1.7.2.1 Maximum variation sampling

After the informed consent process, each participant underwent a structured interview using the Stage of Change questionnaire (considered as pretesting or pilot test for the Thai questionnaire usability). Recruitments of participants with various conditions (Table 4) was used. We estimated that approximately 20 patients and 20 caregivers would satisfy the saturation.

Table 4 Planned sampling (phase 1)

Characteristics	Precontemplation stage (n)	Action/ maintenance stage (n)
Male	2-3	2-3
Female	2-3	2-3
Buddhist	2-3	2-3
Other religion	2-3	2-3

7.1.7.2.2 In-depth interviews

The interview guide was used (see details in appendix 5 and 6) for semi-structured interviews. The interview guide covered general perceptions regarding illness and current treatment, benefits and barriers to ACP, and values and beliefs related to ACP. The principal investigator, who had experience in qualitative studies and palliative care, was the only interviewer. We pilot-tested the interview guide with three patients with the same features as the formal informants to evaluate the comprehensibility of the questions. Permission for audio records was requested before the interviews. Patients and caregivers were interviewed separately. The caregiver was interviewed first followed by the patient. This step was justified to ensure additional safeguards for the elderly (alleviating physical fatigue from the interviews and gathering any precautions regarding sensitive information which the interviewer should be careful about). The interviewer also took notes when interviewing. At the end of the interviews, the interviewer summarized the information received to get feedback/corrections from the informants. While we were collecting data, a few questions were added to capture more detailed data based on what the interviewer learned from the previous interviews. The interviews took approximately 45 minutes per session and the interviewer did not know the informants before the interviews. Data saturation was discussed among the researchers, including one experienced palliative care nurse and one oncology nurse to decide on a case-by-case basis whether any new themes and subthemes emerged after a recent analysis and whether the collected data was sufficient to exemplify the study theoretical concept.¹⁴⁸

7.1.8 Data analysis

We applied a thematic analysis framework¹⁴⁹ and several approaches to ensure credibility and transferability of data.¹⁵⁰ Credibility was established through

investigator triangulation and peer debriefing. Transferability was established through thick descriptions of the data. The first four transcripts, including the field note data, were given to two coders, SS and PL. The coders first familiarized themselves with the data by going through the transcripts line by line. The initial codes were compared, critically discussed, and agreed upon by the two coders for initial agreements. SS continued to code the remaining transcripts and record emerging codes in a form of coding dictionary. Additions or modifications of the codes and its dictionary were logged on a daily basis for subsequent auditing. Broader meanings of the codes were identified in terms of themes after examining the whole dataset. The components of the Health Beliefs Model¹⁰² were identified a priori as a beneficial approach to theming the informants' thoughts. The framework encompasses beliefs and perceptions which could potentially modify the readiness of a patient to engage in advance care planning. The findings were debriefed with one experienced oncologist and one palliative care consultant to ensure solid interpretations and conclusions. The data were managed and analyzed using Microsoft Excel and the R language and environment. Themes and subthemes are provided with descriptions and examples of the relevant verbatim quotes.

7.2 Study Phase 2: Cross-sectional study

7.2.1 Target population

Elderly with cancer and their families in Southern Thailand

7.2.2 Study population

Elderly with cancer and their primary caregiver visiting the oncology radiotherapy clinic, Songklanagarind Hospital, Songkhla Province, Thailand, between August 2023 and October 2024.

7.2.3 Inclusion criteria (for indexed elderly)

1. Thai adult aged 60 years or more
2. Diagnosed with non-hematological cancer
3. Can understand and communicate in Thai

7.2.4 Exclusion criteria (for indexed elderly)

1. No primary caregiver

2. Physically unwell
3. In moderate or severe pain
4. Head and neck cancer (limited verbal communicability)
5. Brain tumor
6. Psychological disorder such as major depressive disorder or dementia
7. Participating in two or more research projects

7.2.5 Inclusion criteria (for primary caregiver of the indexed elderly)

1. Thai adult aged 18 years or more
2. Having spent the highest hours in taking care of the elderly (in case there are more than one caregiver)
3. Literate in the Thai language
4. Not employed to take care of the index elderly

7.2.6 Exclusion criteria (for primary caregiver of the indexed elderly)

Not applicable

7.2.7 Sample size calculation

7.2.7.1 Required sample size for Objective 1

The required sample size was calculated to assess an infinite population proportion of elderly in different stages of readiness for ACP (equation 1). Type 1 error (alpha) was determined at 0.05. The proportion of elderly patients who are ready for ACP (preparation, action, or maintenance stage of readiness for ACP engagement) was based on a previous study,¹⁴⁶ and took into account cultural differences in ACP readiness learned from the pretest step in the qualitative study. We finally redefined the assumed proportion at 0.6.

$$n = \frac{z_{1-\frac{\alpha}{2}}^2 p(1-p)}{d^2} \quad (1)$$

We set the precision (d) of the estimated proportion to be 0.06. We determined our sample size for this objective as 256 (512 participants in total).

7.2.7.2 Required sample size for Objective 2

We aimed to develop and examine the structural relationships between family mechanisms and readiness for ACP engagement using a Bayesian Network (BN). However, there has not been a definite method to obtain the required sample size for BN structural learning. With a large number of parameters, a larger sample size can provide more precise structure of the BN; thus, the number of conditioning cases can be sufficient for learning.¹⁵¹ There is a rule of thumb that the sample size should be at least equal to the number of independent parameters in the network. Thus, sample size can vary based on the structure built, for example, a sample size of 384, 408 and 505 were reported in learning BN structure with 24, 26, and 73 nodes, respectively.^{151–153} Therefore, we assessed that the required sample size for objective 1 can be sufficient to learn a BN structure at a certain network size.

7.2.7.3 Final required sample size

After consulting with the oncology nurses, we assumed that Thai families were generally willing to participate in the study which applies a self-report or a brief interview. A 10% assumption of missing data was considered. As a result, we planned to recruit a total of 568 participants, considering the feasibility of the data collection process and response rate. This required sample size was altered from the first computation (1,100 participants because we learned from our qualitative study that approximately 60% (see section 7.2.7.1: Sample size calculation) of the elderly persons were ready (categorized as preparation, action, or maintenance) for ACP discussions.

7.2.8 Study variables and outcome measurement

Data on elderly persons and their families were collected from structured interviews, self-reported questions, and electronic medical records (EMR). Table 5 summarizes the study variables and the sources of data. The total time required to complete the data collection per family was 10 – 15 minutes.

7.2.8.1 Outcome variable

Stage of readiness for ACP engagement

Readiness for ACP is conceptualized by the Transtheoretical model (Stages of Change). Individuals in higher stages of readiness would be more ready, or motivated, to engage in ACP activities such as discussing goals of care with their doctors. This variable is an ordinal variable with four categories, including

Precontemplation (PC), Contemplation (C), Preparation (P) and Action/maintenance (AC/M) which corresponds to 6 types of ACP behaviors: 1) advance directives of living will documentation, 2) documenting power of attorney for healthcare (DPAHC), 3) discussions about the quality of life (goal of care) with family, 4) discussions about the quality of life (goal of care) with clinicians, 5) discussions about life-sustaining treatment (LST) with family, and 6) having discussions about LST with clinicians. For instance, a patient might be in the pre-contemplation stage for having a living will documentation; however, be in preparation for having discussions about goals of care with family. The questionnaire is based on findings from a previous qualitative study³⁷ applying the Transtheoretical model¹⁰¹. The questionnaire includes a set of stepwise questions, which starts by asking general questions and then focusing on the specific types of ACP behaviors. Particularly, the questions pertaining discussing the use of LST with the family (the 5th ACP behavior) additionally includes a special case of contemplation, in which the respondent is ready but their family does not seem to be ready for the discussion. In our Bayesian network structure learning, the readiness of all six ACP behaviors were grouped into “ready” (preparation, action, and maintenance), and “not ready” (pre-contemplation and contemplation) for compact representation (their practical meanings are retained; all stages in the same group require the same/very similar intervention to promote motivation). Further details can be found in Appendix 7.

7.2.8.2 Exposure variables

Family mechanisms include variables that are related to the family of the elderly cancer patients. The operational definition of family mechanisms in the study context is as follows, “a set of variables related to family, spanning socio-demographic and socio-economic characteristics of the family members, authority in the family (head of the family), relationship with the sick person (the elderly cancer patients), type of family structure, family size, unofficially nominated healthcare proxy of the sick person, family functioning, and each family member’s perceptions of ACP”. Other related factors encompass clinical factors: elderly patient’s health status, understanding of current treatment and illness, quality of information received from the clinician, comorbidity, cancer types, and cancer-related visits.

7.2.8.2.1 Head of the family

This variable was based on the perceived relationship with the head of household. The responses included: 1) respondent is the head of household, 2) wife or husband or partner, 3) son/daughter (unmarried), 4) son/daughter (married), 5) son/daughter-in-law, 6) grandchild, 7) parent/parent-in-law, 8) sibling, 9) other relative, and 10) domestic assistant/non-relative. This information was from a self-rated questionnaire completed by the primary caregiver.

7.2.8.2.2 Caregiver's relationship with the elderly

The relationship of the caregiver was based on biological and/or a legally bound relationship with the indexed elderly. The responses included: 1) wife or husband or partner, 2) son/daughter (unmarried), 3) son/daughter (married), 4) son/daughter-in-law 5) grandchild, 6) parent/parent-in-law, 7) sibling, and 8) other relatives. This information was acquired from a self-rated questionnaire completed by the primary caregiver.

7.2.8.2.3 Type of family

Family types was defined as a general family structure based on the classification provided by the United Nations Population Fund Thailand Country Office.⁵⁴ This variable includes 2 main family types: nuclear family and extended family. The details regarding the classification of family structure are provided in the literature review section. The responses included: 1) living with husband or wife (without children), 2) living with parents or child (or children), 3) living with grandparents, working age children, and/or grandchildren (three generation), 4) living with grandparents or grandchildren, and 5) others. Number 1) and 2) are grouped as nuclear family while 4) is extended family. This information is from a self-rated questionnaire completed by the primary caregiver.

7.2.8.2.4 Family size

The number of people in the elderly's family defines this variable. This definition includes people who the caregiver perceives that they have commitment to take care of each other within the family (not limited to persons living under the same

roof). This information is from a self-rated questionnaire completed by the primary caregiver.

7.2.8.2.5 Unofficial healthcare proxy

The authority of medical care decisions, when the elderly is incapable of making this decision, that the primary caregiver has based on the presence of the family's authority system. There can be no one who has such authority. The responses included: 1) him/herself being the person who had such authority, 2) other children, 3) spouse or husband of the indexed elderly, 4) other family members, and 5) there is no such person. This information is from a self-rated questionnaire completed by the primary caregiver.

7.2.8.2.6 Family functioning

Family functioning was defined as the dynamics in a family and are grouped into seven domains: problem-solving, communication, role, affective responsiveness, affective involvement, and behavioral control.⁸⁴ This variable was measured by the Family State and Functioning Assessment Scale.⁸⁷ The instrument is a self-rated questionnaire consisting of 25 items. We asked the caregivers to complete this questionnaire. The items are measured on a 4-point Likert scale ranging from "1-strongly disagree" to "4-strongly agree". There are five domains in this measurement: Family support, Discipline, Communication and problem-solving, Emotional status, and Relationship. Total family functioning was computed by summing the scores from all categories. The total score of the domain was categorized into low, moderate, and high based on the developers' guidance. The instrument was tested for its reliability (domain-specific and overall Cronbach's alpha ranged from 0.70 to 0.84).

7.2.8.2.7 Individual Perceptions Towards ACP

The perceptions were measured by a cross-cultural adaptation of the Decisional Balance and Values/Beliefs instrument developed by Fried and colleagues.¹⁴⁶ The original instrument is a self-rated questionnaire consisting of 19 items. The Decisional Balance questions cover perceptions related to the pros and cons of ACP and the Values/Beliefs questionnaire asks about health beliefs/tradeoffs related to ACP. The items are measured on a 5-point Likert scale ranging from "1- strongly

disagree” to “5-strongly agree”. The adaptation of the original instrument resulted in two versions: 1) guide questions for structured interviews of elderly participants and 2) self-rated questionnaire for the primary caregiver. Two sets of questions ask similar questions, the points of view of which are based on the elderly circumstances (detailed questions are provided in the Data recording form section).

7.2.8.2.8 Age

The age of the indexed elderly and the caregiver was collected. This information was obtained from a self-reported questionnaire completed by the primary caregiver, but for the elderly, the age was also checked with the EMR.

7.2.8.2.9 Gender

Gender is a 3-category variable referring to the gender stated in the identification card. Patient’s and the caregiver’s genders include male, female, and other. This information was obtained from a self-reported questionnaire completed by the caregiver.

7.2.8.2.10 Education

Education level is an ordinal variable referring to the highest level of education completed. It includes both patients’ and relative’s education levels. The responses included: 1) never went to school, 2) primary school, 3) junior high school, 4) high school, 5) vocational certificate, 6) associate degree, 7) vocational diploma, 8) bachelor's degree, and 9) higher than bachelor's degree. This information was from a self-reported questionnaire completed by the caregiver.

7.2.8.2.11 Occupation

Occupation is a 9-category variable referring to the current working status of patient and the caregiver. The responses include 1) civil servant/state enterprise, 2) private sector employee, 3) small-scale vendor/service provider, 4) business owner/entrepreneur, 5) laborer/manual worker, 6) retired/homemaker, 7) agriculture/ fishery, 8) independent professions (e.g., lawyers, architects), and 9) student. This information was from a self-reported questionnaire completed by the caregiver.

7.2.8.2.12 Religion

Religion is a 4-category nominal variable of the current religious belief of the patient and the caregiver. The responses included: 1) Islam, 2) Buddhism, 3) Christianity, and 4) Other. This information was from a self-reported questionnaire completed by the caregiver.

7.2.8.2.13 Marital status

Marital status is a 4-category nominal variable referring to the current marital status of the patient and the caregiver. The responses included: 1) single, 2) married with children, 3) married with no children, and 4) widowed/divorced/separated. This information was from a self-reported questionnaire completed by the caregiver

7.2.8.2.14 Family monthly income

Family monthly income refers to the total income in the family in the past few months or at the present time. The responses include 7 categories (in Thai baht): 1) no more than 5,000, 2) 5,001 to 10,000, 3) 10,001 to 20,000, 4) 20,001 to 30,000, 5) 30,001 to 40,000, 6) 40,001 to 50,000, and 7) More than 50,000. This information was from a self-reported questionnaire completed by the primary caregiver.

7.2.8.2.15 Health insurance scheme

This 4-category variable refers to the main health insurance scheme that the patient used in the current medical visit to cover most parts of the medical treatments. The responses included: 1) The Universal Health Coverage scheme, 2) Social Security Scheme, 3) Civil Servant Medical Benefit Scheme, and 4) Other. This information is from the EMR.

7.2.8.2.16 Patient health status

Health status is an ordinal variable defined as the perceived current health status by the patient. The question, asked to the elderly patient, was adapted from the “Self-rated health status” questionnaire¹⁵⁴. The possible responses were: “excellent”, “good”, “fair”, “poor”, or “bad”.

7.2.8.2.17 Understanding of current treatment

This ordinal variable refers to the perceived level of understanding regarding the current treatment that the elderly have. The elderly were asked this question with possible responses being: “very clear”, “clear”, “moderate”, “poor”, and “very poor”.

7.2.8.2.18 Quality of information regarding illness received from a physician

This ordinal variable refers to perceived information regarding illness and treatment that the elderly have received from their doctor. The elderly were asked this question with possible responses being: “very clear”, “clear”, “moderate”, “very little”, and “very poor”.

7.2.8.2.19 Cancer type and comorbidity

This information, containing the International Classification of Diseases, 10th edition, was retrieved from the EMR. Modified Charlson comorbidity score was computed to represent the extent of comorbidity using the “comorbidity” package in R.

7.2.8.2.20 Number of cancer clinic visits

Number of visits is a continuous variable representing the number of clinic visits that the patient has had for cancer care. The information was obtained from the EMR.

Table 5 Study variables and data sources

Elderly person	Caregiver	EMR
• Stages of readiness for ACP • Individual perceptions towards ACP • Health status • Understanding of the current treatment • Information regarding illness received from the physician	• Head of the family • Caregiver's relationship with the elderly • Type of family • Family size • Unofficial proxy • Family functioning • Individual perceptions towards ACP	• Age • Health insurance scheme of the indexed elderly • Cancer type • Number of visits for cancer care. • Comorbidity

	• Sociodemographic characteristics (age, gender, education, occupation, religion, marital status) of the indexed elderly person and the caregiver • Family monthly income	
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7.2.9 Study procedure

7.2.9.1 Preparatory phase

After the Institutional Review Board approved the study protocol on 22nd August 2023, we informed the oncology clinic and pretested the study steps with all the clinic staff. The oncologists agreed to let the oncology nurse inform the patients briefly about the research project. Subsequently, the nurses sent all potential participants to meet the investigator for informed consent. The reasons for exclusion due to the exclusion criteria and reasons for refusal were recorded. We recruited the participants consecutively from 22 August 2023 to 10 October 2024.

All project investigators were qualified palliative care providers, including a palliative care clinician (the principal investigator) and two palliative care ward nurses (research assistants). The two research assistants were trained to conduct the interviews, explain informed consent, handle self-reported questionnaires, manage patients who displayed signs of physical distress and psychological reactions, and answer questions asked by the participants regarding the study protocol. In addition, they were trained in Good Clinical Practice using an online training program and followed the project ethical standards outlined in section 8. The 4-hour training session covered a 1-hour lecture, a 1-hour data collection workshop, site visits, and a 1-hour ethical guideline training. The lecture included issues regarding ACP and elderly cancer patients, study site orientation, and the Kobo toolbox application.¹⁵⁷ The roleplay practice for data collection using the application was held in the workshop.

We modified the original Decisional Balance, and Values/Beliefs questionnaire into two versions, the patient and caregiver versions, to allow a comparison of how individuals on each side perceive ACP qualities, by incorporating our earlier qualitative findings (see details in Table 6). Both versions allowed the

respondent (patient or caregiver) to assess the extent of perceived pros and cons of ACP engagement in the index patient. Accordingly, patients assessed the pros and cons of all ACP activities that involved themselves, whereas caregivers assessed whether the activities involved the patients in their care. The Stage of Change questionnaire was adapted through a translation process without modifying the questionnaire. We applied the WHO cross-cultural adaptation of a study instrument approach¹⁵⁵ to ensure the quality of study tools. Our panel of investigators assessed the quality of initially translated questionnaires to maintain cultural and semantic equivalence. The panel included three palliative care physicians. A Thai instructor, fluent in English and specializing in international collaboration performed a backtranslation of the questionnaire to assess the consistency between the English and Thai versions. Further, three external experts in palliative care evaluated the content validity of the final version of the questionnaire. They applied the item-objective congruence index, for which the optimal cutoff point was 0.5 (range: 0.67–1).

The Decisional Balance and Values/Beliefs questionnaires were modified based on the findings from the qualitative study and subsequently pre-tested with a group of representative respondents. Cognitive interviews were conducted with four participants (two patients and two family caregivers) to evaluate the thought process (e.g., recall and judgement) while responding to the questionnaire using the “think aloud” method. Contents of the questionnaire were evaluated by three experts: two palliative care providers from two university hospitals and one senior palliative care nurse. Subsequently, 17 older adults and 13 caregivers were asked to respond to the questionnaire and rate the clarity (“totally unclear” to “totally understandable”). With the experts’ evaluations on the contents of the final questionnaire, the item-objective congruence index was applied, for which the optimal cutoff point was 0.5 (range: 0.67–1). A pilot test showed the time taken to complete the Decisional Balance and Values questionnaire was approximately 10 minutes and, overall, items were rated “mostly understandable” or “all understandable”. The questionnaire’s internal consistency reached an acceptable level (Cronbach’s alpha values of 0.83 and 0.71 for Decisional Balance (with reversed scale on CON) and Values/Beliefs, respectively). The Stage of Change questionnaire was pre-tested in the qualitative phase using the questionnaire to screen the participants. No modification issues were found.

Table 6 Adaptation of the questionnaire text after the qualitative study

Part	Original version	Modified version	Justification
Decisional balance	None	Healthcare proxy appointments will make the decision-making on [patient] future medical care among [patient] family members easier.	Family health surrogates played important roles in the ACP process in the Thai context.
	If you fill out a document such as a living will, the doctors are more likely to “pull the plug” too soon.	It is possible that [patient] would not receive standard clinical care if [patient] decides to accept or refuse some treatment ahead of time.	1. Unfamiliarity regarding a living will and its concepts (referential meaning) ¹⁴⁵ 2. Concerns of potentially receiving medical care lower than the standard (e.g., stopping life-saving measures) were one of the perceived potential cons of ACP
	It would be hard to do advance care planning because I don’t like thinking about being very ill.	Making an advance care plan means not being careless about any potential changes in health	Reframing the question test to be sensitive to the informants’ expressions regarding views on potential illnesses (connotative meaning) ¹⁴⁵
Values/ Beliefs	None	The treating physician is too busy for any ACP activities	Informants’ expressions regarding views to the current healthcare context
	None	Initiating discussions to plan for any worsening health is a sign that treatments are going to stop	Informants’ expressions regarding views on the current healthcare context

Remarks: the omitted (15) items were assessed acceptable/equivalent to the original item

7.2.9.2 Sampling method

We used a consecutive sampling technique to recruit participants, keeping the ratio of males and females proportional to the clinic population (see Table 7). We invited all eligible participants as indicated by the oncology nurses (gatekeepers). A certain number of patients were not accessible due to the gatekeeper's screening and workflow constraints (e.g., patients were sent from the hospital wards to have their radiotherapy through a specialized track). We kept track of the recruitment process until the number of participants reached the required sample size (204 data collection days). The process of recruitment through time is summarized in Figure 4.

Table 7 Sampling frame

Study participant	Sex	N
Source population (eligible patients)	Male	435 (54.9%)
	Female	346 (45.1%)
Sample (consented)	Male	154 (54.1%)
	Female	126 (45.9%)

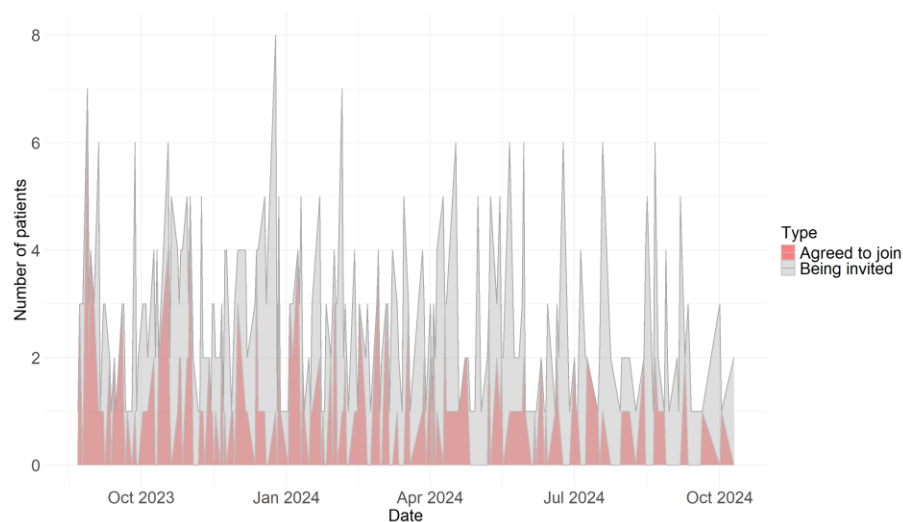


Figure 4 Recruitment progress

7.2.9.3 Data collection

The coordinated oncology nurse screened all patients visiting the clinic and sent the patients to the investigators for the informed consent process. The investigators collected the data using structured interviews for the patients and self-

rated questionnaires for the caregivers. Special consideration regarding the interviews were asked from the caregivers to avoid conflicts between investigator, caregiver, and patient. The interviews and questionnaire responses were conducted in the radiotherapy clinic to ensure any patient's medical needs would be served effectively. The Kobo Toolbox online data record form was used for structured interviews with the patient. A paper-based, self-report questionnaire was given to the caregiver, and data entry was later conducted using double entry in the Kobo Toolbox. The data from patient and caregiver participants from the same family were linked using a family identification number.

7.2.10 Data analysis

Demographic and other characteristics of the participants are described separately (patient and caregiver) or were aggregated (family) using descriptive statistics such as mean, median, and percentage. Proportions of participants' readiness for different ACP engagement are shown by bar plots with their 95% multinomial confidence intervals. Readiness for ACP engagement was presented fully by bar charts with 95% multinomial confidence intervals. Missing data were assessed if they could be corrected by triangulation of different data sources (electronic health records and questionnaires). The remaining missing data were checked for their mechanism and imputed using multiple imputations by MICE package in R. As missing data was presented only in caregiver responses, we applied only family and caregiver predictors for the imputation and created 5 imputed sets to be examined if retrieved data sets were invariant. Afterward, the complete data was used for computing intraclass correlation and confirmatory factor analysis (CFA). The results were also confirmed that there were no variations between the statistics among the imputed data. However, only one of the five sets was used for presentation.

7.2.10.1 Comparing perceived pros and cons of ACP between patients and caregivers and CFA

Bar graphs were used to describe perceptions related to ACP. Consistency of ratings in each item between patients and caregivers was computed

using intraclass correlation analysis for consistency. This step provides a detailed understanding of each ACP concern, which can be inconsistent among patients and their caregivers. Subsequently, only the adapted pros-cons (Decisional balance) questionnaire was tested for its proposed theoretical configuration (i.e., pros and cons) to maintain construct equivalence and to be used as potential theoretically intervenable variables (i.e., patients' pros and cons, and caregivers' pros and cons) in the next part of the analysis. Our qualitative findings were used to refine the original items or to develop new items (adding the item). We used the lavaan package in R to perform the CFA. The CFA models were specified based on standard rules for model specification for multi-factor models.¹⁵⁶ A correlated structure between the pros and cons was assumed. Weighted least square estimator was used to handle the nature of Likert-type variables in the CFA. For the caregiver CFA, models were tested on five imputed data sets. Fit indices for the model were assessed using the root-mean-square error of approximation (RMSEA), standardized root-mean-square residual (SRMR), and comparative fit index (CFI). As missing values were presented, we checked that the models were fit in all imputed datasets. The models' cut points were examined by dynamic fit indices (DFIs) applying the dynamic package in R. This approach allows us to identify more robust fit indices cut points for the user-specified model.¹⁵⁷ Factor scores were computed based on summing raw scores within the same factor, and the scores were summed and transformed to a T-score by multiplying the standardized score by 10 and adding 50 (mean = 50, standard deviation = 10). This traditional approach was used by the questionnaire developers and other studies,^{101,146} also it allows preserving the original item variance.¹⁵⁸

7.2.10.2 Bayesian network learning and inference

Due to the limited sample size, we applied a conservative approach to reduce data fragmentation when performing Bayesian network learning (see Appendix 12 for selection details), resulting in reducing the number of variables (the number of parameters would be reduced thus the model becomes less susceptible to overfitting). We scoped the variables to be used in structured learning using the qualitative findings since there is a lack of clear understanding of relationships between family mechanisms and ACP engagement in the Thai context. Firstly, total family functioning was used

rather than separate family functioning categories. The total family functioning score was dichotomized to high and moderate/low per questionnaire developers' suggestions.⁸⁷ Second, family background variables were clustered using latent class analysis (LCA). Among the family characteristics (i.e., caregiver's relationship, family structure, head of the family, and unofficial family proxy), we applied the poLCA package in R to conduct the LCA. Caregiver's and patient's age, sex, education, and religion were assigned as covariates for the LCA models. This approach was selected as an alternative to identify more compact family background characteristics. The number of two to four classes was examined based on the theoretical family features and behaviors together with the size of each predicted classes).¹⁵⁹

Our BNs were both data-driven and domain expert-knowledge supported.¹⁶⁰ Due to the discrete nature of associated variables and the current development of BN learning through the score-based algorithm, we applied discrete BN for structured learning in this study.¹³⁴ We used several approaches to enhance robustness. Firstly, the study variables were assigned to time tiers based on the information sources, for example, EMR was used to ensure the temporal quality of comorbidity. Table 8 and 9 detail the temporal assignment and methods used in the learning procedure, respectively. This type of learning has become an acceptable standard in BN learning since it improves the likelihood of the graph explaining the data both conceptually and statistically.¹⁶¹ After considering variable temporality, we considered using domain experts in family and palliative medicine to determine mandatory relationships (i.e., arcs)¹⁶² and decide if the final graph was understandable. In addition, a priori network consideration was conducted with three domain experts, to rate their agreement on the presence of mandatory arcs and their directions regarding family variables and ACP using a 3-level scale: "disagree", "uncertain", and "agree". This approach allowed us to incorporate domain knowledge with more objective suggestions compared to qualitative suggestion alone.¹⁶³ The arcs were considered mandatory when the agreement was unanimous (all experts chose "agree"). Since missingness was presented, two score-based learning algorithms (Hill-climbing and Greedy search) with penalized node averaged scores were used to define choice BN structures.^{164,165} ACP variables were transformed by which their categories were grouped into "ready" (originally, prepared and action) and "not ready" (originally, pre-

contemplation and contemplation), also discretization turned pro and con variables to low (score ≤ 50) and high (score > 50). We examined the learned networks using network scores, number of network parameters, predictive loss (incorrect prediction in 10-fold cross-validation), and network understandability (reasonably directed arcs and ability to capture relationships) as feedback by the experts was considered.¹⁶⁰ Figure 5 summarizes the structured learning steps. Finally, one DAG was chosen to represent the causal relationships and was used for parameter learning. R packages bnlearn, graphviz, igraph, and caret were used along with GeNIe modeler.

Parameter learning allows us to acquire probability in the graph and the likelihood of the model-implied probability space to the observed data. Our parameter learning was based on an estimated posterior probability approach (see Appendix 10 for details). Parameter learning also allows further inferences using the network features. Sensitivity analysis was conducted using GeNIe modeler to validate the BN by identifying nodes which are sensitive to alteration of the posterior probability of target ACP outcomes; the higher the sensitivity value, the more sensitive the target variable would vary if there is any change in the queried node parameters. For the inference task, exact inference was chosen due to a relatively small parameter space.¹³⁴

We also performed intervention analysis to illustrate the average causal effect (CE) of certain variables on ACP. This approach allows us to prioritize several strategies to enhance readiness for ACP under mimicking intervention activity using the privilege of BN inference. To illustrate, we employed “do-operator” on a potential causal variable and computed the hypothetical outcome posterior probability change.^{135,166} Variables would be identified as causal for ACP only if they are parents of the ACP outcomes. The steps included: 1) determining a node to be intervened (causal variable), 2) applying “do-operator”: removing the intervened node’s incoming arc, thus it becomes parentless (it is hypothetically forced to have a certain value) and thus a causal BN (CBN) is produced for the hypothesis, 3) comparing the original BN with the CBN using Bayes factor (BF), and 4) query the posterior probability of readiness for ACP engagement using causal variable fixed to the target category (e.g., high versus low level of perceived pros of ACP).^{136,166} The extent a hypothetical CBN can be evidence for intervention effect is considered when $BF > 1$ (preferably > 10 for a strong level of evidence).^{166,167} The Average causal effect was computed by comparing

the ACP probability between two fixed conditions. The R package causal pathway was used to confirm causal routes and GeNIe modeler was used to conduct intervention analysis.

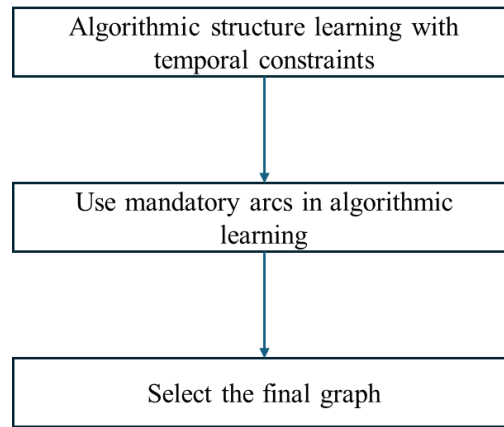


Figure 5 Steps applied to define BN structure

Table 8 Temporal assignment for variables in Bayesian network learning

Time 1	Time 2	Time 3	Time 4	Time 5	Time 6
Comorbidity Previous resuscitation experience	Family type	Family functioning *	Quality of medical counseling Understan ding of the illness Prior awareness for ACP in patients	Readiness for goal- of-care discussions Readiness for LST use discussions Readiness for healthcare surrogate appointment Perceived pros and cons of ACP**	Living will/ advance directive documentation

Remarks: * assigned to Time 3 – 6, ** variables belonging to patient and caregiver participants, prior awareness for ACP in caregivers were not assigned

Table 9 Structured learning methods

Structural expectation-maximization algorithm	Model averaging algorithm
1. Preparing nodes (variables) with observed marginal probability (empty network) 2. Using available information from the available data to fit in the network 3. Performing missing data imputation using exact inference 4. Estimating network score 5. Using a score-based algorithm (Hill-climbing or Greedy search) to learn a possible directed acyclic graph (DAG) by adding arcs 6. Comparing likelihood estimation between the recent network with the prior network to find improvement in the score (if there is any prior network) 7. Replacing the empty (or prior) network with the current network and repeating steps 2 – 6 until convergence of network score is reached.	1. Bootstrap sampling of observations from the dataset 2. Using a score-based algorithm to create DAGs 3. Storing the learned networks in the forms of arcs and presenting their directions 4. Repeating the sampling procedure up to the specified number of iterations (500) 5. Averaged the overall arcs (per a specified threshold – in this case – 95% confidence) and common directions (> 50% presence).

8. Ethical Consideration

The project was approved by the Human Research Ethics Unit, Songklanagarind Hospital (project ID REC.65-417-9-1).

8.1 Informed consent process

We set posters/flyers at the patient registration area to promote the project. To ensure privacy, the nurse in charge of patient care introduced the project to potential volunteers. An available counseling room at the oncology radiation therapy clinic was used as an interview room for the participants. Interested individuals approached the researcher at the interview point, who then explained the project details to the potential participants, including both elderly participants and their caregivers, in the interview room.

If the patient met the project's criteria, the researcher provided information about ACP and the project, ensuring awareness of the interview topic.

During this process, the researcher informed the patient that participation was completely voluntary, and they were a researcher who was not involved in the patient's care, to reduce the impact from perceived coercion or undue influences. The patients were given 10 minutes to consider participating in the project or making an appointment at a later date. If a patient was interested in participating, he/she informed the researcher at the interview point. The researcher obtained written consent to participate in the project or a fingerprint in cases where the participant is unable to write.

8.2 Additional safeguards

8.2.1 Physical Aspects

Elderly cancer patients who volunteered for the study may have experienced fatigue during the interview process. To minimize this risk, the researcher implemented several measures. When the questionnaire was designed, the number of questions for elderly participants was limited to minimize the interview time (in Phase 1) or within 20 minutes (in Phase 2). Prior to the interview, the researcher screened elderly participants according to the project's criteria to assess their initial readiness before proceeding with the interview. During the interview, the researcher coordinated with caregivers at the interview area to provide assistance if the elderly participant required help from their caregiver. In addition, the researcher remained aware of any signs of fatigue during the interview and would stop the interview if they showed signs of exhaustion or illness. At the same time, the interviewer conducted a preliminary assessment, provided first aid if necessary, and arranged for further care as appropriate. Additionally, the researcher scheduled the interview for elderly participants to take place as close as possible to the caregiver's participation. This ensured that both the caregiver and the elderly participant finished the data collection process without any unnecessary delays.

8.2.2 Psychological Aspects

To reduce anxiety among participants, the researcher revised the informed consent document to avoid using the term "cancer." This adjustment applied to both the information sheet and the consent form. Elderly participants and caregivers might feel anxious when discussing ACP. During the interview, the interviewer, who was a palliative care provider, stayed aware of any signs of emotional distress and

adjusted the interview accordingly (e.g., skipping certain questions). If a participant became visibly uncomfortable, the interviewer paused the interview, offered emotional support, and responded with empathy following the guidelines established by Baile et al.¹⁶⁸ Timely referral to a psychologist was ensured in case any severe distress presented.

8.3 Confidentiality and data management

Confidentiality of the patient's information was ensured. The interviews involving patients and caregivers were conducted separately to ensure privacy. Personal information was not recorded in the data recording form. The participants' EMR data were retrieved anonymously through the Digital Innovation and Data Analytics, resulting in a merged de-identified dataset being used in the data analysis. The project papers were kept in a secured locker. Electronic data is being stored in a secured personal laptop of the principal investigators. All the records, including audiotape will be kept securely per the Personal Data Protection Act 2012, for at least 5 years after the study.

CHAPTER 3

RESULTS

9 Qualitative Results

9.1 Informant characteristics

We invited 138 patients to participate in the qualitative interviews. One hundred and six (76.8%) declined and 10 (7.2%) did not attend their scheduled interview. The common reasons for non-participation were: the duration of the interview was too long (n=87), busy with ongoing treatment (n=16), and uncomfortable with discussing their situation (n=13). Finally, we conducted in-depth interviews with sixteen patients and sixteen caregivers (Table 11 and Table 12). Thirteen of each were Buddhist And five patients and six caregivers had a bachelor's degree or higher. The median family size was 4 (range 2 – 10). Fifteen patients were married and currently staying with their children.

Head and neck cancer and prostate cancer were the two most common primary cancer types And two had two primary cancer sites. Metastasis was present in four patients. Most were recently diagnosed with cancer (within one year) and were undergoing cancer treatment. In general, the informants were well-functioning (Eastern Cooperative Oncology Group grade 1).

9.2 Thematic analysis

The interviews revealed three themes reflecting the perceptions and attitudes of the informant towards ACP. First, the older patients and families saw ACP as an advantageous opportunity for their medical care. Second, they had certain beliefs or qualities that are hindrances to ACP engagement. Third, cues to ACP initiation, in which different situations or qualities can be observed to decide timely ACP discussions. Table 10 summarizes themes and subthemes from the study.

Table 10 Themes and subthemes

Theme	Subtheme
1. Advantageous opportunity	1. Introspection of life values through invited communications 2. Conveying one's will to trustable others while still capable
2. Contemplations and barriers to ACP	1. Perceived low utility of ACP 2. Rely on capable others 3. Perceived functional gap 4. Unfamiliarity with advance directives and living wills 5. Maintaining optimism by avoiding bad news 6. Prioritizing the family decision authority over oneself
3. Cues for ACP initiation	1. Perceived conformity with religious principles 2. Multiple health conditions 3. Awareness of low chance for recovery 4. Experience suffering from medical treatments 5. Not wishing to burden the family 6. Having a close caretaker 7. Trusting doctor-patient relationship

9.2.1 Theme 1: Advantageous Opportunity

Many individuals acknowledged the significant benefits of ACP. The informant saw ACP fostering introspection about their life values, and ensuring the preservation of their dignity when life-sustaining decisions arise.

Introspection of life values through invited communications

It was uncommon for the patients to feel that writing down their preferences would be a good idea. However, some saw ACP as an exercise to contemplate with oneself values and beliefs, in terms of medical care preferences.

“They (healthy persons) should be able to think about what they would want at the end of life, and thus be able to do it (write a living will). Eventually, persons who become sick and have troublesome symptoms would be aware of what treatments were about to be given to them.” (P7)

When timing is appropriate, an invitation to ACP would help them consider what they wished to have and wished not to have, ahead of time:

“I would be feeling neutral if my doctor started the conversation. I think we (the patient and the doctor) should always discuss this. The first time is when a patient is still

healthy. Second, the discussion should be done when the patient has or is informed of some abnormal symptoms. Third, it should be done when the symptoms worsen. (P10)

His wife also expressed the same feeling and provided some comments on having involved by the roles of health surrogate and advance directive:

“I think I can handle that (being a surrogate) [smile], because at the end we will not be able for speak for ourselves ... it (advance directive) would be a guidance for our team (pointing to the interviewer and the patient) ... although I’m not a very good writer, we have told our children everything (in handling the parents’ funeral)” (F10)

Conveying one’s wills to the trustable others while still capable

ACP was perceived as a process to convey messages regarding one’s preferences to family members and their doctors. Some informants felt that taking part in ACP meant a thoughtful act for their values at a time when they were still well-functioning and to link their values with future potential changes in their health, especially if it started to deteriorate.

“If she (the daughter) thinks I should be intubated, I should follow her. This is an actual plan made in advance. If any bad things happen, this thing (the document indicating the surrogate) can authorize her for decision-making.” (P5)

“It is good because I can leave my instructions for my doctor to follow. Those punctures, those resuscitations, are not preferred.” (P16)

Another informant, who was a soldier, shared that living will could carry his wills to ensure that his dignity will be preserved while he can also do good things for other people.

“The doctor would help me to see which state is a life without quality, meaning that I am at a time I cannot either serve this country or enjoy eating or traveling. We should not end up in an intensive care unit, should we? Let the younger and healthier people use the facility.” (P15)

9.2.2 Theme 2: Contemplations and Barriers to ACP

Families and older patients valued ACP differently. The informants expressed their concerns regarding ACP, in which one could contemplate about taking

part in ACP as if they were in the patient's shoes. Apart from contemplating being in the patient's shoes, the patients expressed concerns related to the family of which stakes were considered for the family caregivers who were perceived to be the actual decision-makers at the patients' end of life.

Perceived low utility of ACP

ACP utility was contemplated on its currency and the chance of being applied. One informant expressed concerns regarding the currency advance directives and living will despite their potential benefits.

"The document (living will) can instruct the families clearly, but we cannot be sure if they are up to date. However, if there is no document at all, the communication would be limited to 'at present', so we cannot understand much about what the patient's preferences are. Most people would easily say something like he/she could face the end of life and not require any resuscitations. But if they severely suffered from such conditions, they might instead ask for full medical support." (P10)

In addition, although the directives could be helpful at the time death is approaching and/or the doctor is going to put them on long-term machine dependence, patients might think such conditions have a very low chance of occurring in most people; some people can speak for themselves until the very last minute.

"Some people can document their will and leave it with their doctors or relatives to say whether they want or do not want some kind of treatment when they cannot speak for themselves... But it would not be useful if they were still able to speak for themselves. In my experience, some people can speak until their last breaths. For me, I think I need some time to think if the documentation suited me. I think I better not do it (document the will) at this time because there would be a small chance for general patients to apply this. Let's say, I have never seen or heard of them being applied." (P19)

Rely on capable others

It was not uncommon that advance decisions in some elderly patients with cancer were transferred to some important others. Some patients thought that they

had a limited capacity to decide on medical treatments, unlike their physician or their children, who had more knowledge and a better understanding of the topic.

“It is up to my doctor how the treatment would be chosen ... It is up to my kids. These or those treatments are all up to them, all of them. I am used to relying on them. I am incapable of deciding about these things (medical treatments).” (P9)

Another patient said that she would always agree with what was advised by the clinicians.

“If the doctor advises me to receive any treatment, I will follow her advice. That’s it. It is unnecessary to tell her. She just does her job, so do I ... she does her job; I follow her advice, this and that. That’s all, nothing more than that.” (P17)

Perceived functional gap

Some patients perceived that health deterioration was too far from worth considering at the moment while they were generally well-functioning; thinking about receiving treatment while the patient was living almost normally did not sound reasonable. This gap creates the perception that making advance decisions is too early.

“(A living will) is suitable for people who are already sick. Some people cannot devise this kind of thing because they are currently active, and they might be still ignorant of the chance of becoming ill.” (P12)

His wife also shared similar thoughts.

“We are worried about what has not arrived yet. Thinking about having him (the patient) intubated is [briefly silent]. We are still at the point that he is still capable of eating. If it is already the time, we must make up our minds and let the physician do their work.” (P8)

Unfamiliarity of advance directives and living wills

Living wills and advance directives were new to the patients. Some of the informants misunderstood that it was the same as the will to arrange individual’s properties, as they were more familiar with the term ‘general will’.

“Living will ... I haven’t heard about that, only the will for the properties that I have heard about.” (P5)

Only one family had knowledge about living wills and advance directives. In this family, most of the patient's children were well-educated and had high-income jobs. The patient shared that the document had functioned well in her son's (who was a clinician) case when he was severely ill.

"When Doc (her son) was alive, he also instructed to us (via his advance directives), no more pain and no further procedures." (P16)

Maintaining optimism by avoiding bad news

Some of the participants were uncomfortable with ACP as they tried to maintain an optimistic caring environment for oneself and the family. They focused on fostering hope for a cure for themselves (cancer patients) or for the patients (family members), while discussing values and preferences for medical care seemed to be all about handling incurableness and dying.

"I preferred not to talk with my family about this (advance decisions) because my mom is quite old. She did not seem prepared for this. We often mention pleasant stuff and rarely talk about something that could be stressful. My wife might be ok to plan for stuff like this, but it could also be another story because she is still young, and we don't have kids. She is scared that she will lose me ... I think we should not discuss about this... because sometimes it feels like cursing myself." (P6)

A family member of the oldest old cancer patients also shared similar thoughts.

"I have never asked the physician if the cancer is at what stage. Whether she could ... she could live for how long further; I have never asked because I thought it would create pressure in the atmosphere. I know it is close. It is surely about to happen ... We, her kids, never asked something like that because we have prepared ourselves for things that would occur to our mother. But it is better not to learn about it." (F16)

Sometimes, family members and the clinician might conspire to withhold actual information and prevent the patient from participating in ACP discussions.

"At the hospital, the doctor let only me know the information. She said "It is inoperable. It is far gone, and the risk is too high to take". The doctor only told me, and I would take the information to my brothers, but not my mom ... The doctor

said “You (the patient) don’t need to go into the room. You must be tired because of getting the X-ray so you can wait in front of the room”. Although the patient was very willing to learn about the results, we avoided telling her the major ones.” (F17)

Prioritizing the family decision authority over oneself

Advance directives were seen as a document which can help communicate the patient’s wishes, especially when there are no immediate relatives. However, some patients expressed concern about conflicts in family views despite clear understanding about the rationale, owing to differences in values.

“If the family is multi-generational, I think this kind of document (advance directive) has limited benefits because at that time, there could be husband or wife, their kids, or even their parents for some patients, thus the document could create conflicts among people. Suppose I wrote it in my way, but my kids instead say, “It is worthwhile to just add one minute to my life”, and then the document is there forcing them to follow it. These troubles would not happen to a writer like me, but the families could feel guilty for what they have decided.” (P10)

Similarly, a patient who had spent 18 years as a monk expressed that his experience made him feel his wife might see things differently so what he wanted might not be accepted. Such contemplation had kept his willingness to share his preference with his wife quiet until the present.

“I could have donated my body to the hospital already if I was not considerate of my wife. We have never talked about this, but this is what I have been thinking about ... It has been 2 years since she has been involved in the treatment and everything, so it is somewhat difficult. If I do not tell her, there could be quarrels.” (P12)

9.2.3 Theme 3: Cues for ACP Initiation

The informants shared some patients’ qualities that might have prompted them to initiate ACP communication with their loved ones or with the treating physician, which if some of them were expressed, would convey a sense that the patient was ready for ACP discussions or appointing a surrogate decision-maker for health care.

Perceived conformity with religious principles

ACP is analogous to an important religious principle in both Buddhism and Islam, which is to always be aware of uncertainty in life and be prepared for it.

“It (deterioration of health) could be expected at some point for everyone. She is, in my opinion, a kind of religious person...She always says something like loss is certain for us; we are born, grow, fall ill, and die... It is good to let her know that she could plan for herself if (the cancer) is incurable [lowering voice]. (F5)

“I can make up my mind for this. I think we are born, grow, fall, and die ... It is a natural way of life” (P4)

Multiple health conditions

One cancer patient had been thinking about uncertainty in health due to multiple comorbidities. The patient’s contemplations might have prompted him to share his wishes with his family members.

“He (the patient) looked depressed at that time. For me, his reaction was understandable because he was old and had multiple conditions. He might feel uncertain about what would happen in the future, so I think we must start talking [quietly subdued laughter]. We must talk and prepare; I ask him “what do you think about that”; we talk about this kind of stuff. He is a person who is already aware of the uncertainty, I think.” (F7)

Awareness of low chance for recovery

When there are certain possibilities for irreversible or aggressive cancer, some patients understand that medical treatments will be ineffective or only try to prolong life. And when they decide to share such thoughts with the care providers, prognosis statements and discussions for palliative care could be timely provided.

“If I was aware that there would be only a small chance for a person to survive the cancer, I would tell the doctor to let him/her go instead of trying to cut something out of him/her. Aggressive treatment would only create unnecessary pain and likely be ineffective.” (P5)

Another informant thought similarly; she added that there was no value in putting patients who are at the end of life on a life-sustaining machine.

“I mean, if I am aware that it is very likely that I am going to die in a short period of time and the doctor will keep resuscitating me for nothing, or on the other hand, there are some conditions for which the doctor would possibly put me on a long-term machine, I would choose neither of them.” (P13)

Experience suffering from medical treatments

Most informants had heard of or had indirect experience of invasive medical procedures, and some of the patients had had direct experience of such procedures. These experiences prompted engagement in ACP by being unwilling to let themselves or their loved ones experience the same thing again.

“I told my doctor, if the disease is severe and untreatable, or whatever, to not do anything to me. The time when I was intubated made me aware of how much I hate my life being under that condition. Even though I was moved to the post-surgery ward (after the surgery), the tube was still with me keeping my mouth open. I was aware that I was sick, but I was so thirsty, and drinking was prohibited. I was in real pain having a tube in my mouth.” (P13)

Some caregivers could understand how it would be to have a tube in the mouth. One informant also expressed similar thoughts.

“Some patients ... they are exhausted; they want to sleep. If a treatment causes suffering, they would prefer not to receive it because they have suffered enough. To get intubated is real suffering. It would be all dried up, the throat. I can remember the moment my mom struggled to say “water”, then I cried.” (F16)

Not wishing to burden the family

While discussing care plan, one may express his/her wishes not to be a totally care-dependent such that it would greatly cause great burden for the family. Some patients could imagine how life-sustaining treatments could burden their own body and its consequences for their children. These thoughts were found in both patients who were recently retired and the oldest-old.

“Everyone will arrive at that point. I think I would like to pass painlessly, which is to be managed in any way to be pain-free. If I am about to pass, I and my kids agreed that we would choose not to undergo any burdensome treatments like surgery... The kids were worried about me being paralyzed and bed bound. They said they could handle it if it happens... I said I preferred not to burden my kids, let them live their lives. It cannot be stopped when I have to go.” (P5)

Another patient shared his awareness of creating a chronic burden to the family as a result of putting a patient on a long-term life-sustaining machine and commented on his perceived benefits of living will together with a family-related dilemma.

“If it (the use of a life-sustaining machine) is not too long, like 45 days, I think it is acceptable ... But, it is difficult to tell (if other people would see a living will as beneficial) because people have different beliefs. Some relatives are attached to the patients. They might insist on sustaining the patient’s life to be as long as possible. But for me, I reaffirm what I said.” (P15)

Having a close caretaker

Having a family member with a close relationship with the patient could help the patient identify a surrogate decision-maker for healthcare.

“No discomfort here, I confirm that. I can write (her daughter’s) name as my surrogate decision-maker. It is exactly her because she is the one closest to me and knows a lot about my health.” (P5)

Trusting doctor-patient relationships

Many informants expressed the opinion that trust in their physician would help them feel comfortable with what was suggested by the physician, including an invitation to take part in ACP. One of them compared trust in their physician and adhering to their advice with her adherence to religious principles.

“Allah gives us the capability to think and consider things using our brain... We have always adhered to religious principles, but when it comes to diseases and their treatment, we trust our physician as our number one resource. (F9)

Table 11 Characteristics of patient informants

ID	Characteristics (sex, age, religion, marital status, occupation)	Education	Primary cancer	YOD	ECOG
P3	Male, 68, Buddhist, married, agriculture	Primary school	Esophagus	<1	3
P4	Female, 68, Buddhist, married, self-employed	High school	Breast	1	1
P5	Female, 66, Muslim, married, retired teacher	Bachelor's degree	Breast	4	2
P6	Male, 62, Buddhist, married, government officer	Bachelor's degree	Larynx	<1	1
P7	Male, 78, Buddhist, married, self-employed	High school	Prostate	<1	1
P8	Male, 70, Buddhist, married, government officer	High school	Prostate	<1	1
P9	Male, 83, Muslim, married, unemployed	Primary school	Rectum	<1	3
P10	Male, 60, Buddhist, married, academic	Higher than a bachelor's degree	Prostate	5	1
P12	Male, 63, Buddhist, married, retired teacher	Bachelor's degree	Nasopharynx	5	2
P13	Female, 73, Buddhist, married, retired teacher	Higher than a bachelor's degree	Ovary and Colon*	4	3
P14	Male, 60, Muslim, married, government officer	Low vocational school	Esophagus	<1	2
P15	Male, 64, Buddhist, married, retired soldier	High school	Lung	6	1
P16	Male, 75, Buddhist, married, agricultural	Primary school	Rectum*	3	3
P17	Female, 60, Buddhist, married, self-employed	Primary school	Ovary and Cervix	<1	1
P18	Female, 96, Buddhist, married, unemployed	Primary school	Colon*	1	3
P19	Male, 64, Buddhist, married, private employee	Primary school	Nasopharynx	<1	1

* Advanced/metastatic cancer, YOD = years from diagnosis, ECOG = Eastern Cooperative Group Scale

Table 12 Characteristics of caregiver informants

ID	Characteristics (sex, age, religion, marital status, occupation)	Relationship	Education
F3	Female, 47, Buddhist, Employed, married	Daughter	Primary school
F4	Female, 66, Buddhist, Civil servant, single	Related by law	Bachelor's degree
F5	Female, 34, Muslim, Civil servant, married	Daughter	Bachelor's degree
F6	Female, 53, Buddhist, Civil servant	Wife	Bachelor's degree
F7	Female, 71, Buddhist, Unemployed	Wife	Primary school
F8	Female, 64, Buddhist, Civil servant	Wife	Bachelor's degree
F9	Female, 54, Muslim, Fishery, daughter, single	Daughter	High school
F10	Female, 60, Buddhist, Civil servant	Wife	Bachelor's degree
F12	Female, 61, Buddhist, Self-employed	Wife	High school
F13	Female, 44, Buddhist, Housewife	Daughter-in-law	Bachelor's degree
F14	Female, 55, Muslim, Housewife	Wife	Junior high school
F15	Female, 62, Buddhist, Housewife	Wife	Diploma
F16	Female, 65, Buddhist, Civil servant	Wife	High school
F17	Female, 24, Buddhist, Self-employed, single	Daughter	High school
F18	Female, 68, Buddhist, Civil servant, single	Daughter	Primary school
F19	Female, 62, Buddhist, Self-employed	Wife	Primary school

10 Quantitative Results

10.1 Participants characteristics

We screened all 793 patients visiting the study site during the study period. We excluded 142 families based on either patient or caregiver eligibility criteria. A further 364 patients and 1 caregiver from different families declined to participate. Among these refusing families, 44% of the patients were female. Finally, 279 families participated in the study, comprising 279 patients and 279 primary caregivers. As confirmed by the hospital database, the participants were from all provinces in southern Thailand. Figure 6 summarizes the recruitment process.

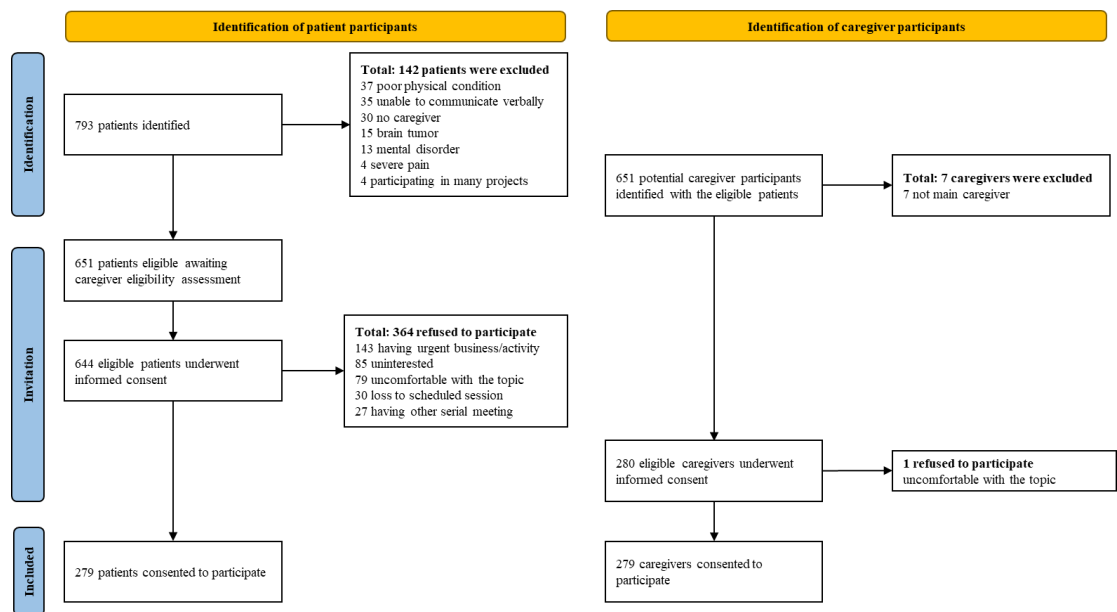


Figure 6 Recruitment process

Two hundred and twenty-four families had complete data. Missing data contributed 1.3% overall while sharing 1% to 9% in certain caregiver variables only. Table 13 summarizes the demographic characteristics of the participants. Many of the patients were aged between 60 and 79 years (median age 68.5 years), and males and females were relatively balanced; however, most caregivers were female and actively working (78.1%). The majority of the patients were self-employed or unemployed.

Approximately 20% and 40% of the patients and their family members, respectively, had heard of any type of ACP (Table 14). Nuclear families were common. The patients were the heads of almost half of the families (48.0%), and approximately half of the caregivers were unofficially authorized as surrogate decision-makers (48.3%). The monthly income of the participating families was mostly below 30,000 THB (57.7%). The caregivers reported high overall family functioning, including family support (e.g., physical and financial support), family discipline (i.e., how responsibility in the family is assigned), relationships (interactions among family members), and communication (e.g., talks frankly). A higher percentage of low-moderate perceived emotional response in the family was seen, compared to other family functioning variables, e.g., family support (Table 15).

Table 13 Individual demographics characteristics

Characteristic	Patient (n = 279)	Caregiver (n = 279)
Age (median, Q1–Q3)	68.5 (64.1 – 73.4)	47.7 (39.4 – 58.2)
Biological sex (n, %)		
Male	151 (54.1)	61 (21.9)
Female	128 (45.9)	218 (78.1)
Marital status (n, %)		
Married	221 (79.2)	191 (68.5)
Single	20 (7.2)	72 (25.8)
Divorced	38 (13.6)	16 (5.7)
Occupation (n, %)		
Government officer (or retired)	62 (22.2)	83 (29.7)
Self-employed	114 (40.9)	153 (54.8)
Unemployed	103 (36.9)	43 (15.4)
Religion (n, %)		
Buddhist	228 (81.7)	227 (81.4)
Muslim	49 (17.5)	50 (17.9)
Christianity	2 (0.7)	2 (0.7)
Highest education (n, %)		
No formal education/lower than primary school	155 (55.6)	55 (19.7)
High school or equivalent	68 (24.4)	82 (29.4)
Bachelor's degree or higher	56 (20.1)	142 (50.9)

Table 14 Prior awareness of ACP among patients and caregivers

Topic	Patient (n = 279)	Caregiver (n = 279)
Prior awareness of ACP (n, %)		
Any types	59 (21.1)	110 (39.4)
Future care plan discussion	11 (3.8)	37 (13.2)
Advance directives	29 (10.1)	42 (14.9)
Living will	11 (3.8)	14 (5.0)
Surrogate decision-maker appointment	44 (15.4)	70 (24.9)
Durable Power of Attorney for Health Care	8 (2.8)	15 (5.3)
Source of prior ACP information (n, %)		
Family	8 (2.8)	12 (4.3)
Friend	9 (3.1)	15 (5.3)
Healthcare provider	37 (12.9)	52 (18.5)
Internet	4 (1.4)	12 (4.3)
Television	9 (3.1)	21 (7.5)

Table 15 Family characteristics

Characteristic	
Structure (n, %)	
Nuclear	185 (66.3)
Extended	51 (18.3)
Other	43 (15.4)
Number of members (median, range)	5 (1-16)
Monthly income (baht)	
Less than 30,000	162 (57.7)
30,000 – 50,000	49 (17.4)
Higher than 50,000	48 (17.1)
Unsure/unwilling to tell	22 (7.8)
Head (n, %)	
Patient	134 (48.0)
Caregiver (children such as son or nephew)	43 (15.4)
Caregiver (spouse)	30 (10.7)
Other	72 (25.8)
Caregiver's relationship with the patient (n, %)	

Spouse	70 (24.9)
Child	171 (60.8)
Other relative	37 (13.2)
Non-relative	3 (1.1)
Authorized health surrogate (unofficial family proxy) (n, %)	
Participating caregiver	135 (48.3)
Other family member	101 (36.2)
Undetermined	43 (15.4)
Family functioning (n, %)	
Communication and problem-solving skills	
High	206 (73.8)
Low/moderate	65 (23.3)
Missing value	8 (2.9)
Emotional response	
High	112 (40.1)
Low/moderate	160 (57.3)
Missing value	7 (2.5)
Support	
High	225 (80.6)
Low/moderate	48 (17.2)
Missing value	6 (2.2)
Relationship	
High	214 (76.7)
Low/moderate	35 (12.5)
Missing value	30 (10.8)
Discipline	
High	182 (65.2)
Low/moderate	90 (33.1)
Missing value	7 (2.5)

Identifying family background variables

Our 3-class model was justified because of its interpretability while demonstrating good practical (contextually understandable) and statistical (demonstrating desirable entropy) properties. The latent classes were categorized as Enmeshed family (Class 1), Distant family (Class 2), and Complex Family (Class 3). Class 1 (74.2%) represents a nuclear family in which patients were more likely to live

with the family and the caregivers were close relatives (mostly children and spouses). However, the patient was most likely to be the head of the family. Class 2, in which all the patients were single/divorced, shows a lower probability of patients playing roles as the breadwinners and implies a higher probability that relatively distant children or other relatives came and played roles as the primary caregivers. The smallest group (class 3) was more likely to be multigenerational families with children more likely to be the head of the family and playing a role as primary caregivers (see Table 16).

Table 16 Class-conditioned probabilities

Observed variable	Class 1 (n = 207, 74.2%)	Class 2 (n = 48, 17.2%)	Class 3 (n = 24, 8.6%)
Caregiver's relationship (with patient)			
Other	0.101	0.375	0.042
Children	0.575	0.604	0.917
Spouse	0.324	0.021	0.042
Family proxy			
Participating caregiver	0.507	0.417	0.333
Never identified	0.140	0.271	0.083
Another member	0.353	0.312	0.583
Head of family			
Children	0.135	0.375	0.250
Other	0.019	0.271	<0.001
Patient	0.517	0.312	0.500
Spouse	0.329	0.042	0.250
Family types			
Couple with children	0.565	0.146	0.500
Couple without children	0.232	0.021	<0.001
Multigeneration	0.145	0.292	0.292
Other (e.g., living alone)	0.058	0.542	0.208

Remarks: Class 1: enmeshed family, class 2: distant family, class 3: complex family

Clinical status of the patients

The distribution of cancer sites among the patients is shown in Table 17. The top four sites were gastrointestinal tract (23.7%), breast (20.8%), head and neck (20.1%), and male genital organ (9.9%). A few (6.9%) had multiple primaries, and

almost a quarter had metastatic cancer. Most patients perceived their health status to be “good”, understanding towards cancer, and information received. The Universal Health Coverage Scheme and the Civil Servant Medical Benefit Scheme were the two major health schemes used. The median number of visits to a cancer clinic for management or treatment of their disease was 42.

Table 17 Clinical characteristics

Characteristic	
Cancer site (n, %)	
Gastrointestinal tract	65 (23.7)
Breast	57 (20.8)
Head and neck	55 (20.1)
Male genital organ	27 (9.9)
Lung	20 (7.3)
Female genital organ	18 (6.6)
Thyroid	4(1.5)
Other	9 (3.3)
Two or more primary sites	19 (6.9)
Metastatic cancer (n, %)	69 (25.2)
Perceived health status (n, %)	
Good	196 (70.3)
Poor/moderate	83 (29.7)
Level of understanding of their disease (n, %)	
Good	210 (75.3)
Poor/moderate	69 (24.7)
Information received from the treating care provider (n, %)	
Good	255 (91.4)
Poor/moderate	24 (8.6)
Number of cancer clinic visits (median, Q1–Q3)	42 (12.0, 93.5)
Health insurance scheme (n, %)	
Universal Health Coverage	138 (49.5)
Civil Servant Medical Benefit	135 (48.4)
Social Security	6 (2.2)

Remarks: all patients who had high comorbidity score also had metastatic cancer

10.2 ACP engagement and related perceptions

10.2.1 Stages of ACP readiness

Almost all the patients had not documented their directives (only one and two individuals were in the Action and Maintenance stages, respectively) and their DPAHC (five and two individuals were in Action and Maintenance stages, respectively). The patients tended to have ACP discussions with their family rather than their attending doctors. Overall, 32.7%, 34.9%, 32.4%, and 32.7% of the patients were in the “pre-contemplation or contemplation for goal discussion with family”, “goal discussion with doctor”, “LST discussion with family”, and “LST discussion with doctor” stages, respectively. Regarding the stage “contemplating in discussion with their families”, six reported that they were ready to discuss their preferences regarding life-sustaining, but they felt their families were not ready, thus they were categorized as “contemplation”. Most patients (97.6%) had never made a DPAHC, while most of them were ready if being invited (73.0%). Figure 7 illustrates the distribution of the participants’ readiness for ACP engagement (more detailed values are shown in Appendix 11).

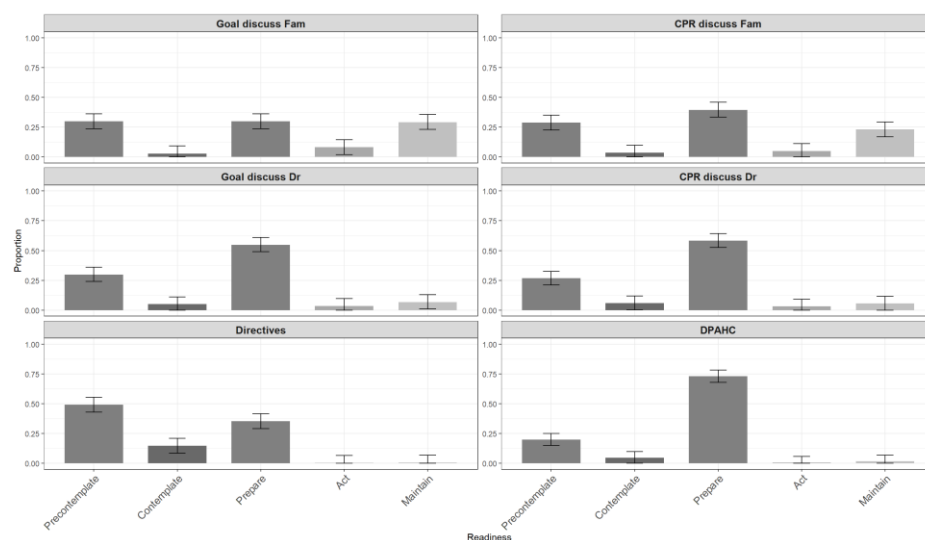


Figure 7 Distribution of readiness for different ACP behaviors. Error bars denote 95% multinomial confidence intervals, and the x-axis ranges from the least (pre-contemplation) to the highest (maintenance) readiness stage

Examining the agreement between several views on ACP and health care among patients and their caregivers, the two parties mostly had inconsistent

perceptions. However, they slightly agreed that engaging in ACP means being careful about uncertainty in the patient's health and increasing a sense of control over treatment when the patient is unconscious. On the other hand, they also slightly agreed upon the view that thinking about such planning could be early at their stage. Participants tended to disagree that ACP would help the patients get their desirable care, and at the same time, they did not agree that the doctors would be aware of the patient's preferences. Table 18 provides details of the dyadic agreement.

Table 18 Congruence of perceptions between patients and caregivers

Item	Brief item text	ICC	95% CI
Values/Beliefs			
DESTIN	Illness was pre-determined, ACP is unnecessary	0.204	-0.006, 0.370
SICKER	ACP is rather suitable for sicker patients	0.167	-0.044, 0.337
TOSTOP	ACP implies the treatments would be stopped	0.050	-0.148, 0.221
FUTILE	LST would have limited effects in elderly	0.044	-0.168, 0.222
ATATIM	The most important thing is focus on today	0.043	-0.196, 0.237
DOCBUS	Doctors are too busy to discuss ACP	-0.051	-0.318, 0.165
DOCKNO	Doctors would know what their patient wants	-0.110	-0.399, 0.119
Pros of ACP			
CAREFL	Engaging in ACP means being careful	0.269	0.075, 0.423
CONTRL	ACP increase one's sense of control	0.235	0.032, 0.396
RELIEF	ACP makes one feel relieved	0.184	-0.032, 0.355
EASECG	ACP ease care planning in family	0.163	-0.061, 0.339
HRMONY	ACP lessens disagreement in family	0.058	-0.192, 0.256
EASEDM	ACP ease future decision-making	0.019	-0.242, 0.226
ENSURE	ACP ensures desirable care	-0.210	-0.529, 0.043
Cons of ACP			
TOOFAR	ACP makes one think of things yet to come	0.225	0.020, 0.387
SADTALK	ACP makes one think patient is dying	0.171	-0.040, 0.340
INFPOS	ACP means contemplating on many issues	0.126	-0.101, 0.306
LOWSTD	It might be prone to low standard care	0.090	-0.119, 0.264
HEAVY	Thinking about deteriorating health	0.046	-0.197, 0.240
UNSTABL	ACP will not be a non-final decision	0.038	-0.217, 0.240

*ICC = Intraclass correlation, CI = Confidence intervals

In general, we also found items in the pro (CAREFL, CONTRL, EASECG, EASEDM, ENSURE, HRMONY, and RELIEF) and con (HEAVY, INFPOS, LOWSTD, SADTALK, TOOFAR, and UNSTBL) categories demonstrated relatively clear agreement and disagreement patterns, respectively (Figure 8). This implies the families leaned towards adopting ACP. On the other hand, questions regarding values and health care demonstrated mixed opinions between patients and caregivers and equivocal patterns within the same group. For example, in DOCKNO, in which there was some disagreement among the dyads, patients slightly leaned towards the belief that the doctors would know what choices were preferable for the patients, while the caregivers equivocally agreed and disagreed. In topics in which a significant agreement was found, the patients and caregivers tended to be positive with the idea that engaging in ACP is to have a sense of control and being mindful. However, in terms of lacking suitability for the moment (TOOFAR), the caregivers were more likely to disagree (62.9% disagree, 20.4% neutral, and 16.7% agree). Detailed distributions are shown in Appendix 12.



Figure 8 ACP-related perceptions

Values on the x-axis represent totally disagree, disagree, neutral, agree, and totally agree.

10.2.2 Decisional Balance model validation (CFA)

Only the pros and cons items were included in this analysis to capture the linkage between individual perceptions based on the firm theoretical background. CFA (Figure 9) confirmed that a 12-item 2-factor patient model (UNSTBL was removed due to low loadings) and a 13-item 2-factor caregiver model fit the data. Both models incorporated residual relationships (covariances) only if they could be explained by the prior qualitative findings, for example, informants who mentioned RELIEF could (somehow) negatively mention SADTALK and HEAVY. Overall, factor loadings in both models were acceptable (approximately 0.7 – 0.8). The Caregiver model demonstrated a desirable fit (CFI > DFI cut point), while the patient model also performed relatively acceptably (SRMR was close to the DFI cut point). The DFIs are shown in Table 19). Caregiver models demonstrated invariant fit across five imputed data. The patterns of caregivers' pros and cons dynamics were also aligned with the patient motivation for ACP (Figure 10).

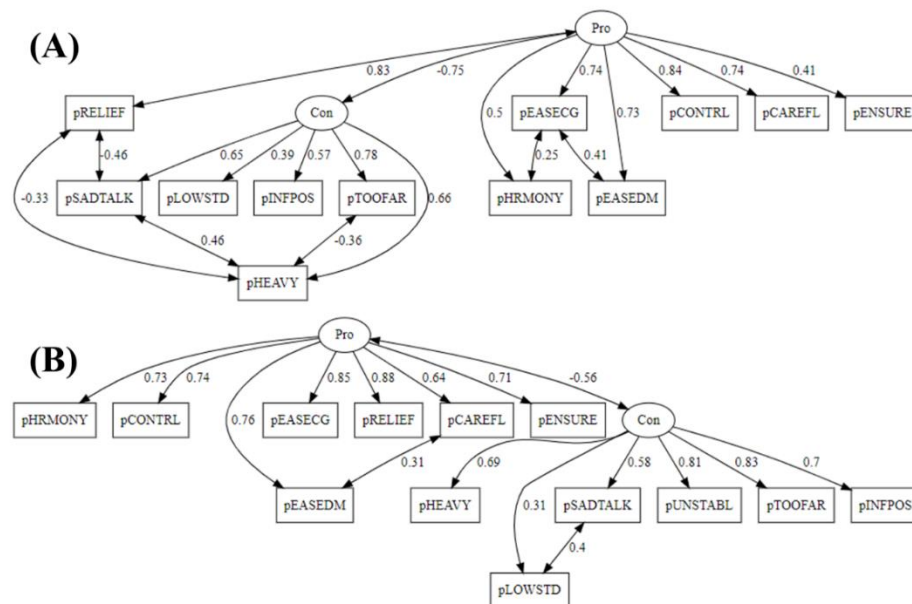


Figure 9 Path diagram showing factor loadings and standardized covariances

Remarks: Oval shapes represent factors (latent construct) of pros and cons of ACP as perceived by the patients (A) and their caregivers (B) “p” implies “perceived”. Unidirectional arrows and bidirectional arrows denote standardized factor loadings and covariances, respectively.

Table 19 CFA fit indices and optimal cut points from dynamic fit indices

Model	Fit measures	Fit indices	DFI cutoffs	Sensitivity
Patient	Chi-square	41.68	N/A	N/A
	Degrees of freedom	47	N/A	N/A
	SRMR	0.38	≤ 0.37	81%
	RMSEA	0	None	41%
	CFI	1	None	42%
Caregiver	Chi-square	156.53	N/A	N/A
	Degrees of freedom	62	N/A	N/A
	SRMR	0.051	≤ 0.050	95%
	RMSEA	0.046	≤ 0.036	78%
	CFI	0.996	≥ 0.988	82%

CFI: Comparative fit indices, DFI: Dynamic fit indices. SRMR: Standardized root-mean-square residual, RMSEA: Root-mean squared error of approximation, N/A: Not applicable.

Remarks: DFI only produces SRMR, RMSEA, and CFI cut points, sensitivity refers to % simulated data (n = 500) achieving fit indices above the cut points when the model is correctly specified, while their specificity values were always identified as 95%.

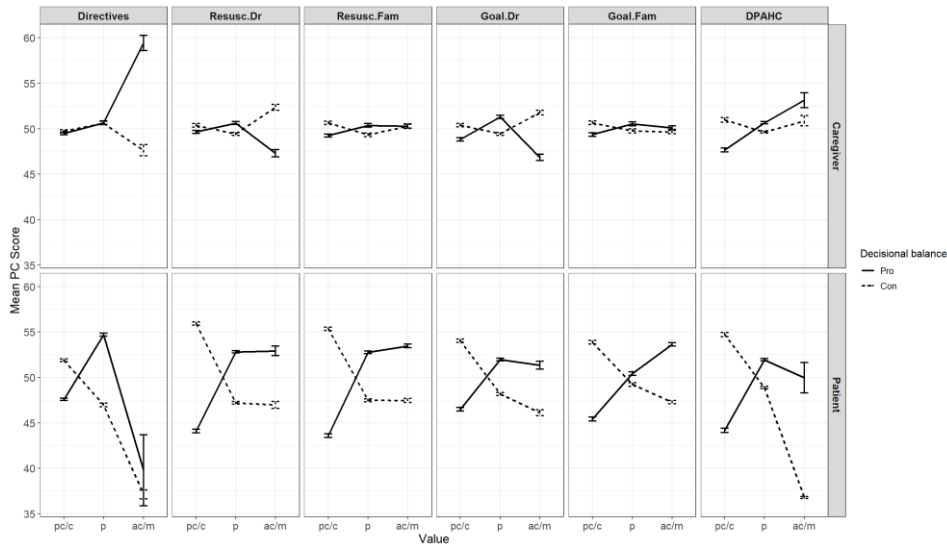


Figure 10 Variations in Pros and Cons (PC score)

Readiness-group mean and its 95% confidence intervals per role in family (patient or caregiver) and types of ACP.

10.3 Bayesian network learning and inference

10.3.1 Structure learning: relationships between family mechanisms and ACP

We applied a conservative approach to identify and validate several network structures to enhance robustness (see Appendix 12 for full details). Table 20 summarizes the representation of the variables in the nodes. In our final model (Figure 11), early-stage factors such as comorbidities (“comorbidity”) and prior resuscitation experiences (“exp_resuscitate”) shaped patients’ understanding of their illness (“understanding”), the quality of medical counseling they received (“counseling”), and their later perceptions of both the elderly patients and caregivers (“careperson_pro”, “careperson_con”, “patient_pro”, and “patient_con”) as well as patient readiness for ACP (“GOAL_fam”, “GOAL_dr”, “CPR_fam”, “CPR_dr”, “DPAHC”, and “Directives”). Family mechanisms, “family_type”, further influenced how patients view ACP. Counseling and understanding enhanced the patient’s ACP familiarity (“acp_familiar_pt”). Ultimately, a patient’s perceived pros and cons of ACP were the key determinants of their readiness for engagement. Notably, the connection between total family functioning (“family_functioning”) and ACP readiness is through common

ancestor nodes: “family type” and “careperson_pro” and “careperson_con”, representing a lack of causal linkage between family functioning and readiness for ACP engagement. As a result of this learning operation, there were 8 arcs in the final BN representation (DAG) which are well-supported by the data (at 95% confidence).

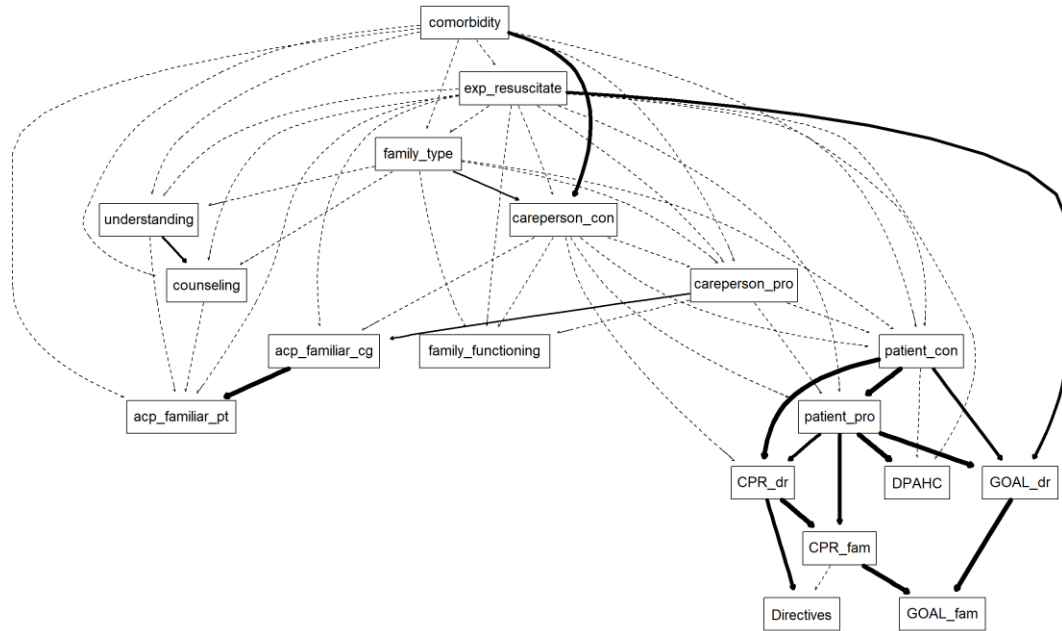


Figure 11 Final Bayesian Network

Arc thickness represents the strength of the relationship between two nodes. Dashed lines represent insignificant relationships (presented in less than 95% of the bootstrap simulations) while solid lines represent significant arcs. Thicker arcs are more significant in explaining the data.

Table 20 Variable description for the BN structure

Node	Description
exp_resuscitate	Patient’s prior experience of being resuscitated
comorbidity	Comorbidity level based on the Modified Charlson’s score
family_type	Family background (from the LCA)
understanding	Self-rated understanding of current illness
counseling	Self-rated quality of care provider information process
acp_familiar_pt	Patient’s prior awareness of legally bound ACP
acp_familiar_cg	Caregiver’s prior awareness of legally bound ACP
patient_pro	Patient’s perceived pros of ACP
patient_con	Patient’s perceived cons of ACP

careperson_pro	Caregiver's perceived pros of ACP
careperson_con	Caregiver's perceived cons of ACP
Directives	Readiness for advance directive documentation
DPAHC	Readiness for durable power of attorney for health care
GOAL_fam	Readiness for goal of care discussion with the family
GOAL_dr	Readiness for goal of care discussion with the care provider
CPR_fam	Readiness for LST use discussion with the family
CPR_dr	Readiness for LST use discussion with the care provider

10.3.2 Parameter learning: model-implied probability parameters

Table 21 shows posterior probabilities acquired from the exact inference of the final BN on each of the evidence variables, without adjusting for other variables (additional conditioning). In terms of the magnitude of posterior probability change, there were relatively high relationships between changing the pros and cons of ACP and the likelihood of a patient being ready for ACP, compared to the other variables. Increasing pro from low to high and decreasing con from high to low were found favorable for any ACP behaviors. If “Resuscitation experience” was related to the patient or relative themselves, we would expect a higher probability of a patient being ready for ACP in all domains. Comorbidity also played a similar role as prior experience, of which the probability of being ready for ACP increases with higher comorbidity (i.e. having metastatic cancer). Family type also affects the posterior probability, observing a complex family would result in a relatively low probability of a patient being ready for ACP (35.1% ready for advance directives vs 73.4% ready for DPAHC), compared to an enmeshed family (37.2% ready for advance directives vs 75.1% ready for DPAHC). However, if comparing the effect of resuscitation experience, comorbidity, and family type to the patients’ pros and cons changes, their effects were relatively trivial. Overall, ACP nodes dominated the sensitivity among themselves (see Figure 12).

Table 21 Conditional probability query and average sensitivity values

Evidence	Types of advance care planning						Average sensitivity
	Directives	DPAHC	GOAL_fam	GOAL_dr	CPR_fam	CPR_dr	
Advance directive (Directives)							0.250
Ready	N/A	0.770	0.712	0.678	0.821	0.851	
Not ready	N/A	0.737	0.640	0.635	0.596	0.584	
Goal discussions with family (GOAL_fam)							0.250
Ready	0.395	0.777	N/A	0.882	0.771	0.756	
Not ready	0.320	0.694	N/A	0.188	0.497	0.536	
Life-sustaining treatment discussions with family (CPR_fam)							0.116
Ready	0.447	0.783	0.756	0.693	N/A	0.894	
Not ready	0.207	0.677	0.477	0.562	N/A	0.237	
DPAHC							0.083
Ready	0.380	N/A	0.691	0.679	0.710	0.715	
Not ready	0.340	N/A	0.593	0.566	0.587	0.586	
Goal discussions with doctor (GOAL_dr)							0.070
Ready	0.386	0.782	0.904	N/A	0.723	0.733	
Not ready	0.341	0.689	0.225	N/A	0.598	0.589	
Life-sustaining treatment discussions with doctor (CPR_dr)							0.067
Ready	0.461	0.785	0.739	0.699	0.889	N/A	
Not ready	0.174	0.673	0.512	0.547	0.228	N/A	
Experience prior resuscitation (exp_resuscitation)							0.029
Self	0.386	0.775	0.714	0.711	0.728	0.733	
Relatives	0.381	0.795	0.726	0.732	0.708	0.720	
Other	0.370	0.749	0.667	0.651	0.679	0.683	
Comorbidity (comorbidity)							0.017
High	0.376	0.752	0.674	0.658	0.694	0.701	
low	0.368	0.748	0.664	0.648	0.674	0.677	
Family background (family_background)							0.007
Enmeshed	0.372	0.751	0.670	0.654	0.685	0.690	
Distant	0.372	0.750	0.666	0.648	0.683	0.689	
Complex	0.351	0.734	0.641	0.626	0.629	0.618	
Patient's perceived pro of ACP (patient_pro)							0.006
High	0.417	0.859	0.769	0.763	0.830	0.825	
Low	0.316	0.621	0.547	0.520	0.504	0.518	

Patient's perceived con of ACP (patient_con)							0.004
High	0.304	0.658	0.542	0.510	0.512	0.461	
Low	0.425	0.825	0.771	0.768	0.819	0.868	
Caregiver's perceived pro of ACP (careperson_pro)							0.002
High	0.375	0.768	0.683	0.670	0.696	0.696	
Low	0.366	0.732	0.652	0.632	0.664	0.671	
Caregiver's perceived con of ACP (careperson_con)							0.003
High	0.361	0.723	0.637	0.615	0.651	0.655	
Low	0.378	0.772	0.692	0.681	0.703	0.707	
Family functioning (family_functioning)							N/A
High	0.370	0.750	0.667	0.651	0.680	0.684	
Moderate	0.369	0.746	0.666	0.651	0.675	0.680	
Awareness PT (acp_familiar_pt)							N/A
Ever	0.376	0.764	0.686	0.676	0.696	0.702	
Never	0.368	0.746	0.662	0.645	0.675	0.678	
Awareness CG (acp_familiar_cg)							N/A
Ever	0.374	0.763	0.681	0.668	0.691	0.695	
Never	0.368	0.743	0.660	0.642	0.673	0.677	
Quality of medical counseling (counselling)							N/A
Good	0.370	0.750	0.668	0.652	0.679	0.679	
Poor	0.369	0.743	0.659	0.639	0.678	0.678	
Understanding of illness (understanding)							N/A
Good	0.371	0.753	0.672	0.658	0.682	0.687	
Poor	0.366	0.734	0.651	0.630	0.669	0.670	

Remarks: N/A = not applicable (any change in context of the local conditional probability with N/A sensitivity did not affect the posterior probability of ACP nodes)

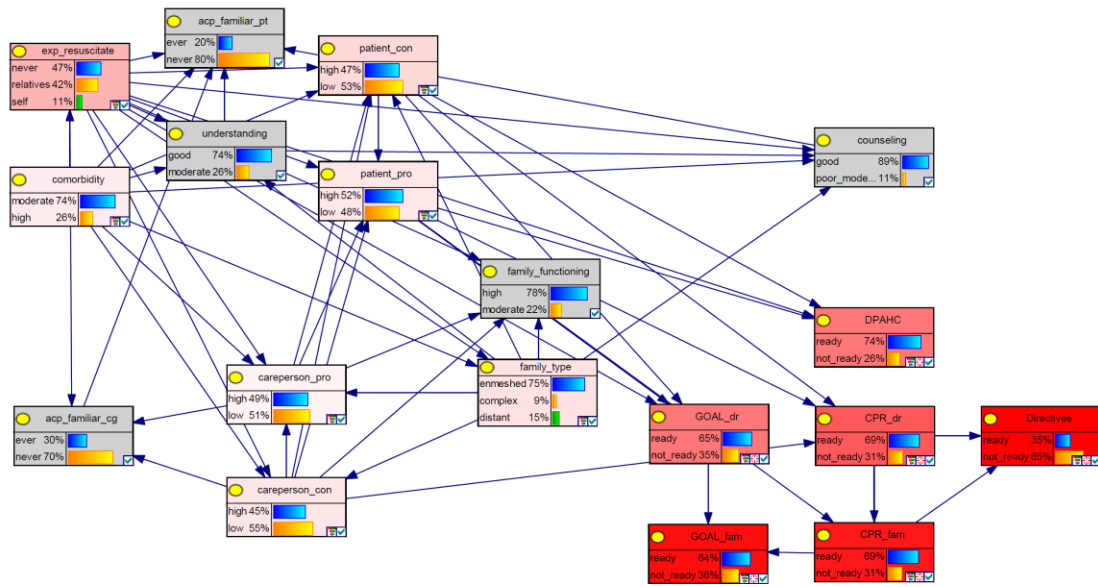


Figure 12 Bayesian network with marginal probability

Redder nodes (rectangles) denote increased sensitivity to change of ACP variables (denoted by ). Grey nodes are variables in which changes in local conditional probability will not be attributable to changes in the target nodes. Tick marks at the lower right indicate that the probability values were updated.

To operate an intervention analysis, we identified four modifiable variables (targets) in which causal pathways to ACP readiness were found (i.e., patient's perceived pros and cons, and caregiver's perceived pros and cons). The analysis involved modifications of the original BN structure to create a causal BN. The four targets required four structure operations to simulate the intervention effect, resulting in significant changes in model-implied probability parameters as denoted by Bayes's factors. Table 22 shows the impact of the modification on the marginal probability of the ACP outcomes. The intervening patient's cons were the most likely causal hypothesis (extreme evidence, $BF = 162.993$). The modifications of the patient's pros and cons demonstrated larger effects compared to modifying the caregiver's pros and cons (see Table 23). To illustrate, increasing a patient's pro would have a higher impact on the DPAHC, while reducing their con would have a greater impact on the other five ACP domains.

Table 22 Marginal probability of ACP outcomes in different causal Bayesian Networks

Network	Directives	DPAHC	GOAL_fam	GOAL_dr	CPR_fam	CPR_dr	BF*
Original BN	0.352	0.741	0.635	0.646	0.691	0.687	Ref.
Intervene patient_pro	0.333	0.667	0.582	0.596	0.619	0.650	26.08
Intervene patient_con	0.318	0.704	0.577	0.590	0.610	0.584	162.99
Intervene careperson_pro	0.350	0.735	0.630	0.641	0.685	0.681	80.23
Intervene careperson_con	0.351	0.741	0.634	0.644	0.689	0.684	32.65

Remarks: *Bayes factor (BF); BF >10 is considered strong evidence supporting an alternative (causal) BN structure

Table 23 Average causal effect of hypothetical interventions

ACP	Intervention* (<i>Int</i>)	$P(ACP do(Int) = low)$	$P(ACP do(Int) = high)$	CE
Directives	patient_pro	0.322	0.389	0.067
	patient_con	0.422	0.273	0.149
	careperson_pro	0.348	0.354	0.006
	careperson_con	0.354	0.348	0.006
DPAHC	patient_pro	0.633	0.839	0.206
	patient_con	0.809	0.659	0.150
	careperson_pro	0.724	0.754	0.030
	careperson_con	0.765	0.711	0.054
GOAL_fam	patient_pro	0.555	0.712	0.157
	patient_con	0.755	0.501	0.254
	careperson_pro	0.622	0.644	0.022
	careperson_con	0.659	0.602	0.057
GOAL_dr	patient_pro	0.572	0.715	0.143
	patient_con	0.763	0.515	0.248
	careperson_pro	0.632	0.655	0.023
	careperson_con	0.676	0.605	0.071
CPR_fam	patient_pro	0.578	0.820	0.242
	patient_con	0.856	0.504	0.352

	careperson_pro	0.676	0.701	0.025
	careperson_con	0.702	0.674	0.028
CPR_dr	patient_pro	0.626	0.771	0.145
	patient_con	0.891	0.453	0.438
	careperson_pro	0.676	0.690	0.014
	careperson_con	0.688	0.680	0.008

CE: Causal effect.

Remarks: * the intervention target increases the perceived pros of ACP (thus $CE = P(ACP|do(pro) = high) - P(ACP|do(pro) = low)$) and decreases the perceived cons of ACP (thus $CE = P(ACP|do(con) = low) - P(ACP|do(pro) = high)$).

CHAPTER 4

DISCUSSION AND CONCLUSION

We applied descriptive qualitative methods in the first phase of our study to understand older patients with cancer and their families regarding ACP engagement. While our informants saw ACP as an advantageous activity, they expressed several aspects of hindrance. The original questionnaire was modified in terms of the number of items and context suitable for the Thai culture, which could be sensitive to ACP activities. In the second phase, we subsequently asked older patients and their caregivers to examine their perceptions regarding ACP and examined whether those perceptions were interconnected with the readiness for ACP engagement, of which the potential relationships were learned from the qualitative study.

1. Qualitative Part

The qualitative study examined the perceptions of elderly cancer patients and their caregiving family members regarding ACP. Participants represented families with diverse socioeconomic backgrounds, often comprising multiple generations, and included elderly patients with various types of cancer, including those with metastatic disease. However, all of our caregiver informants were female. Three key concepts influencing ACP engagement were identified as behavioral modifiers. Families' behaviors toward ACP were shaped by a combination of perceived benefits and barriers, as well as life experiences or cues encountered during their cancer journey. Additionally, our findings revealed variations in benefits, barriers, and cues to a patient's ACP engagement depending on whether the respondent was a patient or caregiver, aligning with observations from previous studies on ACP in older adults.^{169,170}

1.1 ACP as an Opportunity (Pros of ACP)

Participants expressed the belief that ACP provides a beneficial opportunity for cancer patients to ensure their treatment preferences are respected by empowering surrogates to act on their behalf. These perceived benefits align with findings from earlier research on older adults and those with chronic illnesses.^{171–173}

ACP was also seen as a means of gaining control over end-of-life care.^{174,175} Furthermore, participants highlighted the value of ACP as a chance to reflect on personal preferences and share these with family and healthcare providers. This is consistent with a study from South Korea,¹⁷⁶ which found that the ability to assert one's medical care preferences was a primary motivation (38.9%) for making end-of-life decisions.

1.2 Barriers or disadvantages (Cons of ACP)

Several factors hindered the acceptance of ACP among patients, families, and healthcare professionals.¹⁷⁷ Systematic reviews have identified challenges such as patients' limited knowledge of their conditions and ACP, as well as cultural and personal beliefs influencing attitudes toward ACP.^{170,178} Although living wills have been legally recognized in Thailand for over a decade and various ACP documents, such as the Bao Jai (Relieving) booklet and Thai standard forms, are available,⁴⁵ our informants (both patients and caregivers) were unaware of their existence. This lack of awareness may complicate the articulation of end-of-life preferences in Thailand, especially as older adults often have distinct wishes for their care.¹⁷⁹ Additionally, ACP is sometimes perceived as a conversation that conveys distressing information, which may cause stress for patients, families, and even healthcare providers.^{177,180–182} This study found that fear of delivering bad news is a significant barrier to ACP engagement. Families often worried that discussing ACP could distress their loved ones, reduce their motivation, or impair their ability to cope with cancer treatment. These concerns sometimes led families to avoid initiating discussions about values and end-of-life care, or even to collude with healthcare providers in withholding unfavorable news.⁴⁵ Compounding this, elderly cancer patients might hesitate to share their true wishes out of concern for burdening their families. This cultural sensitivity has been noted in earlier studies on Asian families.¹⁷⁸ Despite this, studies report that 87% of general cancer patients and 95% of metastatic or advanced cancer patients in Australia and Thailand^{183,184} prefer to be informed about their condition. However, older cancer patients often accept only the amount of information shared by their physician.¹⁸⁴

1.3 Cues for Initiating ACP

There are no universal guidelines for when ACP conversations should begin. However, previous research suggests they could be prompted by cues, such as the patient initiating the topic, being diagnosed with a new life-limiting illness, or experiencing changes in their health status.^{177,185} We found that cues for ACP discussion include conformity with religious principles regarding being mindful of health, which was applicable in both Buddhism and Islam, multiple comorbidities or awareness of a poor prognosis, and trust in the physician. The relevance of ACP with religious beliefs was also expressed but our participants stated more clearly that the religious principle they felt connected with the intention for ACP was mindfulness, unlike God's influences reported in another context.¹⁸⁶ Healthcare providers who recognize these cues—or foster trusting relationships with patients and families—may be better positioned to initiate ACP discussions more effectively.

2. Quantitative Part

2.1 General discussion of the main findings

This cross-sectional study collected data from multiple sources on stages of readiness for ACP engagement and proposed family-related factors from 279 families (558 individuals) of older people with solid organ malignancies and their primary caregivers who were visiting a university hospital for radiotherapy. The median age of the patients was 68.5 years and the majority of the caregivers were in their 50's. The patient's cancer types were distributed similarly to the target population.¹⁸⁷

In the oncology setting, ACP can be implemented at several points of care in the cancer care stream, for example, at initial diagnosis, advanced stage, or in the terminal phase (prognosis <12 weeks).¹⁸⁸ Bestvina and Polite suggest that there is no consensus on when and where the proper circumstances for implementing ACP should be for cancer patients.¹⁸⁸ In these situations, the roles of nurses, psychiatrists, and palliative care specialists are mentioned. However, conducting an ACP session can be time-consuming and has become a major concern in oncology settings.^{188,189} Some oncologists perceive that such discussions would take away the patient's hope, thus

approximately 40% avoided initiating discussions regarding prognosis until being asked, or when the patient's life was near the end.¹⁹⁰ As a result, discussions pertaining to end-of-life issues were more commonly (55%) held among inpatients rather than outpatients;¹⁹¹ however, it may be too late when older patients become hospitalized as almost one-third of them are cognitively impaired.¹⁹²

2.2 Readiness for ACP engagement in elderly cancer patients

Thai elderly cancer patients had variable readiness towards different ACP behaviors. Participating in discussions about the goal of care and using LST were behaviors that were more common in families than with doctors. In addition, the patients were more likely to be in the “action” or “maintenance” stages for discussing goals than life-sustaining machines. This could reflect the feasibility of discussing medical topics in non-clinical contexts in which the families require professional suggestions for informed decision-making.¹⁹³ Some studies demonstrated the importance of materials for life-sustaining treatment decision-making, such as participation in the effects of short video information (24% became uninterested in CPR and 0% became interested in CPR)¹⁹⁴ and computer-aided applications.¹⁹⁵

It was notable that a large number of patients had never engaged in legally bound ACP (making a DPAHC and documenting a living will), despite the 4% and 20% prevalence of prior awareness of the legalized ACP and surrogate decision-maker appointment, respectively. While participants mostly heard about ACP from health professionals, television programs were the second source of ACP awareness in both patients (3%) and caregivers (7%). This result highlights a significant gap in legalizing ACP and implementing such practices in real clinical practice for patients with cancer as potential target users. A large survey among 2,394 individuals in a Northeastern Thai community showed that awareness regarding Section-12 of the Health Act (2009) were comparable (24%) to our study, but 13% of individuals who were unaware insisted they did not want to engage in these activities.⁶⁶ While compared to other countries such as Australia and Taiwan where palliative care provision is highly developed,¹⁹⁶ patients and caregivers' awareness and experience with ACP were higher (33% and 48.5%, respectively).^{25,197}

2.3 Family mechanisms and readiness for ACP engagement

Advance care planning is a process of patient-family-provider communication. This study shows that family types, family functioning, and individual family member thoughts influence ACP engagement, consistent with previous studies.^{21,198} To elaborate, a family member who is an only active child may conceal the actual information from the patient (as indicated by family #17). This phenomenon was also found in other studies.^{45,199} In our study, almost all families had high or moderate levels of family functioning. This finding is not surprising for a family-oriented country such as Thailand, even after the COVID-19 pandemic.²⁰⁰ Our study also demonstrated a similar influence of family functioning with other studies,³³ but with a much lower effect size. This can be explained through causal relationships in the Bayesian network. Our causal conception shows a lack of effect from family functioning to the patient's readiness for ACP. These findings suggest that family functioning itself might not affect patient's perceptions. Also, we showed that the patient's and caregiver's perceptions of ACP were vastly discordant. Therefore, we believe it might not be effective to encourage caregiving family members to support the other, listen and communicate effectively, respond to emotion, or arrange roles for caregiving in order to promote the elderly's engagement in ACP. Instead, we argue that receiving support from ACP facilitators to enhance the perceived pros and cons of ACP can better motivate the patient's engagement in ACP. Conceptually and statistically, although Bayesian networks can represent associational, causal, or complete relationships,¹⁶² we cannot be certain that our causal pathways are correct. This argument is based on the hypothesis of testability of the causal network, which is justified by likelihood evidences.¹⁶⁶

ACP discussions with families and care providers

It is recommended that ACP should start with a conversation to elicit and understand the individual's preferences, then one may consider, or be invited to, document the preferences.^{15,16} We found that overall, approximately one-third of the patients were not ready for discussions on ACP. The proportions of unprepared patients were similar to a small study of cancer patients in the United States ($n = 13$).²⁰¹ This suggests that two-thirds were ready but never had ACP discussions with their care providers. A systematic review showed that discussions between doctors and families

about ACP are considered complex doctor-family-patient interactions.²¹ In Korea, doctors might see ACP as difficult, mainly because the circumstance is too late; patients become sick (50.6%) and incapable of processing ACP (58.4%), or the caregiver protects their patients from ACP (29.2%).⁶⁵ Findings in Thailand showed that doctors themselves are sometimes reluctant to initiate discussions of ACP because of certain challenges, including lack of communication skills and experience, resistance from patients and caregivers, and the doctor's uncertainty in their prognosis, which can lead to a conspiracy of silence among doctor and caregivers.⁴⁵

We found ACP-related perceptions among patients and caregivers were rarely congruent, except for (small agreement) the timing of ACP and the effects of ACP in the sense of control and mindfulness. However, in general, the patients tended to see ACP discussions as suitable for their current health state. This is similar to the thoughts of adult advanced cancer patients in Taiwan²⁰² and in the US.⁶² Further, our Bayesian network demonstrates patient cons have a greater influence on ACP discussions than the pros, and the caregiver's perceptions have a minor influence on the ACP. From our causal network and perception consistency analysis, we understand better why some family members hinder patients in ACP (perspectives disagreement and lacking links from family functioning to patients' and caregivers' perceptions), or instead experience patient distress when inadvertently allowing or preventing the patient from discussing ACP.^{45,186}

We identified perception targets for intervention to target the patient's decisional balance (perceived pros and cons of ACP), but not explicit methods. This leads to requirements for further intervention designs and tests if the study concept can be useful. A previous study demonstrated a good case of the intervention design.²⁰³ In that study, study brochures provided two stories of patients who had and did not have ACP, showing content promoting pros (i.e., benefit for spouse and children when a husband had ACP) and addressing cons (i.e. regret of a daughter whose mother did not have ACP). Based on our qualitative findings, the story of family #12 can also be used; the regret that the patient had kept his plan with himself because he thought his wife would disagree can be used for intervention design applying the decisional balance concept.

Documenting advance directive/living will and DPAHC

In Thailand, the law indicates that individuals can have a living will and nominate a person in the DPAHC to act on behalf of the patient for the documented preferences in a living will.¹⁸ We found that the readiness for these two types of documentation was remarkably low, which can be indirect evidence of low ACP knowledge in elderly cancer patients in Thailand.⁶⁶

Our Bayesian network demonstrates the potential intervention effects on patients' decisions for creating a DPAHC and advance directives differently. Interventions that target the patient's perceived pros of ACP may produce a higher effect size than the cons for DPAHC. On the other hand, the effects of modifying a patient's perceived cons of ACP slightly dominate when the target outcome is a living will. To arrange contents for the intervention, the messages of family #10 can be applied, which are "there will be someone to ensure what the patient wants – if you nominate your trusted persons as a healthcare proxy" and "although documented preferences might not be up to date – however if you make one – they can be a guidance for the loved ones".

3. Strength, limitations, and implications

3.1 Strengths

Many studies have investigated readiness for ACP and related perceptions of individuals in various populations, with limited studies conducted among cancer patients. Among the several studies examining readiness for advance care planning, this study includes the largest number of participants to date.⁶⁷ In addition, we applied an exploratory-sequential mixed methods approach to develop a culturally appropriate questionnaire. We also acquired a valid questionnaire construct, based on the Decisional Balance concept, using a robust model evaluation (dynamic fit index) for the subsequent cross-sectional study. Secondly, this is the first study comparing the views of cancer patients and the referential views of their caregivers towards ACP. This approach provides information regarding discrepancies in views towards ACP, both descriptively and analytically, which adds insight into why inconsistent family

processes exist and how a conspiracy of silence can, at least partially, be explained by this phenomenon.

Furthermore, we applied Bayesian network structure learning and inference to explain complex relationships between several variables. This approach is flexible and efficient for capturing such relationships by incorporating non-parametric (probabilistic) principles. Using Bayesian networks to model observational data allows for the integration of expert knowledge or new information as updated priors for the original parameters learned from the data. To enhance the robustness of Bayesian networks for causal reasoning, we employed several strategies, including qualitative-study-guided variable selection, temporal constraints, expert knowledge integration, and model comparison across various methods. An additional advantage of Bayesian networks is their ability to assess the sensitivity of variables to contextual changes. We found that, apart from ACP behaviors, prior experience in resuscitation, higher comorbidity, and specific family backgrounds were sensitive to the overall probability of ACP motivations. This was evident when new data or beliefs modified the prior probabilities associated with these three variables. For example, if the network and its parameters are applied in a similar setting with a higher prevalence of patients with resuscitation experience, model users should anticipate potential changes in overall ACP readiness (as both marginal and conditional probabilities are susceptible). This feature enables the network to identify potential generalizability issues. Additionally, if this model is to be applied by decision-makers, they should prioritize collecting data on 1) resuscitation experience, 2) comorbidity profile, and 3) family types. By updating the structure's priors with this information, decision-makers can better estimate the likelihood of ACP engagement readiness in new settings

3.2 Limitations

This study has several limitations. First, in the qualitative phase, we derived our qualitative descriptions from the families of several patients who required radiotherapy. Thus, the findings of this study might have limited generalizability to cancer patients in other settings. Additionally, we had a relatively low response rate.

This may reflect the unfamiliarity with ACP among most Thai families or be partly attributable to our strict protocol on patient's safeguard, which only allowed the interview to be conducted in our consultation room located in the hospital's clinic.

Moreover, of the study patients, all of their caregivers were female. Therefore, the data on caregivers' perspectives could be biased toward gender-related experiences. However, to address this potential bias, we consulted two debriefers with extensive experience in palliative care and oncology to confirm whether the saturation of qualitative information was sufficient to draw at least tentative conclusions regarding a better understanding of attitudes toward ACP, and they agreed upon the capability of the available information to represent the majority of both male and female caregivers' attitudes they have seen.

Second, in the cross-sectional study, we also experienced an unexpectedly low response rate from the invited families, patients, and/or caregivers due to personal constraints and discomfort in discussing ACP topics. This finding could inform future researchers seeking to collect data on a similar topic from both older cancer patients and their caregivers, highlighting the potential for volunteer bias. However, it is possible that this study provides unbiased prevalence estimates of the stages of readiness, as the low response rate is consistent with findings from several previous studies.²³ In addition, we invited all eligible patients and caregivers through consecutive sampling and ensured a balanced sex distribution in the sample. Our post-hoc comparison found that the proportion of patients who were not ready for ACP was similar between participants and non-participants (22% vs. 26%, respectively). Moreover, we tracked the cumulative prevalence of ACP readiness (i.e., goal of care discussions with physicians) throughout the data collection process and did not observe significant fluctuations in the cumulative prevalence, which remained consistently close to 26% for ACP discussions.

Third, there were various issues arising from the Bayesian network analyses. First, Bayesian network structure learning (algorithmic production of causal graph) could yield a biased directed acyclic graph (i.e., the presence of spurious relationships or arcs) if there are any unobserved variables, because the learning algorithm only identify likely independence corresponding to the given variables and the dataset. Nevertheless, our in-depth qualitative guidance could help mitigate this

bias. Apart from that, Bayesian networks require modeling relationships among variables in a one-way direction and operate as a static model, while interactions can change over time. In addition, the fact that we applied a discrete network may have resulted in some loss of information from the original nature of certain continuous and ordinal variables. Since we discretized readiness for ACP engagement into “ready” and “not ready,” the information learned from the model for the target patients would be limited to motivating individuals in the “pre-contemplation” or “contemplation” stages to move toward the “preparation”, “action”, or “maintenance” stages. While such interpretations could be relatively rigid, we believe that they still provide significant insights into promoting motivation for ACP due to the distinct processes of change between pre-contemplation and contemplation compared with the higher stages.¹⁰¹ Furthermore, building a Bayesian network and making probabilistic inferences cannot confirm that interventions would produce the same effects in real-world settings. Its application requires further investigation, such as assessing the cost of interventions and considering influences from caregivers or care provider behaviors.¹⁴⁰

3.3 Implications

3.3.1 Clinical implications

Thai families adhere to strong family-oriented values, such as seniority, filial piety, a conspiracy of silence, and a family system that treats older persons as revered figures.^{45,204} We also demonstrate that families of Thai elderly cancer patients hold similar views. Several contemplations and perceived barriers can hinder a person’s motivation to engage in ACP. Nevertheless, we identified signals of readiness for ACP that include system triggers (e.g., high comorbidity), external cues related to relational autonomy (e.g., feeling like a burden to family), and a trusting doctor-patient relationship. Oncology staff can prioritize highly morbid elderly cancer patients and coordinate with the treating clinicians to initiate ACP discussions. Furthermore, we suggest that the type of family structure can provide valuable clues for clinicians or nurses when considering whether to invite a patient to engage in ACP. Physicians should understand the family dynamics, as ACP engagement is more probable in enmeshed families than in families with complex or unclear decision-making patterns.

However, readiness for ACP engagement should be assessed before initiation to avoid inducing emotional discomfort.^{16,193} Our qualitative findings also support previous studies in Asian populations, which suggest that participating in ACP may cause certain distress among elderly cancer patients and their families.^{56,74,205} Therefore, the process of engaging Thai elderly cancer patients in ACP should be approached with extra caution to minimize emotional distress.

Although concerns related to ACP in Thailand seem substantial, we identified a significant opportunity for families and clinicians to become ready to engage in ACP. Between half and two-thirds of elderly cancer patients demonstrated preparedness for ACP; therefore, patients should still be asked or invited to participate in ACP discussions. In addition, ACP discussion (for goals of care and LST use) with clinicians can be the first step because the clinician can assess perceptions, understandings, preferences regarding medical care, and readiness for any type of ACP, by being aware that the patient is ready for discussion, there will be more possibility to proceed to other types of ACP such as DPAHC or advance directive documentation. Nevertheless, patients who are not ready to engage in ACP should not be left unengaged simply because they are at risk of psychological distress, given the several benefits of ACP for the elderly.⁵⁵ In cases where the patient is not ready, we suggest that the clinician or ACP facilitator focus on enhancing the pros and mitigating the cons of ACP as experienced by the elderly cancer patient. This strategy can yield the highest impact in promoting the patient's readiness for ACP. We recommend using the process of motivational interviewing to engage patients who are not ready (in the "pre-contemplation" or "contemplation" stage) in clinical settings, as motivational interviewing facilitates the establishment of trust between the clinician or nurse and the patient while fostering a favorable decisional balance.^{206,207} Having the primary oncologist provide disease-related information and initiate discussions of ACP allows patients to receive accurate information from a trusted physician.^{23,45} However, promoting ACP engagement by enhancing patient's perceived pros and mitigating perceived cons of ACP also requires significant awareness of inconsistencies in views toward ACP between the patient and their family members. The caregiver may show signs of discomfort or disagreement during the ACP session. Therefore, promotion of

motivational strategies should be conducted in a manner that balances family satisfaction with the patient's right to protect their autonomy.

3.3.2 *Public health implications*

Among elderly cancer patients, particularly in southern Thailand, our findings demonstrate a positive tendency to engage in discussions of ACP with their clinicians (being in preparation for ACP) despite a lack of experience (i.e., a small number of patients have discussed ACP with their clinicians). This highlights an opportunity for the Ministry of Public Health and the National Health Security Office to oversee ACP practice in the cancer population in Thailand. As the proportion of elderly individuals within the cancer population in Thailand increases,⁹ the systematic provision of ACP should prioritize older patients. We found that the patients in this study included those who were newly diagnosed and those undergoing ongoing radiotherapy, yet they lacked ACP experience with their clinicians. For hospitals that serve cancer patients, administrators should identify appropriate opportunities within the care pathway to assign formal roles for ACP facilitators. This recommendation for promoting ACP may require additional resource support. We believe that efficient time and personnel allocation would enable the systematic provision of ACP for a large number of prepared elderly cancer patients in Thai oncology settings.

Furthermore, we recommend that national health promotion and educational bodies (e.g., the Thai Health Promotion Foundation and the Thai Hospice and Palliative Care Society) focus on campaigning based on the stage of change in ACP readiness profiles among cancer patients. Different activities may require unique approaches. As guidelines emphasize the importance of a gentle introduction to ACP and suggest advance directive documentation only if suitable, we propose that the first step should encourage ACP discussions between clinicians or other healthcare providers through the processes of consciousness raising, dramatic relief, and environmental reevaluation. These first-step recommendations are also supported by our Bayesian inference, which indicates that once elderly patients feel more prepared or ready for the discussion, their likelihood of engaging in other types of ACP increases significantly. A recent study highlights possible ways to implement such strategies, including portraying scenarios where decision-making capacity is limited during a

critical illness or demonstrating how ACP can benefit patients when discussing it with family members. These processes, delivered through various forms of media, can address concerns related to ACP—such as the discomfort of thinking about an undesirable future with loved ones—while also emphasizing the benefits of ACP (i.e., allowing introspection of personal values and conveying personal preferences to loved ones with a clear message, which may reduce anxiety). After ACP discussions with care providers have been established, additional in-depth education regarding documentation can be supplemented with printed educational materials, encouragement, or invitations from designated personnel, including clinicians, nurses, social workers, or health volunteers, depending on the context and available resources.

3.3.3 *Research implications*

In the qualitative study, all caregivers of the study patients were female. Future studies should include more male caregivers to evaluate any sex-based differences in perceptions and experiences. Additionally, an in-depth analysis, such as examining male-to-female perception consistency or conducting a confirmatory factor analysis on the invariance fit of the decisional balance structure between male and female caregivers, may be conducted to quantitatively test equivalency. Our CFA models demonstrated an acceptable fit for the observed data with a slightly rigid specification based on the original pros and cons model. Future studies could explore whether a higher-order model would be both statistically and theoretically sound.

Our study pioneered an investigation into the relationship between patients' and caregivers' perceptions of ACP, highlighting how the pros and cons are intertwined. However, other constructs in the TTM, such as the process of change and self-efficacy, were not examined. Future research can explore different processes of change between patients and caregivers. Additionally, ACP engagement behaviors in caregivers (e.g., caregiver involvement in the patient's ACP) and care providers (e.g., readiness of care providers to initiate the conversation) warrant further investigation. Furthermore, ACP might be accomplished at various levels within a community, such as through discussions between patients and their friends or other non-professional contacts. Therefore, future studies should examine ACP motivators among other

parties, such as community members (potential ACP facilitators or volunteers) or religious leaders, and how this holistic readiness might promote consistency between patients' preferences and the actual care they receive.

We modeled complex relationships among several psychosocial variables, including the pros and cons of ACP and readiness to engage in various ACP behaviors, using a discrete Bayesian network. This approach carries several limitations, such as the nature of the data used (e.g., continuous or hybrid). Future studies may investigate other models to better represent relationships and make inferences about ACP and its complex dynamics. Since ACP is part of a long-term dynamic process involving patients, families, and doctors throughout the care journey, dynamic Bayesian network models could be considered to account for changes in perceptions and behaviors over time. Furthermore, investigators may consider applying the learned Bayesian network structure to structural equation modeling to capture relationships among observed and latent variables.

Our intervention analysis was generated from hypothetical causal reasoning rather than true experiments. Future studies could collect data from experimental designs to provide more robust evidence of causal relationships. Changes in readiness for ACP could also be investigated over time to assess long-term effects.

4. Conclusions

Families of Thai elderly cancer patients perceived that ACP discussions are unfamiliar and unnecessary. They believed that such discussions might have low utility, could worry patients and family members, take away optimism, and would not be appropriate in the current situation. However, they acknowledged that ACP could help ensure their preferences would be respected.

Elderly cancer patients in Thailand were mostly prepared to engage in ACP discussions with family members and care providers. However, 65% of patients remained in the pre-contemplation or contemplation stage regarding advance directives or living wills. The fact that many individuals were prepared to discuss ACP with their doctors also suggests that they might have never been invited to do so. Despite a general trend of favorable attitudes towards ACP, disagreements regarding ACP remain

significant. ACP is perceived as a way to be mindful and have a sense of control over future medical care, making the present time an opportune moment to discuss ACP.

The perceived pros and cons of ACP among older patients with cancer in southern Thailand reflect patterns already described in the literature. Pros and cons intersect at the stage before individuals transition to the preparation stage. An older patient motivated by certain ACP behaviors is also more likely to be ready for other ACP behaviors. Documentation of ACP and DPAHC is less likely to occur when other ACP behaviors have not yet been embraced. Patients' perceived pros and cons were found to have a strong influence on overall ACP behaviors when targeted by interventions. Promoting patients' perceived pros of ACP has a greater influence on DPAHC than on other behaviors, while reducing perceived cons of ACP has a stronger effect on the remaining behaviors. We suggest prioritizing the reduction of perceived cons when time is limited, especially in oncology settings. Personalized pros and cons could offer opportunities for designing ACP materials. However, care professionals must be aware of the potential for caregivers to hinder patient engagement in ACP, as patients often hold different views from their caregivers on many aspects of ACP.

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APPENDICES

Appendix 1. Information sheet for phase 1 (elderly)

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1 Version 3.0, Date 14/12/2022	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 1 จาก 7 หน้า

เอกสารชี้แจงผู้เข้าร่วมการวิจัย (สำหรับผู้ป่วย) (เพื่อประกอบการตัดสินใจ)

ชื่อโครงการ (ภาษาไทย) กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้ป่วย
สูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

ชื่อผู้วิจัย นายศุภกร ศรีแผ้ว

สถานที่วิจัย โรงพยาบาลสงขลานครินทร์

ผู้ให้ทุน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ก่อนที่ท่านจะลงนามในหนังสือแสดงเจตนายินยอมร่วมวิจัย ท่านควรได้รับทราบว่

- โครงการนี้เป็นโครงการวิจัย ไม่ใช่ การรักษาตามปกติ
- การเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจ ท่านสามารถตัดสินใจได้อย่างอิสระว่าจะเข้าร่วมหรือไม่
เข้าร่วมการวิจัยนี้ ท่านไม่จำเป็นต้องเข้าร่วมในโครงการวิจัยนี้ และสามารถถอนตัวออกจาก
โครงการได้ทุกเมื่อ โดยจะไม่มีผลกระทบต่อคุณภาพการบริการหรือการรักษาพยาบาลที่ท่านพึงได้รับ
ตามสิทธิ
- ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ ท่านสามารถซักถามข้อสงสัยเกี่ยวกับ
โครงการวิจัยได้ ซึ่งผู้วิจัยจะอธิบายเพิ่มเติมแก่ท่านและตอบข้อซักถามจนท่านเข้าใจ
- นักวิจัยขอความยินยอมต้องให้ ข้อมูลและเวลาที่เพียงพอ ในการตัดสินใจอย่างอิสระ ก่อนที่ท่านจะ
เข้าร่วมโครงการวิจัย ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษาหารือกับญาติพี่น้อง เพื่อน
สนิท แพทย์ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย

การวางแผนการดูแลล่วงหน้า เป็นอย่างไร

การวางแผนการดูแลล่วงหน้า เป็นกิจกรรมที่ผู้ป่วย ครอบครัว หรือทีมผู้ให้บริการสุขภาพเช่น
แพทย์และพยาบาล ปรึกษากันเพื่อวางแผนดูแลของผู้ป่วยเอาไว้ ก่อนที่ผู้ป่วยจะไม่สามารถตัดสินใจด้วย
ตนเองได้ เช่น ผู้ป่วยหนักอาจไม่สามารถสื่อสารให้ผู้อื่นรู้สิ่งที่ต้องการได้ ซึ่งผู้ป่วยสามารถวางแผนนี้ด้วย
ตนเอง แจ้งให้ทราบกันในครอบครัว หรือปรึกษาแพทย์หรือพยาบาลก็ได้ ผู้สูงอายุที่เจ็บป่วยอาจมีสุขภาพ



คณะกรรมการจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

3 1 ค.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 1

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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		หน้า 2 จาก 7 หน้า

แย่งได้ง่ายกว่าวัยทำงานหรือวัยหนุ่มสาว แผนการดูแลตนเองล่วงหน้าจึงเป็นสิ่งที่ผู้สูงอายุ ครอบครัวและทีมผู้รักษาจะสื่อสารเพื่อให้สามารถให้การดูแลในอนาคตได้ตามที่ผู้ป่วยได้ตั้งใจไว้ หากแต่แพทย์บางคนพบว่า การเริ่มสนทนาเกี่ยวกับการวางแผนการดูแลล่วงหน้าไม่สามารถทำได้สำเร็จ กับผู้ป่วยทุกคนและในทุกโอกาส เนื่องจากผู้ป่วยมีระดับความพร้อมที่แตกต่างกัน และครอบครัวมีส่วนสำคัญในการวางแผนดูแลล่วงหน้า ผู้วิจัยจึงต้องการศึกษาว่ากลไกในครอบครัวส่งผลอย่างไรต่อความพร้อมในการวางแผนการดูแลล่วงหน้าของผู้ป่วยและครอบครัวไทย ซึ่งข้อมูลจากการศึกษานี้จะทำให้แพทย์เข้าใจกลไกของครอบครัวต่อความพร้อมของผู้ป่วยและสามารถดูแลผู้ป่วยและครอบครัวได้ดีขึ้น

เหตุใดท่านจึงได้รับเชิญให้เข้าร่วมโครงการวิจัยนี้

ท่านได้รับเชิญให้เข้าร่วมการวิจัย โปรดใช้เวลาในการอ่านเอกสารฉบับนี้ ซึ่งจะช่วยให้ท่านรับทราบ สิ่งต่าง ๆ ที่ท่านจะมีส่วนร่วมในการวิจัยนี้ การตัดสินใจเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจของท่าน หากท่านไม่สมัครใจเข้าร่วมการวิจัย จะไม่มีผลใด ๆ ต่อการดูแลรักษาหรือสิทธิที่ท่านพึงมี

การวิจัยนี้จะคัดเลือก ผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไปที่กำลังรับการรักษาอยู่ ณ คลินิกรังสีรักษา และฟิสิกส์อยู่ ณ ที่พักผู้ป่วยและญาติโรงพยาบาลสงขลานครินทร์ และผู้ดูแลหลักของผู้ป่วยที่มีอายุ 18 ปี ขึ้นไป เข้าร่วมการวิจัย

ระยะเวลาที่จะทำการวิจัยทั้งสิ้นของโครงการนี้ 2 ปี จะมีผู้ป่วยเข้าร่วมการวิจัยนี้ทั้งสิ้น 550 คน และผู้ดูแล 550 คน

ข้อมูลที่ได้จากการทำวิจัยจะนำไปทำอะไร

โครงการนี้ทำขึ้นเพื่อศึกษาความพร้อมในการวางแผนการดูแลล่วงหน้า และค้นหาปัจจัยของ ครอบครัวที่ส่งผลต่อความพร้อมในการวางแผนดูแลล่วงหน้าของผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไป ข้อมูลนี้ จะสามารถใช้ในการประเมินและเตรียมความพร้อมของผู้ป่วยและครอบครัวในการวางแผนการดูแลล่วงหน้าต่อไป

ขั้นตอนการปฏิบัติเมื่อท่านเข้าร่วมโครงการ

ถ้าท่านสมัครใจเข้าร่วมโครงการวิจัยและลงนามในเอกสารยินยอมแล้ว ผู้วิจัยจะขอให้ท่านให้ สัมภาษณ์เป็นเวลาประมาณ 10-15 นาที ผู้วิจัยจะขอให้ท่านให้สัมภาษณ์ในพื้นที่แยกกับผู้ดูแลหรือ ครอบครัวของท่านเพื่อให้ท่านสามารถให้ความเห็นได้อย่างอิสระ ทั้งนี้สถานที่สัมภาษณ์จะอยู่ในบริเวณถัด



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 2

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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จากสถานที่ที่ครอบครัวหรือผู้ดูแลของท่านเพียงเล็กน้อย ระหว่างการสัมภาษณ์ผู้วิจัยจะบันทึกข้อมูลที่ท่านตอบลงในแบบฟอร์มในมือถือ

ประโยชน์ที่ท่านอาจจะได้รับจากการเข้าร่วม

ท่านจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมวิจัยนี้ แต่องค์ความรู้ที่ได้จะถูกนำไปพัฒนาระบบการสื่อสารเพื่อวางแผนการดูแลล่วงหน้าในภาพรวมต่อไป
ความเสี่ยงและความไม่สะดวกสบายที่อาจเกิดจากการเข้าร่วมโครงการ และวิธีการป้องกัน/แก้ไขที่ผู้วิจัยเตรียมไว้หากมีเหตุการณ์ดังกล่าวเกิดขึ้น

คำถามบางข้อเป็นการถามความคิดเห็นของท่านเกี่ยวกับสุขภาพที่ผ่านมา ในปัจจุบันและในอนาคต หากท่านรู้สึกไม่สบายระหว่างการสัมภาษณ์ รู้สึกลำบากใจระหว่างการสัมภาษณ์หรือต้องการให้ติดต่อผู้ดูแลหรือครอบครัวของท่าน สามารถแจ้งผู้สัมภาษณ์เพื่อช่วยติดต่อผู้ดูแลของท่านได้ หรือขอไม่ตอบข้อใดข้อหนึ่ง รวมถึงสามารถหยุดให้สัมภาษณ์ได้ทุกเมื่อ ทั้งนี้กระบวนการสัมภาษณ์ถูกออกแบบให้มีความค่อยเป็นค่อยไป และผู้สัมภาษณ์ที่มีความเชี่ยวชาญในการสัมภาษณ์และสามารถสังเกตอาการ ให้คำแนะนำและดูแลท่านเบื้องต้นได้

ข้อมูลส่วนตัวของท่านจะถูกเก็บไว้อย่างไร และจะมีใครนำไปใช้หรือไม่

นักวิจัยจะบันทึกข้อมูลการตอบคำถามของท่านลงในรูปแบบอิเล็กทรอนิกส์ในคอมพิวเตอร์ของโครงการวิจัยซึ่งต้องใช้รหัสผ่านในการเข้าถึงข้อมูล มีเพียงผู้วิจัยหลักเท่านั้นที่เข้าถึงได้ และจะเก็บข้อมูลของท่านไว้เป็นเวลา 5 ปี หลังจากการวิจัยเสร็จสิ้น หลังจากนั้นจะทำการลบข้อมูลของท่านออกจากฐานข้อมูลของผู้วิจัย

นักวิจัยจะขอเลขประจำตัวผู้ป่วยของท่านเพื่อนำไปตรวจสอบความถูกต้องของข้อมูล เพศ วันเดือนปีเกิด กับข้อมูลในฐานข้อมูลของโรงพยาบาลสงขลานครินทร์ ร่วมกับนำข้อมูลในฐานข้อมูล ได้แก่ ภูมิฐานะของท่าน โรคที่ท่านเคยได้รับการรักษาและจำนวนครั้งที่ท่านเคยมาโรงพยาบาล มารวมกับข้อมูลที่ได้จากแบบสอบถามเพื่อการวิเคราะห์ข้อมูลด้วย

ข้อมูลของท่านที่เกี่ยวข้องกับการวิจัยนี้จะถูกเก็บเป็นความลับตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากลและพระราชบัญญัติคุ้มครองข้อมูลส่วนบุคคล พ.ศ. 2562 การเผยแพร่ผลการวิจัยในการประชุมวิชาการหรือในวารสารวิชาการจะไม่มีข้อมูลที่ระบุตัวตนหรือเชื่อมโยงถึงตัวตนได้ หากข้อมูลบางส่วนจะมีการนำไปลงในระบบฐานข้อมูลที่วารสารวิชาการกำหนด เพื่อแบ่งปันให้นักวิจัยอื่นได้ทราบ ข้อมูลเหล่านี้จะอยู่ในรูปแบบที่ไม่สามารถระบุตัวตนหรือเชื่อมโยงถึงตัวตนได้ อย่างไรก็ตาม อาจมีบุคคล



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 3

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 3.0, Date 14/12/2022	หน้า 4 จาก 7 หน้า

บางกลุ่มที่ขอเข้าดูข้อมูลส่วนบุคคลของท่านได้ ได้แก่ คณะกรรมการจริยธรรมการวิจัยในคน ผู้ประสานงานวิจัย ผู้กำกับดูแลการวิจัย และเจ้าหน้าที่จากสถาบันหรือองค์กรของรัฐที่มีหน้าที่ตรวจสอบ เพื่อตรวจสอบความถูกต้องของข้อมูลและขั้นตอนการวิจัย

ท่านมีสิทธิถอนตัวจากโครงการหรือไม่ และต้องทำอะไร

ท่านสามารถขอหยุดการสัมภาษณ์ได้ทุกเมื่อ โดยแจ้งกับนักวิจัยผู้สัมภาษณ์ การหยุดหรือถอนตัวจะไม่ส่งผลต่อการดูแลที่ท่านได้รับอยู่

หากท่านขอยกเลิกการให้สัมภาษณ์หลังจากที่ท่านได้เข้าร่วมโครงการวิจัยแล้ว ข้อมูลส่วนตัวของท่านจะไม่ถูกบันทึกเพิ่มเติม อย่างไรก็ตามข้อมูลอื่นๆของท่านอาจถูกนำไปใช้เพื่อประเมินผลการวิจัย

ท่านต้องเสียค่าใช้จ่ายในการเข้าร่วมโครงการวิจัยหรือไม่ และอย่างไร

โครงการนี้ไม่มีค่าใช้จ่าย โดยท่านจะได้รับเงินชดเชยเพื่อเป็นค่าเสียเวลาในการสัมภาษณ์ จำนวน 100 บาท

หากท่านไม่เข้าร่วมโครงการวิจัยนี้ ท่านมีทางเลือกอื่นอย่างไรบ้าง

ท่านไม่จำเป็นต้องเข้าร่วมโครงการนี้หากท่านไม่ต้องการ โดยจะไม่มีผลต่อการได้รับการตามมาตรฐานที่ท่านจะได้รับ

หากท่านได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัยหรือมีข้อสงสัยเกี่ยวกับสิทธิของท่าน สามารถขอรับคำปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะแพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com เพื่อให้มั่นใจว่าสิทธิ ความเป็นส่วนตัว และความเป็นอยู่ที่ดีของท่าน ได้รับความคุ้มครองตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากล

อาสาสมัครโปรดให้ความสำคัญ - ท่านจะได้รับเอกสารชี้แจงและหนังสือแสดงเจตนายินยอมที่มีข้อความเดียวกันกับที่นักวิจัยเก็บไว้ 1 ชุด ท่านควรเก็บไว้กับตัวเพื่อเป็นหลักฐานและอ่านเมื่อมีข้อสงสัย - ส่วนท้ายหนังสือแสดงเจตนายินยอมเข้าร่วมโครงการ จะต้องมี 1) ลายมือชื่อของท่าน 2) ลายมือชื่อนักวิจัยที่ให้คำอธิบายเกี่ยวกับโครงการ และ 3) วันที่ที่ลงนาม ซึ่งท่านต้องเป็นผู้ลงวันที่ด้วยตนเอง
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คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์ 31 ส.ค. 2565
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 4

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1 Version 3.0, Date 14/12/2022	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 5 จาก 7 หน้า

หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย (Informed Consent Form)

วันที่.....เดือน.....พ.ศ.

ข้าพเจ้า (นาย /นาง /นางสาว).....นามสกุล.....
 อายุ.....ปี อยู่บ้านเลขที่.....หมู่.....ตำบล.....อำเภอ.....
 จังหวัด.....

ขอแสดงเจตนายินยอมเข้าร่วมการวิจัย ในโครงการวิจัยเรื่อง กลไกของครอบครัวกับความพร้อมใน
การวางแผนการดูแลส่งผ่านในผู้ป่วยสูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

โดยข้าพเจ้าได้อ่านเอกสารคำอธิบายโครงการวิจัย และ /หรือ ได้รับฟังคำอธิบายจาก..... และได้รับทราบถึงรายละเอียดของโครงการวิจัยเกี่ยวกับวัตถุประสงค์และระยะเวลา
 ที่ทำการวิจัย ขั้นตอน และวิธีการปฏิบัติที่ข้าพเจ้าต้องปฏิบัติ ผลประโยชน์ที่ข้าพเจ้าจะได้รับ ผลข้างเคียง
 เช่น รู้สึกไม่สบายใจ ที่อาจเกิดขึ้นจากการเข้าร่วมโครงการ ตลอดจนค่าตอบแทนที่จะได้รับ และค่าใช้จ่ายที่
 ข้าพเจ้าจะต้องรับผิดชอบจ่ายเอง และได้มีโอกาสซักถามและได้รับคำตอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลา
 เพียงพอในการอ่านและทำความเข้าใจข้อมูลในเอกสารให้ข้อมูลสำหรับผู้เข้าร่วมการวิจัยอย่างถี่ถ้วน และ
 ได้รับเวลาเพียงพอในการตัดสินใจว่าจะเข้าร่วมการวิจัยนี้

และข้าพเจ้ายินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย โดยให้นำเสนอเป็น
 ข้อมูลโดยรวมจากการวิจัยนั้นแต่จะไม่เผยแพร่ ต่อสาธารณะเป็นรายบุคคล ทั้งนี้ข้าพเจ้า สามารถถอนตัว
 หรืองดเข้าร่วมการวิจัยได้ทุกเมื่อ โดยจะไม่มีผลกระทบและไม่เสียสิทธิใด ๆ ในการรับบริการและการ
 รักษาพยาบาลที่ข้าพเจ้า จะได้รับต่อไปในอนาคต



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ส.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 5

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารแจ้งผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 3.0, Date 14/12/2022	หน้า 6 จาก 7 หน้า

หากข้าพเจ้ามี ข้อข้องใจเกี่ยวกับขั้นตอนของการวิจัยหรือเกิดผลข้างเคียงที่ไม่พึงประสงค์จาก การวิจัยกับตัวข้าพเจ้า ข้าพเจ้าสามารถติดต่อกับ นายแพทย์ศุภกร ศรีแผ้ว ได้ที่ **สาขาวิชาเวชศาสตร์ ครอบครัวและเวชศาสตร์ป้องกัน** โทรศัพท์ 0-7445-1331-4 และ **0652377732** ได้ตลอด 24 ชั่วโมง

หากได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารแจ้งผู้เข้าร่วมการวิจัย ข้าพเจ้าสามารถขอรับ ค่าปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะ แพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือทางจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com

ข้าพเจ้า เข้าใจข้อความในเอกสารแจ้งผู้เข้าร่วมการวิจัย และหนังสือแสดงเจตนายินยอมนี้โดย ตลอดแล้ว จึงได้ลงนามยินยอมเข้าร่วมโครงการ

ลายมือชื่อผู้เข้าร่วมโครงการวิจัย

.....

(.....)

วันที่.....เดือน.....พ.ศ.....

ลายมือชื่อผู้อธิบาย/ ผู้ขอความยินยอม

.....

(.....)

วันที่.....เดือน.....พ.ศ.....



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 6

เอกสารแจ้งผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

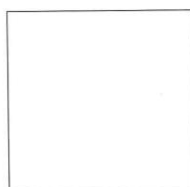
	เอกสารแจ้งผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1 Version 3.0, Date 14/12/2022	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 7 จาก 7 หน้า

กรณีอาสาสมัครผู้เข้าร่วมวิจัย ไม่สามารถอ่านหนังสือได้ ผู้ที่อ่านข้อความทั้งหมดแทนอาสาสมัครผู้เข้าร่วมวิจัย คือจึงได้ลงลายมือชื่อไว้ในฐานะพยาน ว่า
อาสาสมัครเข้าใจเกี่ยวกับโครงการ

ลงชื่อ	วันที่.....
(.....)	(วว/ดด/ปปปป)

พยาน (ผู้อ่านข้อความให้อาสาสมัครฟัง)

ข้าพเจ้าไม่สามารถอ่าน เขียนหนังสือได้ แต่มีผู้อ่านข้อความในแบบคำยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี
ข้าพเจ้าจึงพิมพ์ลายนิ้วหัวแม่มือขวาของข้าพเจ้าในแบบคำยินยอมนี้ด้วยความเต็มใจ



พิมพ์ลายนิ้วหัวแม่มือขวา ของ นาย/นาง/นางสาว.....(อาสาสมัครผู้ร่วมวิจัย)

ลงชื่อ วันที่.....
(.....) (วว/ดด/ปปปป)
พยานคนที่ 1

ลงชื่อ วันที่.....
(.....) (วว/ดด/ปปปป)
พยานคนที่ 2



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 7

เอกสารแจ้งผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

Appendix 2. Information sheet for phase 1 (caregivers)

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1 Version 3.0, Date 14/12/2022	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 1 จาก 7 หน้า

เอกสารชี้แจงผู้เข้าร่วมการวิจัย (สำหรับผู้ดูแลผู้ป่วย) (เพื่อประกอบการตัดสินใจ)

ชื่อโครงการ (ภาษาไทย) กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้ป่วย
สูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

ชื่อผู้วิจัย นายศุภกร ศรีแผ้ว

สถานที่วิจัย โรงพยาบาลสงขลานครินทร์

ผู้ให้ทุน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ก่อนที่ท่านจะลงนามในหนังสือแสดงเจตนายินยอมร่วมวิจัย ท่านควรได้รับทราบว่า

โครงการนี้เป็นโครงการวิจัย ไม่ใช่ การรักษาตามปกติ

การเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจ ท่านสามารถตัดสินใจได้อย่างอิสระว่าจะเข้าร่วมหรือไม่เข้าร่วมการวิจัยนี้ ท่านไม่จำเป็นต้องเข้าร่วมในโครงการวิจัยนี้ และสามารถถอนตัวออกจากโครงการได้ทุกเมื่อ โดยจะไม่มีผลกระทบต่อคุณภาพการบริการหรือการรักษาพยาบาลที่ท่านพึงได้รับตามสิทธิ

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ ท่านสามารถซักถามข้อสงสัยเกี่ยวกับโครงการวิจัยได้ ซึ่งผู้วิจัยจะอธิบายเพิ่มเติมแก่ท่านและตอบข้อซักถามจนท่านเข้าใจ

นักวิจัยขอความยินยอมต้องให้ ข้อมูลและเวลาที่เพียงพอ ในการตัดสินใจอย่างอิสระ ก่อนที่ท่านจะเข้าร่วมโครงการวิจัย ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษาหารือกับญาติพี่น้อง เพื่อนสนิท หรือแพทย์ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย

การวางแผนการดูแลล่วงหน้า เป็นอย่างไร

การวางแผนการดูแลล่วงหน้า เป็นกิจกรรมที่ผู้ป่วย ครอบครัว หรือทีมผู้ให้บริการสุขภาพเช่น แพทย์และพยาบาล ปรึกษากันเพื่อวางแผนดูแลของผู้ป่วยเอาไว้ ก่อนที่ผู้ป่วยจะไม่สามารถตัดสินใจด้วยตนเองได้ เช่น ผู้ป่วยหนักอาจไม่สามารถสื่อสารให้ผู้อื่นรู้สิ่งที่ต้องการได้ ซึ่งผู้ป่วยสามารถวางแผนนี้ด้วยตนเอง แจ้งให้ทราบกันในครอบครัว หรือปรึกษาแพทย์หรือพยาบาลก็ได้ ผู้สูงอายุที่เจ็บป่วยอาจมีสุขภาพแย่ลงได้ง่ายกว่าวัยทำงานหรือวัยหนุ่มสาว แผนการดูแลตนเองล่วงหน้าจึงเป็นสิ่งหนึ่งที่ผู้สูงอายุ ครอบครัวและทีมผู้รักษาจะสื่อสารการเพื่อให้สามารถให้การดูแลในอนาคตได้ตามที่ผู้ป่วยได้ตั้งใจไว้



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 1

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 3.0, Date 14/12/2022	หน้า 2 จาก 7 หน้า

หากแต่แพทย์บางคนพบว่าการเริ่มสนทนาเกี่ยวกับการวางแผนการดูแลล่วงหน้าไม่สามารถทำได้สำเร็จกับผู้ป่วยทุกคนและในทุกโอกาส เนื่องจากผู้ป่วยมีระดับความพร้อมที่แตกต่างกัน และครอบครัวมีส่วนสำคัญในการวางแผนดูแลล่วงหน้า ผู้วิจัยจึงต้องการศึกษาว่ากลไกในครอบครัวส่งผลอย่างไรต่อความพร้อมในการวางแผนการดูแลล่วงหน้าของผู้ป่วยและครอบครัวไทย ซึ่งข้อมูลจากการศึกษานี้จะทำให้แพทย์เข้าใจกลไกของครอบครัวต่อความพร้อมของผู้ป่วยและสามารถดูแลผู้ป่วยและครอบครัวได้ดีขึ้น

เหตุใดท่านจึงได้รับเชิญให้เข้าร่วมโครงการวิจัยนี้

ท่านได้รับเชิญให้เข้าร่วมการวิจัย โปรดใช้เวลาในการอ่านเอกสารฉบับนี้ ซึ่งจะช่วยให้ท่านรับทราบสิ่งต่าง ๆ ที่ท่านจะมีส่วนร่วมในการวิจัยนี้ การตัดสินใจเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจของท่าน หากท่านไม่สมัครใจเข้าร่วมการวิจัย จะไม่มีผลใด ๆ ต่อการดูแลรักษาหรือสิทธิที่ท่านพึงมี

การวิจัยนี้จะคัดเลือก ผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไปที่กำลังรับการรักษาอยู่ ณ คลินิกรังสีรักษาและฟิสิกส์อยู่ ณ ที่พักผู้ป่วยและญาติโรงพยาบาลสงขลานครินทร์ และผู้ดูแลหลักของผู้ป่วยที่มีอายุ 18 ปีขึ้นไป เข้าร่วมการวิจัย

ระยะเวลาที่จะทำการวิจัยทั้งสิ้นของโครงการนี้ 2 ปี จะมีผู้ป่วยเข้าร่วมการวิจัยนี้ทั้งสิ้น 550 คน และผู้ดูแล 550 คน

ข้อมูลที่ได้จากการทำวิจัยจะนำไปทำอะไร

โครงการนี้ทำขึ้นเพื่อศึกษาความพร้อมในการวางแผนการดูแลล่วงหน้า และค้นหาปัจจัยของครอบครัวที่ส่งผลต่อความพร้อมในการวางแผนดูแลล่วงหน้าของผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไป ข้อมูลนี้จะสามารถใช้ในการประเมินและเตรียมความพร้อมของผู้ป่วยและครอบครัวในการวางแผนการดูแลล่วงหน้าต่อไป

ขั้นตอนการปฏิบัติเมื่อท่านเข้าร่วมโครงการ

ถ้าท่านสมัครใจเข้าร่วมโครงการวิจัยและลงนามในเอกสารยินยอมแล้ว ผู้วิจัยจะขอให้ท่านตอบแบบสอบถามด้วยตนเองประมาณ 30 นาที



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 2

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: REC. 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
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ประโยชน์ที่ท่านอาจได้รับจากการเข้าร่วม

ท่านจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมวิจัยนี้ แต่องค์ความรู้ที่ได้จะถูกนำไปพัฒนากระบวนการสื่อสารเพื่อวางแผนการดูแลล่วงหน้าในภาพรวม

ความเสี่ยงและความไม่สะดวกสบายที่อาจเกิดจากการเข้าร่วมโครงการ และวิธีการป้องกัน/แก้ไขที่ผู้วิจัยเตรียมไว้หากมีเหตุการณ์ดังกล่าวเกิดขึ้น

คำถามบางข้อเป็นการถามความคิดเห็นของท่านเกี่ยวกับผู้ป่วยที่ท่านกำลังดูแลในด้านสุขภาพที่ผ่านมา ในปัจจุบันและในอนาคต หากท่านรู้สึกลำบากใจระหว่างการตอบแบบสอบถาม สามารถข้ามหรือไม่ตอบข้อใดข้อหนึ่งได้ รวมถึงหยุดตอบแบบสอบถามได้ทุกเมื่อ

ข้อมูลส่วนตัวของท่านจะถูกเก็บไว้อย่างไร และจะมีใครนำไปใช้หรือไม่

นักวิจัยจะนำข้อมูลที่ท่านตอบกรอกลงในแบบบันทึกข้อมูลอิเล็กทรอนิกส์ในคอมพิวเตอร์ของโครงการวิจัยซึ่งต้องใช้รหัสผ่านในการเข้าถึงข้อมูล มีเพียงผู้วิจัยหลักเท่านั้นที่เข้าถึงได้ และจะเก็บข้อมูลของท่านไว้เป็นเวลา 5 ปี หลังจากการวิจัยเสร็จสิ้น หลังจากนั้นจะทำการลบข้อมูลของท่านออกจากรฐานข้อมูลของผู้วิจัย

ข้อมูลของท่านที่เกี่ยวข้องกับการวิจัยนี้จะถูกเก็บเป็นความลับตามมาตราฐานจริยธรรมการวิจัยในคนระดับสากลและพระราชบัญญัติคุ้มครองข้อมูลส่วนบุคคล พ.ศ. 2562 การเผยแพร่ผลการวิจัยในการประชุมวิชาการหรือในวารสารวิชาการจะไม่มีข้อมูลที่จะระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ หากข้อมูลบางส่วนจะมีการนำไปลงในระบบฐานข้อมูลที่วารสารวิชาการกำหนด เพื่อแบ่งปันให้นักวิจัยอื่นได้ทราบ ข้อมูลเหล่านี้จะอยู่ในรูปแบบที่ไม่สามารถระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ อย่างไรก็ตาม อาจมีบุคคลบางกลุ่มที่ขอเข้าถึงข้อมูลส่วนบุคคลของท่านได้ ได้แก่ คณะกรรมการจริยธรรมการวิจัยในคน ผู้ประสานงานวิจัย ผู้กำกับดูแลการวิจัย และเจ้าหน้าที่จากสถาบันหรือองค์กรของรัฐที่มีหน้าที่ตรวจสอบ เพื่อตรวจสอบความถูกต้องของข้อมูลและขั้นตอนการวิจัย

ท่านมีสิทธิถอนตัวจากโครงการหรือไม่ และต้องทำอะไร

ท่านสามารถขอหยุดการทำแบบสอบถามได้ทุกเมื่อ โดยแจ้งกับนักวิจัยผู้สัมภาษณ์ การหยุดหรือถอนตัวจะไม่ส่งผลต่อการดูแลที่ท่านได้รับอยู่



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 3

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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		หน้า 4 จาก 7 หน้า

หากท่านขอหยุดการตอบแบบสอบถามหลังจากที่ท่านได้เข้าร่วมโครงการวิจัยแล้ว ข้อมูลส่วนตัวของท่านจะไม่ถูกบันทึกเพิ่มเติม อย่างไรก็ตามข้อมูลอื่น ๆ ของท่านอาจถูกนำไปเพื่อประเมินผลการวิจัย

ท่านต้องเสียค่าใช้จ่ายในการเข้าร่วมโครงการวิจัยหรือไม่ และอย่างไร

โครงการนี้ไม่มีค่าใช้จ่าย โดยท่านจะได้รับเงินชดเชยเพื่อเป็นค่าเสียเวลาในการตอบแบบสอบถามจำนวน 100 บาท

หากท่านไม่เข้าร่วมโครงการวิจัยนี้ ท่านมีทางเลือกอื่นอย่างไรบ้าง

ท่านไม่จำเป็นต้องเข้าร่วมโครงการนี้หากท่านไม่ต้องการ โดยจะไม่มีผลต่อการได้รับการบริการตามมาตรฐานที่ท่านจะได้รับ

หากท่านได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัยหรือมีข้อสงสัยเกี่ยวกับสิทธิของท่าน สามารถขอรับคำปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะแพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com เพื่อให้มั่นใจว่าสิทธิ ความเป็นส่วนตัว และความเป็นอยู่ที่ดีของท่าน ได้รับความคุ้มครองตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากล

อาสาสมัครโปรดให้ความสำคัญ

ท่านจะได้รับเอกสารชี้แจงและหนังสือแสดงเจตนายินยอมที่มีข้อความเดียวกันกับที่นักวิจัยเก็บไว้ 1 ชุด ท่านควรเก็บไว้กับตัวเพื่อเป็นหลักฐานและอ่านเมื่อมีข้อสงสัย

ส่วนท้ายหนังสือแสดงเจตนายินยอมเข้าร่วมโครงการ จะต้อง มี 1) ลายมือชื่อของท่าน 2) ลายมือชื่อนักวิจัยที่ให้อธิบายเกี่ยวกับโครงการ และ 3) วันที่ที่ลงนาม ซึ่งท่านต้องเป็นผู้ลงวันที่ด้วยตนเอง



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
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31 ธ.ค. 2565

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หน้า 4

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

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		หน้า 5 จาก 7 หน้า

**หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย
(Informed Consent Form)**

วันที่.....เดือน.....พ.ศ.

ข้าพเจ้า (นาย /นาง /นางสาว).....นามสกุล.....
อายุ.....ปี อยู่บ้านเลขที่.....หมู่.....ตำบล.....อำเภอ.....
.....จังหวัด.....

ขอแสดงเจตนายินยอมเข้าร่วมการวิจัย ในโครงการวิจัยเรื่อง *กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้ป่วยสูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย*

โดยข้าพเจ้าได้อ่านเอกสารคำอธิบายโครงการวิจัยและ /หรือได้รับฟังคำอธิบายจาก..... และได้รับทราบถึงรายละเอียดของโครงการวิจัยเกี่ยวกับวัตถุประสงค์และระยะเวลาที่ทำการวิจัย ขั้นตอน และวิธีการปฏิบัติตัวที่ข้าพเจ้าต้องปฏิบัติ ผลประโยชน์ที่ข้าพเจ้าจะได้รับ ผลข้างเคียง เช่น รู้สึกไม่สบายใจ ที่อาจเกิดขึ้นจากการเข้าร่วมโครงการ ตลอดจนค่าตอบแทนที่จะได้รับ และค่าใช้จ่ายที่ข้าพเจ้าจะต้องรับผิดชอบจ่ายเอง และได้มีโอกาสซักถามและได้รับคำตอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลาเพียงพอในการอ่านและทำความเข้าใจข้อมูลในเอกสารให้ข้อมูลสำหรับผู้เข้าร่วมการวิจัยอย่างถี่ถ้วน และได้รับเวลาเพียงพอในการตัดสินใจว่าจะเข้าร่วมการวิจัยนี้

และข้าพเจ้ายินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย โดยให้นำเสนอเป็นข้อมูลโดยรวมจากการวิจัยนั้นแต่จะไม่เผยแพร่ ต่อสาธารณะเป็นรายบุคคล ทั้งนี้ข้าพเจ้า สามารถถอนตัวหรืองดเข้าร่วมการวิจัยได้ทุกเมื่อ โดยจะไม่มีผลกระทบและไม่เสียสิทธิใด ๆ ในการรับบริการและการรักษาพยาบาลที่ข้าพเจ้า จะได้รับต่อไปในอนาคต



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31 ธ.ค. 2565

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หน้า 5

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

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หากข้าพเจ้ามี ข้อข้องใจเกี่ยวกับขั้นตอนของการวิจัยหรือเกิดผลข้างเคียงที่ไม่พึงประสงค์จาก
การวิจัยกับตัวข้าพเจ้า ข้าพเจ้าสามารถติดต่อกับ นายแพทย์ศุภกร ศรีแผ้ว ได้ที่ **สาขาวิชาเวชศาสตร์
ครอบครัวและเวชศาสตร์ป้องกัน** โทรศัพท์ 0-7445-1331-4 และ **0652377732** ได้ตลอด 24 ชั่วโมง

หากได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารแจ้งผู้เข้าร่วมการวิจัย ข้าพเจ้าสามารถขอรับ
คำปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่สำนักงานคณะกรรมการพิจารณาจริยธรรมการวิจัย คณะ
แพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือทางจดหมายอิเล็กทรอนิกส์
medpsu.ec@gmail.com

ข้าพเจ้า เข้าใจข้อความในเอกสารแจ้งผู้เข้าร่วมการวิจัย และหนังสือแสดงเจตนายินยอมนี้โดย
ตลอดแล้ว จึงได้ลงนามยินยอมเข้าร่วมโครงการ

ลายมือชื่อผู้เข้าร่วมโครงการวิจัย

.....

(.....)

วันที่.....เดือน.....พ.ศ.....

ลายมือชื่อผู้อธิบาย/ ผู้ขอความยินยอม

.....

(.....)

วันที่.....เดือน.....พ.ศ.....



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คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

31 ธ.ค. 2565

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หน้า 6

เอกสารแจ้งผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

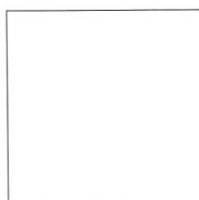
	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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		หน้า 7 จาก 7 หน้า

กรณีอาสาสมัครผู้เข้าร่วมวิจัย ไม่สามารถอ่านหนังสือได้ ผู้ที่อ่านข้อความทั้งหมดแทนอาสาสมัครผู้เข้าร่วมวิจัย คือจึงได้ลงลายมือชื่อไว้ในฐานะพยาน ว่า
อาสาสมัครเข้าใจเกี่ยวกับโครงการ

ลงชื่อ	วันที่.....
(.....)	(ว/ด/ป/ปปป)

พยาน (ผู้อ่านข้อความให้อาสาสมัครฟัง)

ข้าพเจ้าไม่สามารถอ่าน เขียนหนังสือได้ แต่มีผู้อ่านข้อความในแบบคำยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี
ข้าพเจ้าจึงพิมพ์ลายนิ้วหัวแม่มือขวาของข้าพเจ้าในแบบคำยินยอมนี้ด้วยความเต็มใจ



พิมพ์ลายนิ้วหัวแม่มือขวา ของ นาย/นาง/นางสาว.....(อาสาสมัครผู้ร่วมวิจัย)

ลงชื่อ วันที่.....
(.....) (ว/ด/ป/ปปป)

พยานคนที่ 1

ลงชื่อ วันที่.....
(.....) (ว/ด/ป/ปปป)

พยานคนที่ 2



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
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หน้า 7

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 3 วันที่ 14 ธันวาคม 2565

Appendix 3. Information sheet for phase 2 (elderly)

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 6.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 1 จาก 8 หน้า

เอกสารชี้แจงผู้เข้าร่วมการวิจัย (สำหรับผู้ป่วย)

(เพื่อประกอบการตัดสินใจ)

ชื่อโครงการ (ภาษาไทย) กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้ป่วย

สูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

ชื่อผู้วิจัย นายแพทย์ศุภกร ศรีแล้ว

สถานที่วิจัย โรงพยาบาลสงขลานครินทร์

ผู้ให้ทุน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ก่อนที่ท่านจะลงนามในหนังสือแสดงเจตนายินยอมร่วมวิจัย ท่านควรได้รับทราบว่

โครงการนี้เป็นโครงการวิจัย ไม่ใช่ การรักษาตามปกติ

การเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจ ท่านสามารถตัดสินใจได้อย่างอิสระว่าจะเข้าร่วมหรือไม่เข้าร่วมการวิจัยนี้ ท่านไม่จำเป็นต้องเข้าร่วมในโครงการวิจัยนี้ การลงนามยินยอมเข้าร่วมวิจัยในเอกสารที่เกี่ยวข้องนี้เป็นเพียงเพื่อให้ผู้ตรวจสอบแน่ใจว่าท่านตัดสินใจตอบคำถามของผู้วิจัย ไม่ได้เป็นสัญญาหรือข้อผูกมัดทางกฎหมาย และสามารถถอนตัวออกจากโครงการได้ทุกเมื่อ โดยจะไม่มีผลกระทบต่อคุณภาพการบริการหรือการรักษาพยาบาลที่ท่านพึงได้รับตามสิทธิ

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ ท่านสามารถซักถามข้อสงสัยเกี่ยวกับโครงการวิจัยได้ ซึ่งผู้วิจัยจะอธิบายเพิ่มเติมแก่ท่านและตอบข้อซักถามจนท่านเข้าใจ

นักวิจัยขอความยินยอมต้องให้ ข้อมูลและเวลาที่เพียงพอ ในการตัดสินใจอย่างอิสระ ก่อนที่ท่านจะเข้าร่วมโครงการวิจัย ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษากับญาติพี่น้อง เพื่อนสนิท แพทย์ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 ธ.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 1

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 6.0, Date 26/12/2023	หน้า 2 จาก 8 หน้า

การวางแผนการดูแลล่วงหน้า เป็นอย่างไร

การวางแผนการดูแลล่วงหน้า เป็นกิจกรรมที่ผู้ป่วย ครอบครัว หรือทีมผู้ให้บริการสุขภาพเช่น แพทย์และพยาบาลปรึกษากันเพื่อวางแผนดูแลของผู้ป่วยเอาไว้ ก่อนที่ผู้ป่วยจะไม่สามารถตัดสินใจด้วยตนเองได้ เช่น ผู้ป่วยหนักอาจไม่สามารถสื่อสารให้ผู้อื่นรู้สิ่งที่ต้องการได้ ซึ่งผู้ป่วยสามารถวางแผนนี้ด้วยตนเอง แจ้งให้ทราบกันในครอบครัว หรือปรึกษาแพทย์หรือพยาบาลก็ได้ ผู้สูงอายุที่เจ็บป่วยอาจมีสุขภาพแอลงได้ง่ายกว่าวัยทำงานหรือวัยหนุ่มสาว แผนการดูแลตนเองล่วงหน้าจึงเป็นสิ่งที่ผู้สูงอายุ ครอบครัวและทีมผู้รักษาจะสื่อสารการเพื่อให้สามารถให้การดูแลในอนาคตได้ตามที่ผู้ป่วยได้ตั้งใจไว้ หากแต่แพทย์บางคนพบว่าการเริ่มสนทนาเกี่ยวกับการวางแผนการดูแลล่วงหน้านี้ไม่สามารถทำได้สำเร็จกับผู้ป่วยทุกคนและในทุกโอกาส เนื่องจากผู้ป่วยมีระดับความพร้อมที่แตกต่างกัน และครอบครัวมีส่วนสำคัญในการวางแผนดูแลล่วงหน้า ผู้วิจัยจึงต้องการศึกษาว่ากลไกในครอบครัวส่งผลอย่างไรต่อความพร้อมในการวางแผนการดูแลล่วงหน้าของผู้ป่วยและครอบครัวไทย ซึ่งข้อมูลจากการศึกษานี้จะทำให้แพทย์เข้าใจกลไกของครอบครัวต่อความพร้อมของผู้ป่วยและสามารถดูแลผู้ป่วยและครอบครัวได้ดีขึ้น

เหตุใดท่านจึงได้รับเชิญให้เข้าร่วมโครงการวิจัยนี้

ท่านได้รับเชิญให้เข้าร่วมการวิจัย โปรดใช้เวลาในการอ่านเอกสารฉบับนี้ ซึ่งจะช่วยให้ท่านรับทราบสิ่งต่างๆ ที่ท่านจะมีส่วนร่วมในการวิจัยนี้ การตัดสินใจเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจของท่าน หากท่านไม่สมัครใจเข้าร่วมการวิจัย จะไม่มีผลใด ๆ ต่อการดูแลรักษาหรือสิทธิที่ท่านพึงมี

การวิจัยนี้จะคัดเลือก ผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไปที่กำลังรับการรักษาอยู่ ณ คลินิกรังสีรักษาและฟิสิกส์อยู่ ณ ที่พักผู้ป่วยและญาติโรงพยาบาลสงขลานครินทร์ และผู้ดูแลหลักของผู้ป่วยที่มีอายุ 18 ปีขึ้นไป เข้าร่วมการวิจัย

ระยะเวลาที่จะทำการวิจัยทั้งสิ้นของโครงการนี้ 2 ปี จะมีผู้ป่วยเข้าร่วมการวิจัยนี้ทั้งสิ้น 550 คน และผู้ดูแล 550 คน



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 10 ธ.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 2

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 6.0, Date 26/12/2023	หน้า 3 จาก 8 หน้า

ข้อมูลที่ได้จากการทำวิจัยจะนำไปทำอะไร

โครงการนี้ทำขึ้นเพื่อศึกษาความพร้อมในการวางแผนการดูแลล่วงหน้า และค้นหาปัจจัยของครอบครัวที่ส่งผลต่อความพร้อมในการวางแผนดูแลล่วงหน้าของผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไป ข้อมูลนี้สามารถใช้ในการประเมินและเตรียมความพร้อมของผู้ป่วยและครอบครัวในการวางแผนการดูแลล่วงหน้าต่อไป

ขั้นตอนการปฏิบัติเมื่อท่านเข้าร่วมโครงการ

ถ้าท่านสมัครใจเข้าร่วมโครงการวิจัยและลงนามในเอกสารยินยอมแล้ว ผู้วิจัยจะขอให้ท่านให้สัมภาษณ์เป็นเวลาประมาณ 10-15 นาที ผู้วิจัยจะขอให้ท่านให้สัมภาษณ์ในพื้นที่แยกกับผู้ดูแลหรือครอบครัวของท่านเพื่อให้ท่านสามารถให้ความเห็นได้อย่างอิสระ ทั้งนี้สถานที่สัมภาษณ์จะอยู่ในบริเวณถัดจากสถานที่ที่ครอบครัวหรือผู้ดูแลของท่านเพียงเล็กน้อย ระหว่างการสัมภาษณ์ผู้วิจัยจะบันทึกข้อมูลที่ท่านตอบลงในแบบฟอร์มในมือถือ

ประโยชน์ที่ท่านอาจจะได้รับจากการเข้าร่วม

ท่านจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมวิจัยนี้ แต่องค์ความรู้ที่ได้จะถูกนำไปพัฒนาระบบการสื่อสารเพื่อวางแผนการดูแลล่วงหน้าในภาพรวมต่อไป

ความเสี่ยงและความไม่สะดวกสบายที่อาจเกิดจากการเข้าร่วมโครงการ และวิธีการป้องกัน/แก้ไขที่ผู้วิจัยเตรียมไว้หากมีเหตุการณ์ดังกล่าวเกิดขึ้น

คำถามบางข้อเป็นการถามความคิดเห็นของท่านเกี่ยวกับสุขภาพที่ผ่านมา ในปัจจุบันและในอนาคต หากท่านรู้สึกไม่สบายระหว่างการสัมภาษณ์ รู้สึกลำบากใจระหว่างการสัมภาษณ์หรือต้องการให้ติดต่อผู้ดูแลหรือครอบครัวของท่าน สามารถแจ้งผู้สัมภาษณ์เพื่อช่วยติดต่อผู้ดูแลของท่านได้ หรือขอไม่ตอบข้อใดข้อหนึ่ง รวมถึงสามารถหยุดให้สัมภาษณ์ได้ทุกเมื่อ ทั้งนี้กระบวนการสัมภาษณ์ถูกออกแบบให้มีความค่อยเป็นค่อยไป และผู้สัมภาษณ์ที่มีความเชี่ยวชาญในการสัมภาษณ์และสามารถสังเกตอาการ ให้คำแนะนำและดูแลท่านเบื้องต้นได้

ข้อมูลส่วนตัวของท่านจะถูกเก็บไว้อย่างไร และจะมีใครนำไปใช้หรือไม่



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

13 JAN 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 3

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
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นักวิจัยจะบันทึกข้อมูลการตอบคำถามของท่านลงในรูปแบบอิเล็กทรอนิกส์ในคอมพิวเตอร์ของโครงการวิจัยซึ่งต้องใช้รหัสผ่านในการเข้าถึงข้อมูล มีเพียงผู้วิจัยหลักเท่านั้นที่เข้าถึงได้ และจะเก็บข้อมูลของท่านไว้เป็นเวลา 5 ปี หลังจากการวิจัยเสร็จสิ้น หลังจากนั้นจะทำการลบข้อมูลของท่านออกจากฐานข้อมูลของผู้วิจัย

นักวิจัยจะขอเลขประจำตัวผู้ป่วยของท่านเพื่อนำไปตรวจสอบความถูกต้องของข้อมูล เพศ วันเดือนปีเกิด กับข้อมูลในฐานข้อมูลของโรงพยาบาลสงขลานครินทร์ ร่วมกับนำข้อมูลในฐานข้อมูล ได้แก่ สิทธิการรักษา ภูมิลำเนาของท่าน โรคที่ท่านเคยได้รับการรักษาและวันที่ท่านมาโรงพยาบาล มารวมกับข้อมูลที่ได้จากแบบสอบถามเพื่อการวิเคราะห์ข้อมูลด้วย

ข้อมูลของท่านที่เกี่ยวข้องกับการวิจัยนี้จะถูกเก็บเป็นความลับตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากลและพระราชบัญญัติคุ้มครองข้อมูลส่วนบุคคล พ.ศ. 2562 การเผยแพร่ผลการวิจัยในการประชุมวิชาการหรือในวารสารวิชาการจะไม่มีข้อมูลที่ระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ หากข้อมูลบางส่วนจะมีการนำไปลงในระบบฐานข้อมูลที่วารสารวิชาการกำหนด เพื่อแบ่งปันให้นักวิจัยอื่นได้ทราบ ข้อมูลเหล่านี้จะอยู่ในรูปแบบที่ไม่สามารถระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ อย่างไรก็ตาม อาจมีบุคคลบางกลุ่มที่ขอเข้าถึงข้อมูลส่วนบุคคลของท่านได้ ได้แก่ คณะกรรมการจริยธรรมการวิจัยในคน ผู้ประสานงานวิจัย ผู้กำกับดูแลการวิจัย และเจ้าหน้าที่จากสถาบันหรือองค์กรของรัฐที่มีหน้าที่ตรวจสอบ เพื่อตรวจสอบความถูกต้องของข้อมูลและขั้นตอนการวิจัย

ท่านมีสิทธิถอนตัวจากโครงการหรือไม่ และต้องทำอย่างไร

ท่านสามารถขอยุติการสัมภาษณ์ได้ทุกเมื่อ โดยแจ้งกับนักวิจัยผู้สัมภาษณ์ การหยุดหรือถอนตัวจะไม่ส่งผลกระทบต่อสิทธิที่ท่านได้รับอยู่

หากท่านขอยกเลิกการให้สัมภาษณ์หลังจากที่ท่านได้เข้าร่วมโครงการวิจัยแล้ว ข้อมูลส่วนตัวของท่านจะไม่ถูกบันทึกเพิ่มเติม อย่างไรก็ตามข้อมูลอื่นๆของท่านอาจถูกนำไปใช้เพื่อประเมินผลการวิจัย



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 4

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 6.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 5 จาก 8 หน้า

ท่านต้องเสียค่าใช้จ่ายในการเข้าร่วมโครงการวิจัยหรือไม่ และอย่างไร

โครงการนี้ไม่มีค่าใช้จ่าย โดยท่านจะได้รับเงินชดเชยเพื่อเป็นค่าเสียเวลาในการสัมภาษณ์ จำนวน 100 บาท

หากท่านไม่เข้าร่วมโครงการวิจัยนี้ ท่านมีทางเลือกอื่นอย่างไรบ้าง

ท่านไม่จำเป็นต้องเข้าร่วมโครงการนี้หากท่านไม่ต้องการ โดยจะไม่มีผลต่อการได้รับการบริการตามมาตรฐานที่ท่านจะได้รับ

หากท่านได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัยหรือมีข้อสงสัยเกี่ยวกับสิทธิของท่าน สามารถขอรับคำปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่หน่วยจริยธรรมการวิจัยในมนุษย์ คณะแพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com เพื่อให้มั่นใจว่าสิทธิ ความเป็นส่วนตัว และความเป็นอยู่ที่ดีของท่าน ได้รับความคุ้มครองตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากล

อาสาสมัครโปรดให้ความสำคัญ

ท่านจะได้รับเอกสารชี้แจงและหนังสือแสดงเจตนายินยอมที่มีข้อความเดียวกันกับที่นักวิจัยเก็บไว้ 1 ชุด ท่านควรเก็บไว้กับตัวเพื่อเป็นหลักฐานและอ่านเมื่อมีข้อสงสัย

ส่วนท้ายหนังสือแสดงเจตนายินยอมเข้าร่วมโครงการ จะต้องมี 1) ลายมือชื่อของท่าน 2) ลายมือชื่อนักวิจัยที่ให้คำอธิบายเกี่ยวกับโครงการ และ 3) วันที่ที่ลงนาม ซึ่งท่านต้องเป็นผู้ลงวันที่ด้วยตนเอง



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 ม.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 5

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย

(Informed Consent Form)

วันที่.....เดือน.....พ.ศ.

ข้าพเจ้า (นาย /นาง /นางสาว).....นามสกุล.....อายุ.....ปี อยู่
บ้านเลขที่.....หมู่.....ตำบล.....อำเภอ.....จังหวัด.....

ขอแสดงเจตนายินยอมเข้าร่วมการวิจัย ในโครงการวิจัยเรื่อง กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลส่งผ่านในผู้ป่วยสูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

โดยข้าพเจ้าได้อ่านเอกสารคำอธิบายโครงการวิจัยและ /หรือได้รับฟังคำอธิบายจาก..... และได้
รับทราบถึงรายละเอียดของโครงการวิจัยเกี่ยวกับวัตถุประสงค์และระยะเวลาที่ทำการวิจัย ขั้นตอน และวิธีการ
ปฏิบัติตัวที่ข้าพเจ้าต้องปฏิบัติ ผลประโยชน์ที่ข้าพเจ้าจะได้รับ ผลข้างเคียง เช่น รู้สึกไม่สบายใจ ที่อาจเกิดขึ้นจาก
การเข้าร่วมโครงการ ตลอดจนค่าตอบแทนที่จะได้รับ และค่าใช้จ่ายที่ข้าพเจ้าจะต้องรับผิดชอบจ่ายเอง และได้มี
โอกาสซักถามและได้รับคำตอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลาเพียงพอในการอ่านและทำความเข้าใจข้อมูลใน
เอกสารให้ข้อมูลสำหรับผู้เข้าร่วมการวิจัยอย่างถี่ถ้วน และได้รับเวลาเพียงพอในการตัดสินใจว่าจะเข้าร่วมการวิจัย
นี้

และข้าพเจ้ายินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย โดยให้นำเสนอเป็นข้อมูลโดยรวมจาก
การวิจัยนั้นแต่จะไม่เผยแพร่ ต่อสาธารณะเป็นรายบุคคล ทั้งนี้ข้าพเจ้า สามารถถอนตัวหรืองดเข้าร่วมการวิจัยได้
ทุกเมื่อ โดยจะไม่มีผลกระทบและไม่เสียสิทธิใด ๆ ในการรับบริการและการรักษาพยาบาลที่ข้าพเจ้า จะได้รับ
ต่อไปในอนาคต



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 6

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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หากข้าพเจ้ามี ข้อข้องใจเกี่ยวกับขั้นตอนของการวิจัยหรือเกิดผลข้างเคียงที่ไม่พึงประสงค์จากการวิจัยกับตัว
ข้าพเจ้า ข้าพเจ้าสามารถติดต่อกับ นายแพทย์ศุภกร ศรีแก้ว ได้ที่ สาขาวิชาเวชศาสตร์ครอบครัวและเวชศาสตร์
ป้องกัน โทรศัพท์ 0-7445-1331-4 และ 096-1943406 ได้ตลอด 24 ชั่วโมง

หากได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัย ข้าพเจ้าสามารถขอรับคำปรึกษา/แจ้ง
เรื่อง/ร้องเรียน ได้ที่หน่วยจริยธรรมการวิจัยในมนุษย์ คณะแพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์
0-7445-1157 หรือทางจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com

ข้าพเจ้า เข้าใจข้อความในเอกสารชี้แจงผู้เข้าร่วมการวิจัย และหนังสือแสดงเจตนายินยอมนี้โดยตลอดแล้ว จึงได้ลง
นามยินยอมเข้าร่วมโครงการ

ลายมือชื่อผู้เข้าร่วมโครงการวิจัย

.....

(.....)

วันที่.....เดือน.....พ.ศ.....

ลายมือชื่อผู้อธิบาย/ ผู้ขอความยินยอม

.....

(.....)

วันที่.....เดือน.....พ.ศ.....



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 ม.ค. 2565

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 7

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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		หน้า 8 จาก 8 หน้า

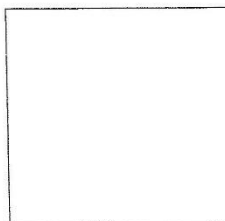
กรณีอาสาสมัครผู้เข้าร่วมวิจัย ไม่สามารถอ่านหนังสือได้

ผู้ที่อ่านข้อความทั้งหมดแทนอาสาสมัครผู้เข้าร่วมวิจัย คือจึงได้ลง
ลายมือชื่อไว้ในฐานะพยาน ว่าอาสาสมัครเข้าใจเกี่ยวกับโครงการ

ลงชื่อ	วันที่.....
(.....)	(ว/ด/ป/ปป)

พยาน (ผู้อ่านข้อความให้อาสาสมัครฟัง)

ข้าพเจ้าไม่สามารถอ่าน เขียนหนังสือได้ แต่มีผู้อ่านข้อความในแบบคำยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี
ข้าพเจ้าจึงพิมพ์ลายนิ้วหัวแม่มือขวาของข้าพเจ้าในแบบคำยินยอมนี้ด้วยความเต็มใจ



พิมพ์ลายนิ้วหัวแม่มือขวา ของ นาย/นาง/นางสาว.....(อาสาสมัครผู้ร่วมวิจัย)

ลงชื่อ วันที่.....
(.....) (ว/ด/ป/ปป)

พยานคนที่ 1

ลงชื่อ วันที่.....
(.....) (ว/ด/ป/ปป)

พยานคนที่ 2



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 มี.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 8

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 6 วันที่ 26 ธันวาคม 2566

Appendix 4. Information sheet for phase 2 (caregivers)

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 5.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 1 จาก 8 หน้า

เอกสารชี้แจงผู้เข้าร่วมการวิจัย (สำหรับผู้ดูแลผู้ป่วย)

(เพื่อประกอบการตัดสินใจ)

ชื่อโครงการ (ภาษาไทย) กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้ป่วย
สูงอายุและครอบครัว ณ โรงพยาบาลตติยภูมิในภาคใต้ของประเทศไทย

ชื่อผู้วิจัย นายแพทย์ศุภกร ศรีแก้ว

สถานที่วิจัย โรงพยาบาลสงขลานครินทร์

ผู้ให้ทุน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ก่อนที่ท่านจะลงนามในหนังสือแสดงเจตนายินยอมร่วมวิจัย ท่านควรได้รับทราบว่า

โครงการนี้เป็นโครงการวิจัย ไม่ใช่ การรักษาตามปกติ

การเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจ ท่านสามารถตัดสินใจได้อย่างอิสระว่าจะเข้าร่วมหรือไม่เข้าร่วม
การวิจัยนี้ ท่านไม่จำเป็นต้องเข้าร่วมในโครงการวิจัยนี้ การลงนามยินยอมเข้าร่วมวิจัยในเอกสารที่
เกี่ยวข้องนี้เป็นเพียงเพื่อให้ผู้ตรวจสอบแน่ใจว่าท่านตัดสินใจตอบคำถามของผู้วิจัย ไม่ได้เป็นสัญญาหรือ
ข้อผูกมัดทางกฎหมาย และสามารถถอนตัวออกจากโครงการได้ทุกเมื่อ โดยจะไม่มีผลกระทบต่อคุณภาพการ
บริการหรือการรักษาพยาบาลที่ท่านพึงได้รับตามสิทธิ

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ ท่านสามารถซักถามข้อสงสัยเกี่ยวกับโครงการวิจัยได้ ซึ่ง
ผู้วิจัยจะอธิบายเพิ่มเติมแก่ท่านและตอบข้อซักถามจนท่านเข้าใจ

นักวิจัยขอความยินยอมต้องให้ ข้อมูลและเวลาที่เพียงพอ ในการตัดสินใจอย่างอิสระ ก่อนที่ท่านจะเข้าร่วม
โครงการวิจัย ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษากับญาติพี่น้อง เพื่อนสนิท แพทย์
ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 1

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 5.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 2 จาก 8 หน้า

การวางแผนการดูแลล่วงหน้า เป็นอย่างไร

การวางแผนการดูแลล่วงหน้า เป็นกิจกรรมที่ผู้ป่วย ครอบครัว หรือทีมผู้ให้บริการสุขภาพเช่น แพทย์และพยาบาลปรึกษากันเพื่อวางแผนดูแลของผู้ป่วยเอาไว้ ก่อนที่ผู้ป่วยจะไม่สามารถตัดสินใจด้วยตนเองได้ เช่น ผู้ป่วยหนักอาจไม่สามารถสื่อสารให้ผู้อื่นรู้สิ่งที่ต้องการได้ ซึ่งผู้ป่วยสามารถวางแผนนี้ด้วยตนเอง แจ้งให้ทราบกันในครอบครัว หรือปรึกษาแพทย์หรือพยาบาลก็ได้ ผู้สูงอายุที่เจ็บป่วยอาจมีสุขภาพแยลงได้ง่ายกว่าวัยทำงานหรือวัยหนุ่มสาว แผนการดูแลตนเองล่วงหน้าจึงเป็นสิ่งที่ผู้สูงอายุ ครอบครัวและทีมผู้รักษาจะสื่อสารการเพื่อให้สามารถให้การดูแลในอนาคตได้ตามที่ผู้ป่วยได้ตั้งใจไว้ หากแต่แพทย์บางคนพบว่าการเริ่มสนทนาเกี่ยวกับการวางแผนการดูแลล่วงหน้านี้ไม่สามารถทำได้สำเร็จกับผู้ป่วยทุกคนและในทุกโอกาส เนื่องจากผู้ป่วยมีระดับความพร้อมที่แตกต่างกัน และครอบครัวมีส่วนสำคัญในการวางแผนดูแลล่วงหน้า ผู้วิจัยจึงต้องการศึกษาว่ากลไกในครอบครัวส่งผลอย่างไรต่อความพร้อมในการวางแผนการดูแลล่วงหน้าของผู้ป่วยและครอบครัวไทย ซึ่งข้อมูลจากการศึกษานี้จะทำให้แพทย์เข้าใจกลไกของครอบครัวต่อความพร้อมของผู้ป่วยและสามารถดูแลผู้ป่วยและครอบครัวได้ดีขึ้น

เหตุใดท่านจึงได้รับเชิญให้เข้าร่วมโครงการวิจัยนี้

ท่านได้รับเชิญให้เข้าร่วมการวิจัย โปรดใช้เวลาในการอ่านเอกสารฉบับนี้ ซึ่งจะช่วยให้ท่านรับทราบสิ่งต่าง ๆ ที่ท่านจะมีส่วนร่วมในการวิจัยนี้ การตัดสินใจเข้าร่วมการวิจัยนี้ขึ้นอยู่กับความสมัครใจของท่าน หากท่านไม่สมัครใจเข้าร่วมการวิจัย จะไม่มีผลใด ๆ ต่อการดูแลรักษาหรือสิทธิที่ท่านพึงมี

การวิจัยนี้จะคัดเลือก ผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไปที่กำลังรับการรักษาอยู่ ณ คลินิกรังสีรักษาและฟิสิกส์อยู่ ณ ที่พักผู้ป่วยและญาติโรงพยาบาลสงขลานครินทร์ และผู้ดูแลหลักของผู้ป่วยที่มีอายุ 18 ปีขึ้นไป เข้าร่วมการวิจัย

ระยะเวลาที่จะทำการวิจัยทั้งสิ้นของโครงการนี้ 2 ปี จะมีผู้ป่วยเข้าร่วมการวิจัยนี้ทั้งสิ้น 550 คน และผู้ดูแล 550 คน

ข้อมูลที่ได้จากการทำวิจัยจะนำไปทำอะไร



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 2

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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โครงการนี้ทำขึ้นเพื่อศึกษาความพร้อมในการวางแผนการดูแลล่วงหน้า และค้นหาปัจจัยของครอบครัวที่ส่งผลต่อความพร้อมในการวางแผนดูแลล่วงหน้าของผู้ป่วยที่มีอายุตั้งแต่ 60 ปีขึ้นไป ข้อมูลนี้จะสามารถใช้ในการประเมินและเตรียมความพร้อมของผู้ป่วยและครอบครัวในการวางแผนการดูแลล่วงหน้าต่อไป

ขั้นตอนการปฏิบัติเมื่อท่านเข้าร่วมโครงการ

ถ้าท่านสมัครใจเข้าร่วมโครงการวิจัยและลงนามในเอกสารยินยอมแล้ว ผู้วิจัยจะขอให้ท่านตอบแบบสอบถามด้วยตนเองประมาณ 30 นาที

ประโยชน์ที่ท่านอาจจะได้รับจากการเข้าร่วม

ท่านจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมวิจัยนี้ แต่องค์ความรู้ที่ได้จะถูกนำไปพัฒนากระบวนการสื่อสารเพื่อวางแผนการดูแลล่วงหน้าในภาพรวม

ความเสี่ยงและความไม่สะดวกสบายที่อาจเกิดจากการเข้าร่วมโครงการ และวิธีการป้องกัน/แก้ไขที่ผู้วิจัยเตรียมไว้หากมีเหตุการณ์ดังกล่าวเกิดขึ้น

คำถามบางข้อเป็นการถามความคิดเห็นของท่านเกี่ยวกับผู้ป่วยที่ท่านกำลังดูแลในด้านสุขภาพที่ผ่านมา ในปัจจุบันและในอนาคต หากท่านรู้สึกลำบากใจระหว่างการตอบแบบสอบถาม สามารถข้ามหรือไม่ตอบข้อใดข้อหนึ่งได้ รวมถึงหยุดตอบแบบสอบถามได้ทุกเมื่อ

ข้อมูลส่วนตัวของท่านจะถูกเก็บไว้อย่างไร และจะมีใครนำไปใช้หรือไม่

นักวิจัยจะนำข้อมูลที่ท่านตอบกรอกลงในแบบบันทึกข้อมูลเล็กทรอนิกส์ในคอมพิวเตอร์ของโครงการวิจัย ซึ่งต้องใช้รหัสผ่านในการเข้าถึงข้อมูล มีเพียงผู้วิจัยหลักเท่านั้นที่เข้าถึงได้ และจะเก็บข้อมูลของท่านไว้เป็นเวลา 5 ปี หลังจากการวิจัยเสร็จสิ้น หลังจากนั้นจะทำการลบข้อมูลของท่านออกจากฐานข้อมูลของผู้วิจัย



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 3

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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ข้อมูลของท่านที่เกี่ยวข้องกับการวิจัยจะถูกเก็บเป็นความลับตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากลและพระราชบัญญัติคุ้มครองข้อมูลส่วนบุคคล พ.ศ. 2562 การเผยแพร่ผลการวิจัยในการประชุมวิชาการหรือในวารสารวิชาการจะไม่มีข้อมูลที่ระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ หากข้อมูลบางส่วนจะมีการนำไปลงในระบบฐานข้อมูลที่วารสารวิชาการกำหนด เพื่อแบ่งปันให้นักวิจัยอื่นได้ทราบ ข้อมูลเหล่านี้จะอยู่ในรูปแบบที่ไม่สามารถระบุตัวตนหรือเชื่อมโยงถึงตัวท่านได้ อย่างไรก็ตาม อาจมีบุคคลบางกลุ่มที่ขอเข้าถึงข้อมูลส่วนบุคคลของท่านได้ ได้แก่ คณะกรรมการจริยธรรมการวิจัยในคน ผู้ประสานงานวิจัย ผู้กำกับดูแลการวิจัย และเจ้าหน้าที่จากสถาบันหรือองค์กรของรัฐที่มีหน้าที่ตรวจสอบ เพื่อตรวจสอบความถูกต้องของข้อมูลและขั้นตอนการวิจัย

ท่านมีสิทธิถอนตัวจากโครงการหรือไม่ และต้องทำอะไร

ท่านสามารถขอหยุดการทำแบบสอบถามได้ทุกเมื่อ โดยแจ้งกับนักวิจัยผู้สัมภาษณ์ การหยุดหรือถอนตัวจะไม่ส่งผลกระทบต่อการศึกษาที่ท่านได้รับอยู่

หากท่านขอหยุดการตอบแบบสอบถามหลังจากที่ท่านได้เข้าร่วมโครงการวิจัยแล้ว ข้อมูลส่วนตัวของท่านจะไม่ถูกบันทึกเพิ่มเติม อย่างไรก็ตามข้อมูลอื่นๆของท่านอาจถูกนำไปใช้เพื่อประเมินผลการวิจัย

ท่านต้องเสียค่าใช้จ่ายในการเข้าร่วมโครงการวิจัยหรือไม่ และอย่างไร

โครงการนี้ไม่มีค่าใช้จ่าย โดยท่านจะได้รับเงินชดเชยเพื่อเป็นค่าเสียเวลาในการตอบแบบสอบถาม จำนวน 100 บาท

หากท่านไม่เข้าร่วมโครงการวิจัยนี้ ท่านมีทางเลือกอื่นอย่างไรบ้าง

ท่านไม่จำเป็นต้องเข้าร่วมโครงการนี้หากท่านไม่ต้องการ โดยจะไม่มีผลการให้บริการตามมาตรฐานที่ท่านจะได้รับ

หากท่านได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัยหรือมีข้อสงสัยเกี่ยวกับสิทธิของท่าน สามารถขอรับคำปรึกษา/แจ้งเรื่อง/ร้องเรียน ได้ที่หน่วยจริยธรรมการวิจัยในมนุษย์ คณะ



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 4

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
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		หน้า 5 จาก 8 หน้า

แพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์ 0-7445-1157 หรือจดหมายอิเล็กทรอนิกส์
medpsu.ec@gmail.com เพื่อให้มั่นใจว่าสิทธิ ความเป็นส่วนตัว และความเป็นอยู่ที่ดีของท่าน ได้รับความ
คุ้มครองตามมาตรฐานจริยธรรมการวิจัยในคนระดับสากล

อาสาสมัครโปรดให้ความสำคัญ

ท่านจะได้รับเอกสารชี้แจงและหนังสือแสดงเจตนายินยอมที่มีข้อความเดียวกันกับที่นักวิจัยเก็บไว้ 1 ชุด ท่านควร
เก็บไว้กับตัวเพื่อเป็นหลักฐานและอ่านเมื่อมีข้อสงสัย

ส่วนท้ายหนังสือแสดงเจตนายินยอมเข้าร่วมโครงการ จะมี 1) ลายมือชื่อของท่าน 2) ลายมือชื่อนักวิจัยที่ให้
คำอธิบายเกี่ยวกับโครงการ และ 3) วันที่ที่ลงนาม ซึ่งท่านต้องเป็นผู้ลงวันที่ด้วยตนเอง



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 15 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 5

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1	วันที่ประกาศใช้: 12 มกราคม 2565
	Version 5.0, Date 26/12/2023	หน้า 6 จาก 8 หน้า

หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย

(Informed Consent Form)

วันที่.....เดือน.....พ.ศ.

ข้าพเจ้า (นาย /นาง /นางสาว).....นามสกุล.....อายุ.....ปี อยู่
บ้านเลขที่.....หมู่.....ตำบล.....อำเภอ.....จังหวัด.....

ขอแสดงเจตนายินยอมเข้าร่วมการวิจัย ในโครงการวิจัยเรื่อง กลไกของครอบครัวกับความพร้อมในการวางแผนการดูแลผู้ป่วยสูงอายุและครอบครัว ณ โรงพยาบาลศตยภูมิในภาคใต้ของประเทศไทย

โดยข้าพเจ้าได้อ่านเอกสารคำอธิบายโครงการวิจัยและ /หรือได้รับฟังคำอธิบายจาก..... และได้
รับทราบถึงรายละเอียดของโครงการวิจัยเกี่ยวกับวัตถุประสงค์และระยะเวลาที่ทำการวิจัย ขั้นตอน และวิธีการ
ปฏิบัติตัวที่ข้าพเจ้าต้องปฏิบัติ ผลประโยชน์ที่ข้าพเจ้าจะได้รับ ผลข้างเคียง เช่น รู้สึกไม่สบายใจ ที่อาจเกิดขึ้นจาก
การเข้าร่วมโครงการ ตลอดจนค่าตอบแทนที่จะได้รับ และค่าใช้จ่ายที่ข้าพเจ้าจะต้องรับผิดชอบจ่ายเอง และได้มี
โอกาสซักถามและได้รับคำตอบเป็นที่พอใจแล้ว ข้าพเจ้ามีเวลาเพียงพอในการอ่านและทำความเข้าใจข้อมูลใน
เอกสารให้ข้อมูลสำหรับผู้เข้าร่วมการวิจัยอย่างถี่ถ้วน และได้รับเวลาเพียงพอในการตัดสินใจว่าจะเข้าร่วมการวิจัย
นี้

และข้าพเจ้ายินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย โดยให้นำเสนอเป็นข้อมูลโดยรวมจาก
การวิจัยนั้นแต่จะไม่เผยแพร่ ต่อสาธารณะเป็นรายบุคคล ทั้งนี้ข้าพเจ้า สามารถถอนตัวหรือตบเข้าร่วมการวิจัยได้
ทุกเมื่อ โดยจะไม่มีผลกระทบและไม่เสียสิทธิ์ใด ๆ ในการรับบริการและการรักษาพยาบาลที่ข้าพเจ้า จะได้รับ
ต่อไปในอนาคต



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

18 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 6

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 5.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 7 จาก 8 หน้า

หากข้าพเจ้ามี ข้อข้องใจเกี่ยวกับขั้นตอนของการวิจัยหรือเกิดผลข้างเคียงที่ไม่พึงประสงค์จากการวิจัยกับตัว
ข้าพเจ้า ข้าพเจ้าสามารถติดต่อกับ นายแพทย์ศุภกร ศรีแก้ว ได้ที่ สาขาวิชาเวชศาสตร์ครอบครัวและเวชศาสตร์
ป้องกัน โทรศัพท์ 0-7445-1331-4 และ 096-1943406 ได้ตลอด 24 ชั่วโมง

หากได้รับการปฏิบัติไม่ตรงตามที่ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัย ข้าพเจ้าสามารถขอรับคำปรึกษา/แจ้ง
เรื่อง/ร้องเรียน ได้ที่หน่วยจริยธรรมการวิจัยในมนุษย์ คณะแพทยศาสตร์มหาวิทยาลัยสงขลานครินทร์ โทรศัพท์
0-7445-1157 หรือทางจดหมายอิเล็กทรอนิกส์ medpsu.ec@gmail.com

ข้าพเจ้า เข้าใจข้อความในเอกสารชี้แจงผู้เข้าร่วมการวิจัย และหนังสือแสดงเจตนายินยอมนี้โดยตลอดแล้ว จึงได้ลง
นามยินยอมเข้าร่วมโครงการ

ลายมือชื่อผู้เข้าร่วมโครงการวิจัย

.....

(.....)

วันที่.....เดือน.....พ.ศ.....

ลายมือชื่อผู้อธิบาย/ ผู้ขอความยินยอม

.....

(.....)

วันที่.....เดือน.....พ.ศ.....



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ 16 ม.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 7

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

	เอกสารชี้แจงผู้เข้าร่วมการวิจัยและ หนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย	AP-025
	รหัสโครงการวิจัย: 65-417-9-1 Version 5.0, Date 26/12/2023	วันที่ประกาศใช้: 12 มกราคม 2565
		หน้า 8 จาก 8 หน้า

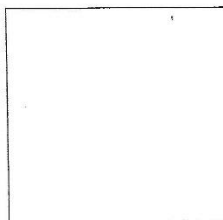
กรณีอาสาสมัครผู้เข้าร่วมวิจัย ไม่สามารถอ่านหนังสือได้

ผู้อ่านข้อความทั้งหมดแทนอาสาสมัครผู้เข้าร่วมวิจัย คือจึงได้ลง
ลายมือชื่อไว้ในฐานะพยาน ว่าอาสาสมัครเข้าใจเกี่ยวกับโครงการ

ลงชื่อ	วันที่.....
(.....)	(ว/ด/ปปป)

พยาน (ผู้อ่านข้อความให้อาสาสมัครฟัง)

ข้าพเจ้าไม่สามารถอ่าน เขียนหนังสือได้ แต่มีผู้อ่านข้อความในแบบคำยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดี
ข้าพเจ้าจึงพิมพ์ลายนิ้วหัวแม่มือขวาของข้าพเจ้าในแบบคำยินยอมนี้ด้วยความเต็มใจ



พิมพ์ลายนิ้วหัวแม่มือขวา ของ นาย/นาง/นางสาว.....(อาสาสมัครผู้ร่วมวิจัย)

ลงชื่อ วันที่.....
(.....) (ว/ด/ปปป)

พยานคนที่ 1

ลงชื่อ วันที่.....
(.....) (ว/ด/ปปป)

พยานคนที่ 2



คณะกรรมการพิจารณาจริยธรรมการวิจัยในมนุษย์

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

๕ ธ.ค. 2567

นักวิจัยต้องมอบสำเนาเอกสารฉบับนี้ให้ผู้เข้าร่วมวิจัย/ผู้ปกครอง เก็บไว้ 1 ชุดด้วย

หน้า 8

เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย

เวอร์ชัน 5 วันที่ 26 ธันวาคม 2566

Appendix 5. Interview guide (elderly informants)

Greeting: Good morning/ afternoon, Ms./ Mr.

Based on what I learned from your response in the interviews earlier, the next interviews are about what do you think about advance care planning

If I may review Advance care planning is a continuous process that clinicians, patients, and family communicate the goals and values of care over the course of care. Either patient or clinician can initiate ACP, and ACP can be discussions of medical care preferences, discussion about time when you are severely ill so you cannot decide for them by yourself, and your doctor and family may want to know if you want life-sustaining treatment, for example, heart or lung machines, to be applied. The communication also covers naming the name of surrogate decision making and making living will.

1. How do you feel about your current treatment, or current plan?

Probe: 1) What do you think about it? 2) How do you feel about the treatment outcome (or plan)?

2. Have you ever planned in advance for your health care or think about a case that your health becomes poorer, and you are unable to make decision by yourself?

Probe: 1) What do you think about ACP (or planning in advance for health care)? 2) how do you feel when you are planning (or thinking about planning)? 3) How do you decide that ACP is needed?

3. Have you ever completed advance directives or living will?

Probe: 1) What do you think about completing the document? 2) how do you feel when you are doing (or not doing) it? 3) How do you decide that the document is needed?

4. Do you think there can be a time that you may need a surrogate to decide on behalf of yourself when you are unable to make it by yourself?

Probe: 1) can you describe how the surrogate will help? 2) how can you decide the surrogate?

5. Is there any information regarding your illness that you need?

Probe: 1) diagnosis 2) prognosis (or prediction) 3) trajectory of illness 4) treatment and its alternative treatments

6. Do you think ACP benefits your health care and why?

Probe: 1) Are there any cons of ACP? Are there any pros of ACP? What extent do you think your beliefs/ religions affect the way you see the illness and its treatment?

7. How likely do you think ACP will benefits you in the future?

Probe: 1) when will it benefit? 2) in what case it will work? 3) in what situation do you think it has cons over benefits?

8. What do you think your loved ones are thinking about your current health and care receiving?

Appendix 6. Interview guide (caregiver informants)

Greeting: Good morning/ afternoon, Ms./ Mr.

Based on what I learned from Ms./ Mr. ... (patient's name) response in the interviews earlier, the next interviews are about what do you think about patient's advance care planning.

If I may review Advance care planning is a continuous process that clinicians, patients, and family communicate the goals and values of care over the course of care. Either patient or clinician can initiate ACP, and ACP can be discussions of medical care preferences, discussion about time when a patient is severely ill so you cannot decide for them by him/ herself, and your doctor and family may want to know if the patient wants life-sustaining treatment, for example, heart or lung machines, to be applied. The communication also covers naming the name of surrogate decision making and making living will.

1. How do you feel about the patient's current treatment, or current plan?

Probe: 1) What do you think about it? 2) How do you feel about the treatment outcome (or plan)?

2. Have you ever thought about planning in advance for the patient's health care or think about a case that the patient health becomes poorer, and he/she is unable to make decision by him/ herself?

Probe: 1) What do you think about ACP (or planning in advance for health care)? 2) how do you feel when the patient is planning (or thinking about planning)? 3) How do you decide that ACP is needed?

3. Have you ever completed advance directives or living will with the patient?

Probe: 1) What do you think about completing the document? 2) how do you feel when the patient is doing (or not doing) it? 3) How do you decide that the document is needed?

4. Do you think there can be a time that the patient may need a surrogate to decide on behalf of yourself when he/ she is unable to make it by him/ herself?

Probe: 1) What do you think about being a surrogate? 2) How do you feel as a potentially appointed surrogate decision-maker?

5. Is there any information regarding the patient's illness that you need?

Probe: 1) diagnosis 2) prognosis (or prediction) 3) trajectory of illness 4) treatment and its alternative treatments

6. Do you think ACP benefits the patient's health care and why?

Probe: 1) Are there any cons of ACP? Are there any pros of ACP? What extent do you think your beliefs/ religions affect the way you see the patient's illness and its treatment?

7. How likely do you think ACP will benefit the patients in the future?

Probe: 1) when will it benefit? 2) in what case it will work? 3) in what situation do you think it has cons over benefits?

8. What do you think your loved one (the patient) is thinking about his/ her current health and care receiving?

9. Do you have any precautions to tell me before I interview the patient?

Appendix 7. Case record form (elderly participants)

For the Interviewer:

1. Before starting the interview, ask the patient if they have a hospital identification card number from Songklanagarind Hospital. If the patient has one, record the hospital ID number in the file: "key_ID_phase2.xlsx" and link it to the Unique ID. If the patient does not have a hospital ID, inform them that permission will be requested later to retrieve the ID from the database. If the patient does not grant permission, record the number as 0000000. If no ID is available or the patient is unsure, record it as 9999999.

2. The interviewer should read each question word-by-word until the end of the sentence, then allow a 5–10 second pause for the volunteer to answer. If the volunteer does not respond, check if they heard the question by speaking slightly louder in a lower tone. If the interviewer determines that the volunteer heard the question but still cannot answer within the given time, record the response as Unsure/Declines to Answer.

Section 1: General information about health status and illness

Before we start, I would like to ask you about ...

#	Question	Response
1	In general, what level do you think your current health is?	☐ 1. Excellent ☐ 2. Good ☐ 3. Fair ☐ 4. Poor ☐ 5. Bad ☐ 8. Not sure ☐ 9. Refuse to answer
2	What extent do you think that you can understand your illness as what has been going on?	☐ 1. Clearly ☐ 2. Partially ☐ 3. Very little ☐ 4. Not at all ☐ 8. Not sure

#	Question	Response
		[] 9. Refuse to answer
3	What extent do you think you're an information about illness and its treatment you have received from your doctor is	☐ 1. Clear ☐ 2. Almost clear ☐ 3. Very little ☐ 4. No information ☐ 8. Not sure ☐ 9. Refuse to answer

Section 2: Awareness of ACP

I would like to give you a brief explanation about Advance care planning. Advance care planning is a continuous process that clinicians, patients, and family communicate the goals and values of care over the course of care. Either patient or clinician can initiate ACP, and ACP can be discussions of medical care preferences, discussion about time when you are severely ill so you cannot decide for them by yourself, and your doctor and family may want to know if you want life-sustaining treatment, for example, heart or lung machines, to be applied. Communication also covers naming the name of surrogate decision making and making living will.

Now we will talk about the specific questions involved in advance care planning

#	Question	Response
1	Have you ever heard about advance care planning?	☐ 1. Yes ☐ 2. No (skip to section 2) ☐ 8. Not sure (skip to section 2) ☐ 9. Refuse to answer (skip to section 2)
2	What types of advance care planning have you heard about?	☐ 1. Advance care planning discussion ☐ 2. Advance directives/ Living wills ☐ 3. Power of attorney for health care ☐ 4. Other ☐ 8. Not sure ☐ 9. Refuse to answer

#	Question	Response
3	Where did you hear about advance care planning	☐ 1. Family and friends ☐ 2. Medical professionals ☐ 3. Internet ☐ 4. Television/ radio ☐ 8. Other ☐ 88. Not sure ☐ 99. Refuse to answer

Section 3: stage of readiness for ACP engagement

Now we will talk about the specific steps involved in advance care planning

#	Question	Response	Code	Action
1	Are you aware that some people do not want to live as long as possible if they have a poor quality of life?	☐ Yes	1	to 2
		☐ No	0	to 9
		☐ Unsure	8	to 9
2	Have you ever thought about whether there could come a time when having a good quality of life would be more important to you than living as long as possible?	☐ Yes	1	to 3
		☐ Unsure	8	to 9
		☐ Don't want to answer	9	to 9
3	Have you talked about your thoughts with a loved one?	☐ Yes	1	to 4
		☐ No	0	to 5
		☐ Don't want to answer	9	to 9
4	When did you do this?	☐ Within the past 6 months	1	to 9
		☐ More than 6 months ago	2	to 9
		☐ Don't want to answer	9	to 9
5	How ready are you to do this?	☐ I am not ready to talk to my loved ones	1	to 6

#	Question	Response	Code	Action
		[] I am thinking about talking to my loved ones in the next 6 months	2	to 6
		[] I am planning on talking to my loved ones in the next 30 days	3	to 6
		[] Never thought about talking to my loved ones about it	4	to 6
		[] Don't want to answer	9	to 6
6	Have you talked about your thoughts with your doctor?	[] Yes	1	to 7
		[] No	0	to 9
		[] No regular doctor	2	to 8
		[] Don't want to answer	9	to 9
7	When did you do this?	[] Within the past 6 months	1	to 9
		[] More than 6 months ago	2	to 9
		[] Don't want to answer	9	to 9
8	How ready are you to do this?	[] I am not ready to talk to my doctor	1	to 9
		[] I am thinking about talking to my doctor in the next 6 months	2	to 9
		[] I am planning on talking to my doctor in the next 30 days	3	to 9
		[] Never thought about talking to my doctor about it	4	to 9
		[] Don't want to answer	9	to 9

#	Question	Response	Code	Action
9	Are you aware that, when people get very sick, there are machines that can be used to keep them alive, such as breathing machines?	☐ Yes	1	to 10
		☐ No	0	to 17
		☐ Unsure	8	to 17
10	Have you ever thought about whether you would want to be kept alive on machines if you were very sick?	☐ Yes	1	to 11
		☐ No	0	to 14
		☐ Unsure	8	to 14
		☐ Don't want to answer	9	to 17
11	Have you talked about your thoughts with a loved one?	☐ Yes	1	to 12
		☐ No	0	to 13
		☐ Don't want to answer	9	to 14
12	When did you do this?	☐ Within the past 6 months	1	to 14
		☐ More than 6 months ago	2	to 14
		☐ Don't want to answer	9	to 14
13	How ready are you to do this?	☐ I am not ready to talk to my loved ones.	1	to 14
		☐ I am thinking about talking about talking to my loved ones in the next 6 months	2	to 14
		☐ I am planning on talking to my loved ones in the next 30 days	3	to 14
		☐ Never thought about talking to my loved ones about it	4	to 14
		☐ I am ready, but my loved ones are not	5	to 14

#	Question	Response	Code	Action
		[] Don't want to answer	9	to 14
14	Have you talked about your thoughts with your doctor?	[] Yes	1	to 15
		[] No	0	to 16
		[] No regular doctor	2	to 17
		[] Don't want to answer	9	to 17
15	When did you do this?	[] Within the past 6 months	1	to 17
		[] More than 6 months ago	2	to 17
		[] Don't want to answer	9	to 17
16	How ready are you to do this?	[] I am not ready to talk to my doctor	1	to 17
		[] I am thinking about talking to my doctor in the next 6 months	2	to 17
		[] I am planning on talking to my doctor in the next 30 days	3	to 17
		[] Never thought about talking to my doctor about it	4	to 17
		[] Don't want to answer	9	to 17
	A living will is not the same as a regular will. This is a piece of paper that generally includes a statement saying that if a person's condition is thought to be terminal or if the person is permanently unconscious, then the person should not be kept			

#	Question	Response	Code	Action
	alive though life support systems.			
17	Have you made out a living will?	☐ Yes	1	to 18
		☐ No	0	to 19
18	When did you do this?	☐ Within the past 6 months	1	to 20
		☐ More than 6 months ago	2	to 20
		☐ Don't want to answer	9	to 20
19	How ready are you to complete a living will?	☐ I am not ready to complete a living will	1	to 20
		☐ I am thinking about completing a living will in the next 6 months	2	to 20
		☐ I am planning to complete a living will in the next 30 days	3	to 20
		☐ Have not thought about it	4	to 20
		☐ Don't want to answer	9	to 20
	Naming a health care proxy means that you have decided on the person that you want to make medical decisions for you when you are unable. It also includes filling out a form stating that this person is your choice for a health care proxy.			
20	Have you filled out a form naming a health care proxy?	☐ Yes	1	to 21
		☐ No	0	end

#	Question	Response	Code	Action
21	When did you do this?	☐ Within the past 6 months	1	end
		☐ More than 6 months ago	2	end
		☐ Don't want to answer	9	end
22	How ready are you to name a health care proxy?	☐ I am not ready to name a health care proxy	1	end
		☐ I am thinking about naming a health care proxy in the next 6 months	2	end
		☐ I am planning to name a health care proxy in the next 30 days	3	end
		☐ Have not thought about it	4	end
		☐ Don't want to answer	9	end

Section 4

Here are some additional beliefs about issues related to advance care planning. Please tell me how strongly you agree with the following statements

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	If I make some document such as a living will, the physician will stop the treatment too soon.					
2	It is not necessary for me to preplan my advance care plan because when I reach a certain age, the physician will not use a life-sustaining devices.					

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
3	It is not necessary for me to make my advance care plan because my personal physician knows my decision on treatment in the end of life period.					
4	It is not necessary for me to make my advance care plan because I can always make my own decision on my treatment.					
5	Making an advance care plan means not to be careless for any potential changes in health					
6	It is not necessary for me to make my advance care plan because there might be a good reason if I am determined to be suffering.					
7	Advance care planning is suitable for the elderly or people who are more ill than me.					
8	Health care proxy appointment will make the decision-making on my future medical care among my family members easier.					
9	Advance care planning seems difficult because I do not like to think about when my health is deteriorating.					
10	Advance care planning will help me to make future decisions more easily if I become seriously ill.					

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
11	The treating physician is too busy for any advance care planning activities					
12	Advance care planning will help family members make decisions about my medical care more easily.					
13	Advance care planning is difficult because there are too many issues related to my future medical care to think about.					
14	I am sure that I will receive preferred medical care when I am unable to make decisions if my physician and my family members are knowledgeable of my medical care preferences in advance.					
15	I feel at ease if I plan and inform my physician and my family members about my advance care planning.					
16	Advance care planning is not suitable for me because I make decisions day by day.					
17	It is possible that I would not receive standard clinical care if I decide to accept or refuse some treatment ahead of time.					
18	Advance care planning will help me control what will happen to me when I become unable to make decisions.					
19	It is not necessary for me to make an advance care planning since my preference may change in the future.					

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
20	Advance care planning for my future medical care makes me feel that I may live a shorter life with my family.					

Appendix 8. Case record form (caregiver participants)

Part 1: General Information about Yourself

☐ Please mark or fill in the blanks [] for each item that corresponds to your information. If you are unsure or feel uncomfortable answering any question, you can skip that question or choose 'Unsure/Prefer not to answer.'

1	Gender	[] Male [] Female [] Other
2	Date of birth	Date: _____ Month: _____ Year: _____
3	Occupation	☐ Government employee/State official ☐ Private sector employee ☐ Trading ☐ Self-employed ☐ General labor ☐ Retired employee ☐ Agriculture ☐ Professional (e.g., doctor, lawyer, architect) ☐ Unemployed/Not working ☐ Other ☐ Unsure/Prefer not to answer
4	Religion	☐ Islam ☐ Buddhism ☐ Christianity ☐ Other
5	Marital status	☐ Single ☐ Married, with children ☐ Married, without children ☐ Widowed/Divorced/Separated ☐ Unsure/Prefer not to answer
6	Highest education level	☐ No formal education ☐ Primary school ☐ Lower secondary ☐ Upper secondary ☐ Vocational certificate ☐ Associate degree ☐ Higher vocational certificate ☐ Bachelor's degree ☐ Postgraduate degree ☐ Unsure/Prefer not to answer
7	Average Family Income per Month (or in recent months) from all Family Members	
	☐ Less than 5,000 Baht ☐ 5,001 to 10,000 Baht ☐ 10,001 to 20,000 Baht ☐ 20,001 to 30,000 Baht ☐ 30,001 to 40,000 Baht ☐ 40,001 to 50,000 Baht	

	☐ More than 50,000 Baht ☐ Unsure/Prefer not to answer
8	8. Number of Family Members (do not need to live in the same household), Including Yourself ____
9	Family Structure of the Patient
	☐ The patient lives with their spouse, without children ☐ The patient lives with their spouse, with children ☐ The patient (possibly with a spouse) lives with children and grandchildren ☐ The patient lives with grandchildren ☐ Other, please specify: _____ ☐ Unsure/Prefer not to answer
11	Your Relationship with the Patient
	☐ Son/Daughter ☐ Husband/Wife ☐ Father/Mother ☐ Relative ☐ Not a relative/Other ☐ Unsure/Prefer not to answer
12	If the patient becomes severely ill and unable to make treatment decisions for themselves and no prior plans are made, who do you think in the family would act as the patient's representative to make medical decisions?
	☐ Yourself ☐ The patient's children (other than yourself) ☐ The patient's spouse (other than yourself) ☐ Other family members ☐ No family members can make the decision ☐ Unsure/Prefer not to answer

Part 2: General Information about the patient

Please mark or fill in the blanks ☐ for each item that corresponds to the patient's information. If you are unsure or feel uncomfortable answering any question, you can skip that question or choose 'Unsure/Prefer not to answer.'

1	Gender	☐ Male ☐ Female ☐ Other
2	Age	_____ year _____ month
3	Occupation	☐ Government employee/State official ☐ Private sector employee ☐ Trading ☐ Self-employed ☐ General labor ☐ Retired employee ☐ Agriculture ☐ Professional (e.g., doctor, lawyer, architect)

		☐ Unemployed/Not working ☐ Other ☐ Unsure/Prefer not to answer
4	Religion	☐ Islam ☐ Buddhism ☐ Christianity ☐ Other
5	Marital status	☐ Single ☐ Married, with children ☐ Married, without children ☐ Widowed/Divorced/Separated ☐ Unsure/Prefer not to answer
6	Highest education level	☐ No formal education ☐ Primary school ☐ Lower secondary ☐ Upper secondary ☐ Vocational certificate ☐ Associate degree ☐ Higher vocational certificate ☐ Bachelor's degree ☐ Postgraduate degree ☐ Unsure/Prefer not to answer
7	How the patient is related to the person you perceived is the head of the family	
	☐ The patient is the head of the family ☐ Husband, wife, or partner ☐ Child ☐ Adopted child ☐ Grandchild ☐ Father or Mother ☐ Sibling ☐ Other relative ☐ Non-relative family member ☐ Unsure/Prefer not to answer	

Section 3 Your opinions regarding the family

✎ Please mark ✓ in the column in which explains/fit with your family condition, please also use the first answer that comes to your mind

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree
1	Your family can solve the common problems quite well, so the problems will not turn chronic				
2	Your family pays attention on the needs of individual				
3	Your family is capable in understanding the feeling of those who are speaking				

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree
4	Your family always care each other, putting oneself in someone's shoes				
5	Emotional expressions are allowed in both sadness and happiness				
6	If ones who are determined to do a task, the others will keep following and warning				
7	There is a commitment that determine who will be responsible for any housework				
8	There is an evaluation if ones do their housework appropriately				
9	Your family assign the work appropriately				
10	Rules in family exists in order to prevent putting oneself in trouble as well as make the other in trouble				
11	Everyone is well-cooperated in complying the family's rules				
12	If the first solution turns out not working, we always have our second plan				
13	Any problem is being said so everyone can help fixing it				
14	There will always be a follow up and analysis for any potentially problematic situation				
15	Family can talk straightforwardly				

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree
16	When a family member talks, everyone can feel what he/she is thinking				
17	It is often that you have to keep your feeling with you				
18	It is often that unnecessary topics are picked up for discussion, while the necessary ones are not				
19	No one listens other's opinion				
20	Family's expenses is higher than income, and that is problematic				
21	Family cannot express what he/ she is feeling				
22	Expression of caring in family seems to be purely curiosity				
23	Family shows that he/ she cares for others only because he/ she wants the other to think that he/ she is a good man				
24	Family is living together, but no one is actually interested in the others				
25	Family members cannot express anger because he/ she is afraid that will upset others				

Section 4 Your prior knowledge regarding advance care planning

☞ Please mark ✓ on the choice that fits with your condition

#	Question	Response
1	Have you ever heard about advance care planning?	☐ 1. Yes ☐ 2. No (skip to section 2) ☐ 8. Not sure (skip to section 2) ☐ 9. Refuse to answer (skip to section 2)
2	What types of advance care planning have you heard about?	☐ 1. Advance care planning discussion ☐ 2. Advance directives/ Living wills ☐ 3. Power of attorney for health care ☐ 4. Other ☐ 8. Not sure ☐ 9. Refuse to answer
3	Where did you hear about advance care planning	☐ 1. Family and friends ☐ 2. Medical professionals ☐ 3. Internet ☐ 4. Television/ radio ☐ 8. Other ☐ 88. Not sure ☐ 99. Refuse to answer

✦ We have provided some brief information about advance care planning below to help you better understand advance care planning. If you already have an understanding of advance care planning, you may skip to the next page to answer the following questions.



The healthcare team will provide care according to medical guidelines and will always discuss the patient's condition with the patient and family. However, the patient may be too sick for any discussion. In such cases, the team may ask the family to discuss future healthcare matters to ensure the patient's wishes are respected. If the team finds that the patient cannot speak for themselves, they will discuss treatment and decision-making options with the family, especially if the patient has not made any prior arrangements. However, if the patient has already planned and informed the team about their wishes when they become sick and incapable of speaking, the team will provide care based on the patient's wishes.

This process is called “advance care planning”

Advance care planning consists of three types:

1. **General Care Planning Goals:** This involves discussing what each patient values and their care goals (for example, in patients with chronic conditions such as diabetes, hypertension, heart disease, chronic lung disease, or cancer). Patients may have preferences regarding which medications they want to use (as medications can have varying therapeutic effects and side effects), or they may have preferences about follow-up care in the future, such as whether they would like it to be at a hospital or a local healthcare facility. Each person may have different preferences.
2. **Planning for Treatment in Critical Emergencies:** In cases where illness is complicated, and the patient is unable to communicate their needs or make decisions, doctors may perform life-saving measures or use life support equipment, such as intubation and mechanical ventilation, or perform CPR. Generally, these treatments are helpful in saving patients from critical conditions. However, if a person is in the natural end stage of life, such interventions might cause suffering without providing benefits. In such cases, the treating doctor and the patient's family may want to know if the patient would want to use life support measures, but the patient is unable to

communicate. Therefore, this decision should be planned in advance. Some people may write this plan down as a document called an "Advance Directive" or "Living Will."

3. Identifying a Decision-Maker for the Patient: This person will represent the family and make decisions in collaboration with the healthcare team about the type of care the patient should receive when the patient is no longer able to decide for themselves."

Section 5 Your opinion regarding advance care planning

✎ The following statements relate to your thoughts and feelings about advance care planning. Please let us know how much you agree with these statements by marking ✓ in the box that best reflects your opinion. There are levels to choose from, ranging from 'Strongly Disagree' to 'Strongly Agree.' You can ask the researcher at any time if you have any questions. If you do not wish to answer any question, you may leave it blank.

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1	If the patient make some document such as a living will, the physician will stop the treatment too soon.					
2	It is not necessary for the patient to preplan the advance care plan because when the patient reaches a certain age, the physician will not use a life-sustaining device.					
3	It is not necessary for the patient to make the advance care plan because the physician knows the patient's decision on treatment in the end of life period.					

#	Question	Strongly Agree	Agree	Neither Agree nor	Disagree	Strongly Disagree
4	It is not necessary for the patient to make the advance care plan because the patient can always make the decision on the treatment.					
5	Making an advance care plan means not to be careless for any potential changes in health					
6	It is not necessary for the patient to make the advance care plan because there might be a good reason if the patient is determined to be suffering.					
7	Advance care planning is suitable for the elderly or people who are more ill than the patient.					
8	Health care proxy appointments will make the decision-making on the patient's future medical care among the family members easier.					
9	Advance care planning seems difficult because the patient does not like to think about when health is deteriorating.					
10	Advance care planning will help the to make future decisions more easily if the patient becomes seriously ill.					
11	The treating physician is too busy for any advance care planning activities					

#	Question	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
12	Advance care planning will help family members make decisions about the patient's medical care more easily.					
13	Advance care planning is difficult because there are too many issues related to the patient's future medical care to think about.					
14	The patient is sure that he/she will receive preferred medical care when he/she is unable to make decisions if the physician and the family members are knowledgeable of his/her medical care preferences in advance.					
15	The patient feels at ease if he/she plans and informs the physician and the family members about his/her advance care planning.					
16	Advance care planning is not suitable for the patient because he/she makes decisions day by day.					
17	It is possible that the patient would not receive standard clinical care if he/she decides to accept or refuse some treatments ahead of time.					
18	Advance care planning will help the patient control what will happen to him/her when the patient becomes unable to make decisions.					

#	Question	Strongly Agree	Agree	Neither Agree nor	Disagree	Strongly Disagree
19	It is not necessary for the patient to make an advance care planning since his/her preference may change in the future.					
20	Advance care planning for the patient's future medical care makes me feel that the patient may live a shorter life with the family.					

Appendix 9. Documentary Proof of Ethical Clearance



คณะกรรมการจริยธรรมการวิจัยในมนุษย์ คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

หนังสือรับรองฉบับนี้ให้ไว้เพื่อแสดงว่า

รหัสโครงการ :	REC.65-417-9-1
ชื่อโครงการ :	กลไกของครอบครัวและความพร้อมในการวางแผนการดูแลล่วงหน้าในผู้สูงอายุที่ป่วยเป็นโรคมะเร็งในจังหวัดสงขลา ประเทศไทย (Family Mechanisms and Readiness for Advance Care Planning Engagement among Elderly Patients with Cancer in Songkhla Province, Thailand)
ผู้วิจัยหลัก :	ศุภกร ศรีแผ้ว สาขาวิชาเวชศาสตร์ครอบครัวและเวชศาสตร์ป้องกัน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์
ผู้ร่วมวิจัย :	สาวิตรี อึ้งนางค์กรชัย สาขาวิชาระบาดวิทยา คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ พลเทพ วิจิตรคุณากร สาขาวิชาเวชศาสตร์ครอบครัวและเวชศาสตร์ป้องกัน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ สุพีชา รุ่งเรือง สาขาวิชาเวชศาสตร์ครอบครัวและเวชศาสตร์ป้องกัน คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ชนิษฐา บ่มไต้ ฝ่ายบริการพยาบาล คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ ศิริพร อินแก้วศรี ฝ่ายบริการพยาบาล คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ รุ่งอรุณ กิตติเชษฐ์ สาขาวิชารังสีวิทยา คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

เอกสารที่รับรอง :

1. แบบเสนอเพื่อขอรับการพิจารณาจริยธรรมการวิจัยในมนุษย์ เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
2. โครงการวิจัยฉบับสมบูรณ์ เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
3. เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย (สำหรับผู้ดูแล ระยะที่ 1) เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
4. เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย (สำหรับผู้ป่วย ระยะที่ 1) เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
5. เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย (สำหรับผู้ดูแล ระยะที่ 2) เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
6. เอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมวิจัย (สำหรับผู้ป่วย ระยะที่ 2) เวอร์ชัน 3.0 ฉบับวันที่ 14 ธันวาคม 2565
7. แบบสอบถาม (สำหรับผู้ดูแล ระยะที่ 1) เวอร์ชัน 1.0 ฉบับวันที่ 14 ธันวาคม 2565
8. แบบสอบถาม (สำหรับผู้ดูแล ระยะที่ 2) เวอร์ชัน 2.0 ฉบับวันที่ 14 ธันวาคม 2565
9. ไปสเตอร์ประชาสัมพันธ์โครงการวิจัย (ระยะที่ 1) เวอร์ชัน 2.0 ฉบับวันที่ 14 ธันวาคม 2565
10. ไปสเตอร์ประชาสัมพันธ์โครงการวิจัย (ระยะที่ 2) เวอร์ชัน 2.0 ฉบับวันที่ 14 ธันวาคม 2565
11. ไปปลิวประชาสัมพันธ์โครงการวิจัย (ระยะที่ 1) เวอร์ชัน 2.0 ฉบับวันที่ 14 ธันวาคม 2565
12. ไปปลิวประชาสัมพันธ์โครงการวิจัย (ระยะที่ 2) เวอร์ชัน 2.0 ฉบับวันที่ 14 ธันวาคม 2565
13. ประวัติผู้วิจัยและหลักฐานการอบรมด้านจริยธรรมการวิจัย

ได้ผ่านการพิจารณาและรับรองจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ โดยยึดหลักจริยธรรมของประกาศเฮลซิงกิ (Declaration of Helsinki) และแนวทางการปฏิบัติการวิจัยทางคลินิกที่ดี (The International Conference on Harmonization in Good Clinical Practice) โดยบรรจุไว้ในการประชุมคณะกรรมการจริยธรรมการวิจัยในมนุษย์ ครั้งที่ 33/2565 ชุดที่ 3 วาระที่ 4.3 วันที่ 28 พฤศจิกายน พ.ศ. 2565

ขอให้นักวิจัยรายงานความก้าวหน้าโครงการวิจัย ทุก 12 เดือน และยื่นต่ออายุก่อนถึงวันหมดอายุอย่างน้อย 30 วัน

ลงชื่อ

(รศ.นพ.บุญสิน ตั้งตระกูลวานิช)

ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์
คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์

Appendix 10. A brief summary of Bayesian Network applications

This section outlines a brief summary for Bayesian network (adapted from Koller and Friedman, and Scutari^{133,134}) in three sections: representation, inference, and learning.

1. Representation

A Bayesian network (BN) is a graphical model that represents probabilistic relationships among variables. It is used for reasoning under uncertainty and consists of two main components:

1.1 Structure

BN presents relationships between random variables in a Directed Acyclic Graph (DAG), where nodes represent random variables. Directed edges/arcs (arrows) connect nodes in the BN and indicate causal or probabilistic dependencies. An absence of an edge/arc implies conditional independence between variables. Here are a set of brief explanations of BN representations: probability distributions, DAGs, and graphical separation and probabilistic independence .

Global and local probability distributions:

- A set of random variables, $X = \{X_1, X_2, \dots, X_i\}$ represents the quantities of interest.
- The multivariate probability distribution of $\mathbf{X}$, known as the global distribution, captures the joint behavior of all variables.
- Each variable $X_i \in \mathbf{X}$ has its own local distribution, representing its probabilistic behavior conditioned on its parent nodes in the network.
- Each node is associated with a Conditional Probability Table (CPT), defining the probability of the variable given its parents. The values of CPT can be derived from an observational data or expert knowledge. In case a node has no parents, its CPT simplifies to the marginal probability of the node.

Directed Acyclic Graph (DAG):

- A Bayesian network includes a DAG, $G = (V, A)$, where:
 - V : Set of nodes, with each $v \in V$ associated with a variable X_i .
 - A : Set of directed arcs, with each arc $a \in A$ representing a direct probabilistic dependency.

Graphical separation and probabilistic independence

To use BN, the model requires a set of formal definitions, firstly, a set of definitions pertaining “Map”. A dependency map (D-map) denotes the conditional independence relationships linking any triplets of variables (three subsets of variables in $\mathbf{X}$) in the DAG having a one-to-one correspondence between the dependency structure of variables in $\mathbf{X}$ and the nodes (V) of the DAG (G) for all disjoint subsets. Based on this definition, nodes which are not separated in the DAG *correspond to dependent variables* in $\mathbf{X}$, while the separated nodes (no linking arcs) *do not necessarily correspond to conditionally independent variables* in $\mathbf{X}$. On the other hand, in case of an independency map (I-map), the arcs in the DAG indicate which variables in $\mathbf{X}$ are conditionally independent. Specifically, nodes that are separated in DAG represent conditionally independent variables in $\mathbf{X}$. However, nodes that are connected in DAG do not always correspond to dependent variables in $\mathbf{X}$. Finally, if a graph is both a D-map and I-map of the probabilistic relationships (i.e., “faithful” or “isomorphic” to the distribution), the graph is called a perfect map. However, it is challenging to find a perfect map from real-world data, thus datasets in general often lack the perfect map.

A DAG (G) is called a Bayesian Network (BN) and denoted as $BN = (G, \mathbf{X})$ if and only if G is a minimal **I-map** of a probability distribution P over the set of variables $\mathbf{X}$. This means that G captures all the conditional independencies in $P(\mathbf{X})$, and none of its arcs can be removed without losing its property of representing the independencies in $P(\mathbf{X})$. This definition allows us to apply the decomposition property for the global distribution $P(\mathbf{X})$ with the Chain Rule as follows.

$$P(\mathbf{X}) = \prod_{i=1}^n P(X_i | \text{Parent}(X_i))$$

The figure below illustrates an example of BN. To formally define, if we are interested in A, {B,C} are the parents of A, {B,C,F,G} are the ancestors of A. Additionally, {D,E} are children of A, and {D,E,K,L} are descendants of A. Using the Chain rule, the global probability $P(A, B, C, D, E, F, G, K, L)$ can be decomposed down into the product of several local probabilities (CPT or marginal probability) as follows.

$$\begin{aligned}
 P(A, B, C, D, E, F, G, K, L) \\
 &= P(G) * P(F) * P(C|G) * P(B|F) * P(A|C, B) * P(E|A) * P(L|E) \\
 &\quad * P(D|A) * P(K|D)
 \end{aligned}$$

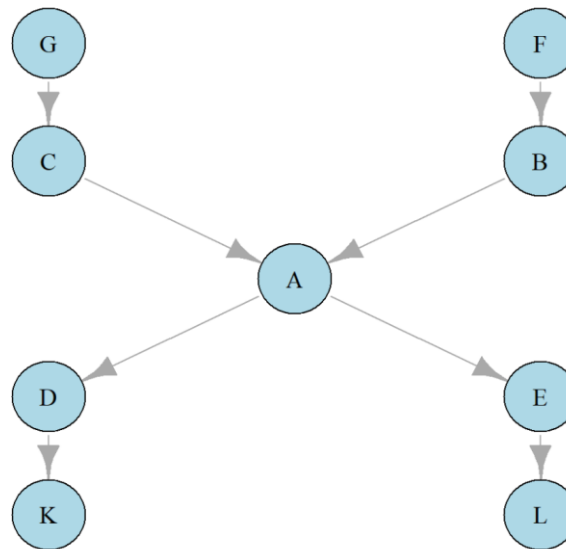


Figure A BN representing $P(A, B, C, D, E, F, G, K, L)$

In addition, the *Local Markov Property* states that each node in a Bayesian network is conditionally independent of its non-descendants (nodes without a path from X_i) given its parents. While parents are not fully independent of their children, Bayes' theorem shows how information about a child can update the distribution of its parents. The equivalence of serial connections allows different Bayesian networks, $X_i \rightarrow X_j \rightarrow X_k$ and $X_i \leftarrow X_j \rightarrow X_k$, to encode the same conditional independencies and represent the same global distribution, forming equivalence classes of DAGs. DAGs are equivalent if they share the same skeleton (underlying undirected graph) and **v-structures** (convergent connections like $X_i \rightarrow X_j \leftarrow X_k$, where X_j is a collider and there is no direct

arc between X_i and X_k). The direction of arcs in v-structures is crucial, as altering them changes the global distribution, unlike serial or divergent connections, which remain probabilistically equivalent.

2. Inference

Inference in a Bayesian network involves querying the model to compute probabilities of interest. Exact inference is a mathematical procedure applying product multiplication and summation of irrelevant variables (variable inference) or belief propagation (message passing). These two types of inference work well when the BN is small (depending on the number of nodes and arcs). But when a network is large, approximate inference would be more efficient. It encompasses various sampling methods (i.e., generating samples from the network to estimate probabilities). These procedure operate through algorithmic ordering to ensure efficient computation.

For instance, one would like to query $P(A, B, C, D, E, F, G)$ from $P(A, B, C, D, E, F, G, K, L)$, using variable elimination. The calculation proceed through summing out the unrelated variables from the product of the global distribution.

$$\begin{aligned}
 P(A, B, C, D, E, F, G) \\
 &= \sum_K \sum_L P(G) * P(F) * P(C|G) * P(B|F) * P(A|C, B) * P(E|A) \\
 &\quad * P(L|E) * P(D|A) * P(K|D)
 \end{aligned}$$

3. Learning

Learning in Bayesian networks involves two aspects: learning the structure and learning the parameters.

Structure Learning

Structure learning identifies the DAG structure of a BN from data. The following methods can be used when appropriate, however, score-based methods are the only available methods at the present to deal with datasets with missing data. In a DAG with p nodes, we may require up to $\frac{1}{2}p(p - 1)$ possible arcs.

- **Constraint-Based Methods:** statistical tests (e.g., independence tests) are used to infer relationships.

- **Score-Based Methods:** a scoring function (e.g., Bayesian Information Criterion, BIC) is defined and selected algorithms search for the structure that maximizes the score of the overall network structure. Penalized node-average likelihood (PNAL) can also be computed by subtracting the BIC with the penalized term. It is recommended for learning BN structures with incomplete data, the closer to zero the score is, the better the network ability to explain the observed data.

$$\text{PNAL} = \frac{1}{n} l(X_i | \text{Parent}(X_i)) - \left(\frac{\log(n)}{2n} |\Theta_{X_i}| \right),$$

where n = number of available data point,

Θ_{X_i} = parameters of a node/variable, and

l = likelihood function

- **Hybrid Methods:** a combination of constraint-based and score-based approaches for improved accuracy is used.

Parameter Learning

Given a fixed BN structure, parameter learning estimates the CPTs for the variables.

- **Complete data:** maximum likelihood estimation (MLE) or Bayesian estimation can be used to compute model-implied probability parameters.
- **Incomplete Data:** expectation-Maximization (EM) can be used to handle noise from missingness.

Bayesian network parameter learning can result in a discrete (multinomial), continuous (Guassian), or mixed network. Generally, discrete BN are commonly used. The corresponding frequency in the data will be applied to compute probability parameters in the network. For example, from the above network, for the model-implied probability of e_1 given a_1 , or $\hat{P}(E = e_1 | A = a_1)$, the parameters (conditional probability) could be derived from the equation:

$$\begin{aligned} \hat{P}(E = e_1 | A = a_1) &= \frac{\hat{P}(E = e_1, A = a_1)}{\hat{P}(A = a_1)} \\ &= \frac{\text{Number of observations for which } E = e_1, A = a_1}{\text{Number of observations for which } A = a_1} \end{aligned}$$

However, in many cases, the learned BN structure may correspond to many instances of data which could result in many zero cells. Thus, we may use estimated posterior probabilities instead of maximum likelihood estimates by incorporating a uniform prior (π) and/or an imaginary sample size (iss) to the empirical probability computation (Bayesian method):

$$\begin{aligned} \text{Posterior probability } \hat{P}(E = e_1, A = a_1) \\ = \frac{iss}{n + iss} \pi_{E=e_1, A=a_1} + \frac{n}{n + iss} \hat{P}(E = e_1, A = a_1) \end{aligned}$$

$$\text{Posterior probability } \hat{P}(A = a_1) = \frac{iss}{n + iss} \pi_{A=a_1} + \frac{n}{n + iss} \hat{P}(A = a_1)$$

And,

$$\begin{aligned} \pi_{E=e_1, A=a_1} &= \frac{1}{\text{number of category in } E * \text{number of category in } A} \\ \pi_{A=a_1} &= \frac{\text{number of category in } E}{\text{number of category in } E * \text{number of category in } A} \end{aligned}$$

Then, compute:

$$\hat{P}(E = e_1 | A = a_1) = \frac{\text{Posterior } \hat{P}(E = e_1, A = a_1)}{\text{Posterior } \hat{P}(A = a_1)}$$

Appendix 11. Distributions of readiness for ACP

Type of ACP	Readiness	Probability	Lower 95% CI	Upper 95% CI
Goal discuss Fam	Action	0.082	0.021	0.146
	Contemplate	0.028	0.000	0.093
	Maintain	0.292	0.231	0.356
	Prepare	0.299	0.238	0.363
	Precontemplate	0.299	0.238	0.363
Goal discuss Dr	Action	0.036	0.000	0.098
	Contemplate	0.050	0.000	0.112
	Maintain	0.068	0.011	0.130
	Prepare	0.548	0.491	0.610
	Precontemplate	0.299	0.242	0.361
CPR discuss Fam	Action	0.050	0.000	0.114
	Contemplate	0.036	0.000	0.100
	Maintain	0.231	0.171	0.295
	Prepare	0.395	0.335	0.459
	Precontemplate	0.288	0.228	0.352
CPR discuss Dr	Action	0.032	0.000	0.092
	Contemplate	0.060	0.004	0.120
	Maintain	0.057	0.000	0.116
	Prepare	0.584	0.527	0.643
	Precontemplate	0.267	0.210	0.326
DPAHC	Action	0.007	0.000	0.059
	Contemplate	0.046	0.000	0.098
	Maintain	0.018	0.000	0.069
	Prepare	0.730	0.680	0.781
	Precontemplate	0.199	0.149	0.251
Directives	Action	0.004	0.000	0.066
	Contemplate	0.146	0.085	0.209
	Maintain	0.007	0.000	0.070
	Prepare	0.352	0.292	0.415
	Precontemplate	0.491	0.431	0.554

Remarks: CI = multinomial confidence intervals

Appendix 12. Robustness of the study Bayesian network (BN)

This section overviews how BNs were built and how we justified the final BN. There are two main sections: variable selection and network validation.

Variable selection

We scope the variable selection using findings from our qualitative study. Themes and subthemes were applied to guide the selection. Supplementary table below shows the selection framework per themes and subthemes.

Supplementary table 1 Application of qualitative findings for variable selection

Qualitative themes/subthemes	Quantitative variables
Advantageous opportunity	Patient's and caregiver's pro of ACP
Contemplations and barriers	Patient's and caregiver's con of ACP and familiarity of ACP
Cues for ACP initiation	
• Multiple health conditions	Comorbidity*
• Awareness of low chance for recovery	Understanding towards illness
• Experience suffering from medical treatments	Experience of prior resuscitation
• Having a close caretaker/ not wishing to burden the family	Family type, Total family functioning
• Trusting doctor-patient relationship	Quality of information received from physician

Remarks: Charlson Comorbidity Score ≥ 8

Network validation

The BN structures were learned from different score-based algorithms with/without mandatory arcs implementation. The empty model (18 variables 0 arcs) had significantly poorer likelihood (score = -11.276) than the identified models. As a result of the expert ratings on a list of choice arcs, 12 mandatory arcs were defined. We examined the robustness of these expert-identified arcs by bootstrapping as the first part

of model averaging (MA) procedure to evaluate whether those expert arcs were presented in most (>50%) of 500 learned (score-based algorithm: HC or GD) structures. As a result, we found that almost all expert arcs were robust, with only one arc (CPR_fam $\rightarrow$ Directives) having a limited strength (15% occurrence among the structures), implying that most expert arcs are justifiable arcs in most circumstances. We decided to apply the whole set of 12 arcs. In procedure without mandatory arcs, we found there were always nodes without linked arcs. Thus, such models could not capture all potential relationships among the variables (see Supplementary table below). However, when the mandatory arcs were added to the learning process. We found that more relationships could be captured while such procedure did not always increase the model size.

Supplementary table 2 Comparison of BN structures

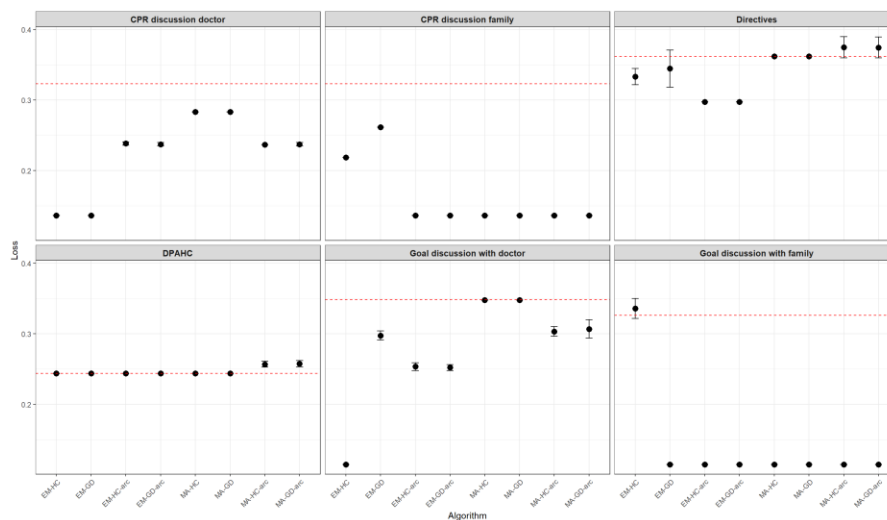
Leaning procedure	Network	Learning algorithm	Score*	N Arc	Node without arc	N Parameter
Structural expectation maximization (EM)	EM-HC	HC	-10.142	16	4	39
	EM-HC-arc	HC + mandatory arcs	-10.041	23	2	59
	EM-GD	tabu	-10.066	18	4	45
	EM-GD-arc	tabu + mandatory arcs	-10.041	23	2	59
Model averaging (MA)	MA-HC	HC	-9.781	42	1	364
	MA-HC-arc	HC + mandatory arcs	-9.561	53	0	361
	MA-GD	tabu	-9.771	42	1	352
	MA-GD-arc	tabu + mandatory arcs	-9.397	56	0	505

Remarks: * Penalized node-averaged score, HC Hill-Climbing, GD 'tabu' Greedy Search, MA Model Averaging

Furthermore, we applied 10-fold cross-validation procedure to validate the choice BN whether it could provide sensible predictions on ACP readiness outcomes. Supplimentary figure 1 below illustrates incorrect predictions of different

learned structures. Prediction loss was used as the indicator, the lower the loss, the better the model predict an outcome correctly. In addition, we applied line of no information as the benchmark (horizontal lines) for another poor prediction property. A value positioned exactly on the line means the model utilize only marginal observed probability to predict the outcome.

The losses slightly varied in “Directives” and “DPAHC”. Adding arcs appeared to slightly affect the losses in larger models (MA-HC and MA-GD), while having relatively larger effects to the losses in smaller models (EM-HC and EM-GD). In general, the model without arcs tended to predict ACP outcomes based on the observed marginal probability, which means information from the other node is not incorporated and they will predict only one common category for the readiness for ACP, all ready or all not ready. This phenomenon also highlights the value of the models with arcs that at least can perform prediction tasks comparably to the non-arc models in most cases, and even performed relatively better in some cases. Also, without these mandatory arcs, the BN models could have several equivalent models in which certain causal paths are insensible (reversing certain arcs will still provide the same mathematical operation and result in the same probabilistic query values) such as pros and cons pointing all together to resuscitation experience. Finally, MA-HC-arc was selected as the best empirical model for further inference.

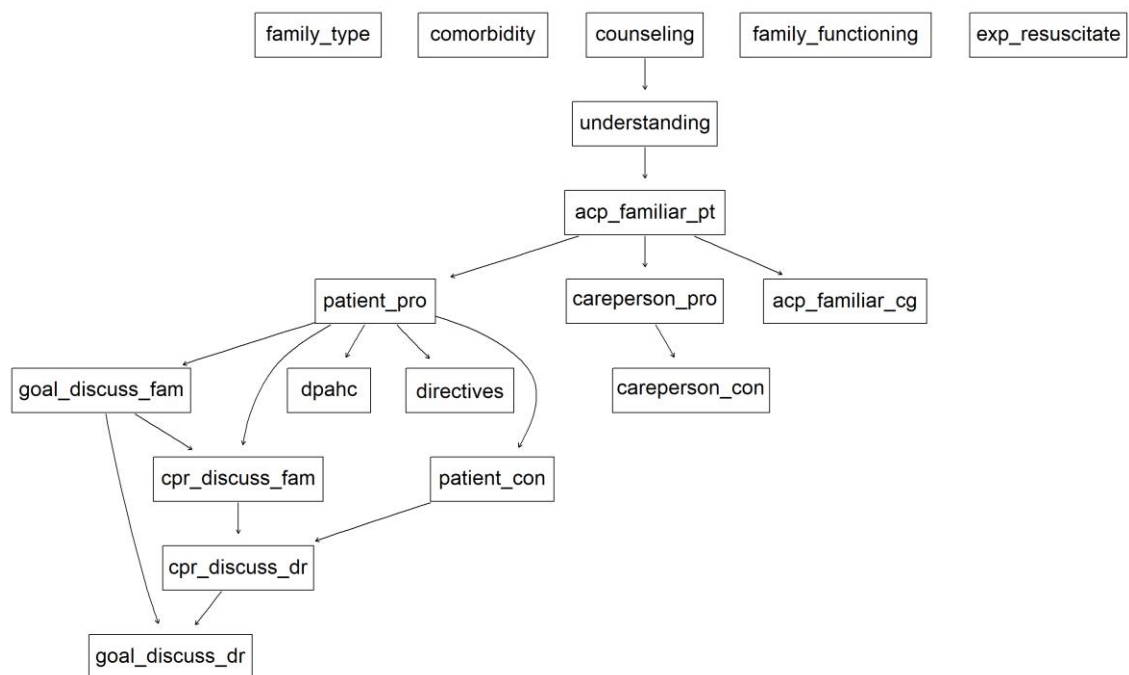


Supplementary figure 1 Incorrect prediction (loss) in learned BNs

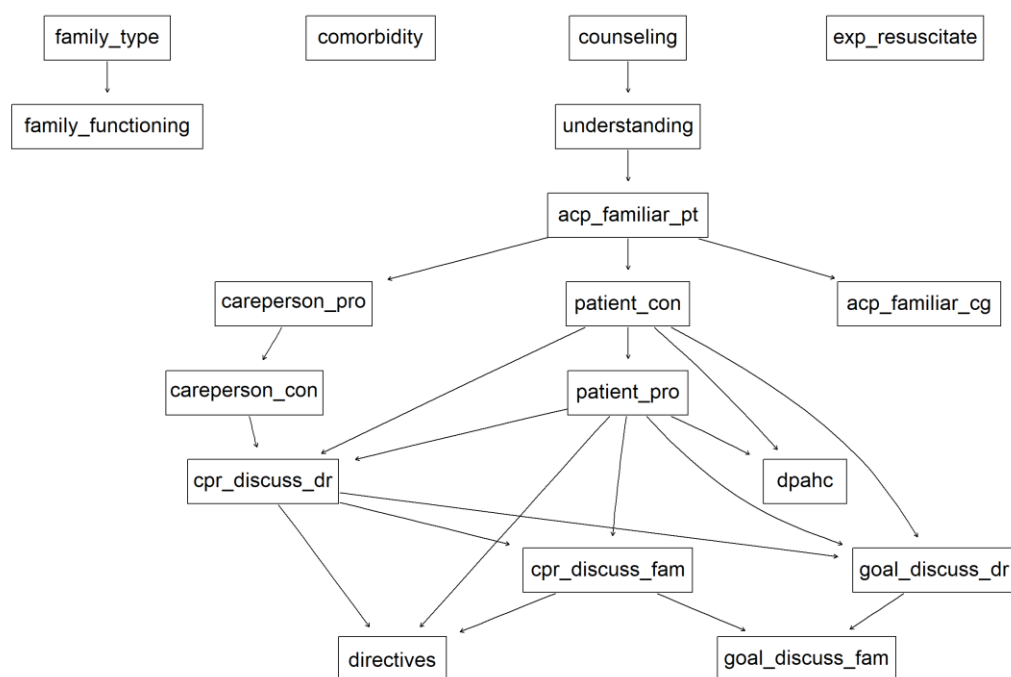
Prediction loss (dots) of different algorithms sorted by the number of parameters in the network (left to right) and their standard deviations (error bars), and

dashed horizontal lines showing the prediction which the predictions are based only on observed marginal probabilities

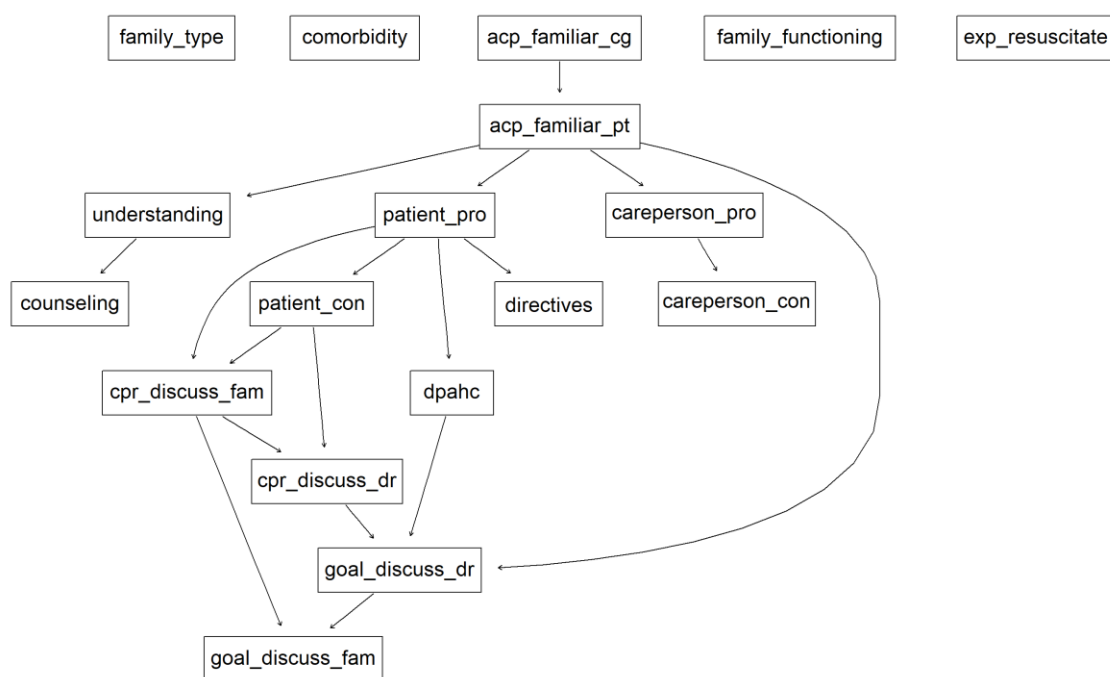
As explained above, eight choice network structures were considered in our study. In this section, the final DAG and the seven omitted structures in the result section were showed below, as the unused alternatives. In general, lack of connection can be seen, meaning that certain nodes were completely independent of the other nodes (variables), leading to a conclusion that such lack of dependency occurred in both in the observed data and in real world. However, we strongly believed that our observations are useful but might not reflect the exact properties of the real-world connectedness because of potential biases (e.g., volunteer and/or response bias) and missingness. Since the likelihood (network score) of higher parameterized models (more arcs, potentially overfitted) tend to be higher than smaller models, the goal is to maintain predictive ability (no or with acceptable loss of predictive accuracy) and understandability (ability to provide reasonable relationship among the variables within and across time tiers). Therefore, we chose a conservative approach to balance the observed data, the algorithmic (probabilistic) process, and the expert knowledge, resulting in choosing the final model shown in the main result section.



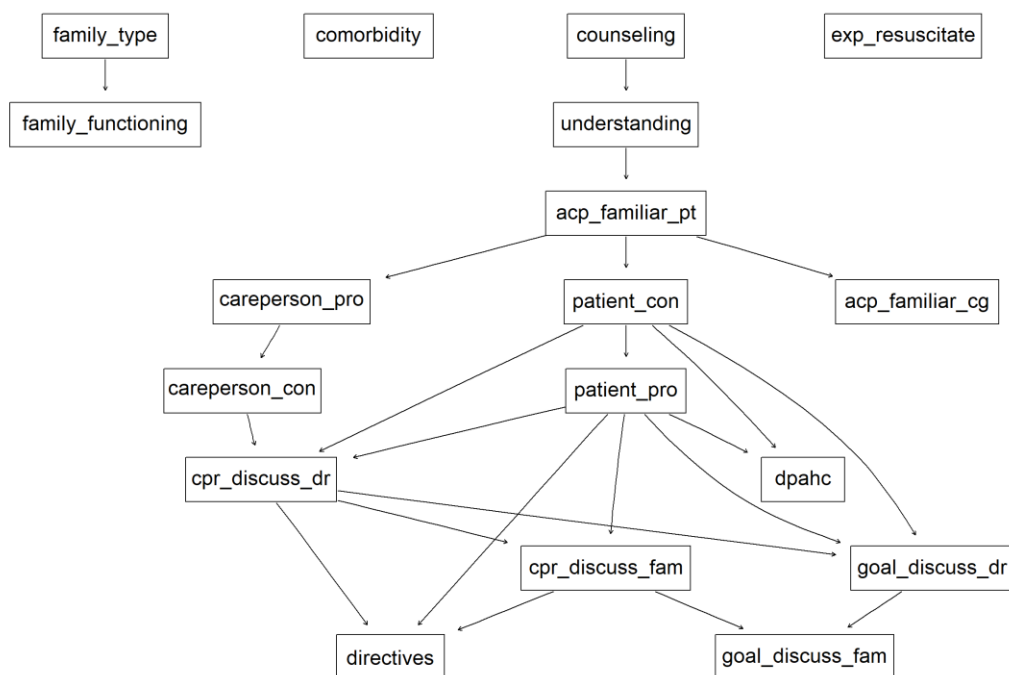
Supplemental figure 2 Learned network structure from Hill-Climbing algorithm



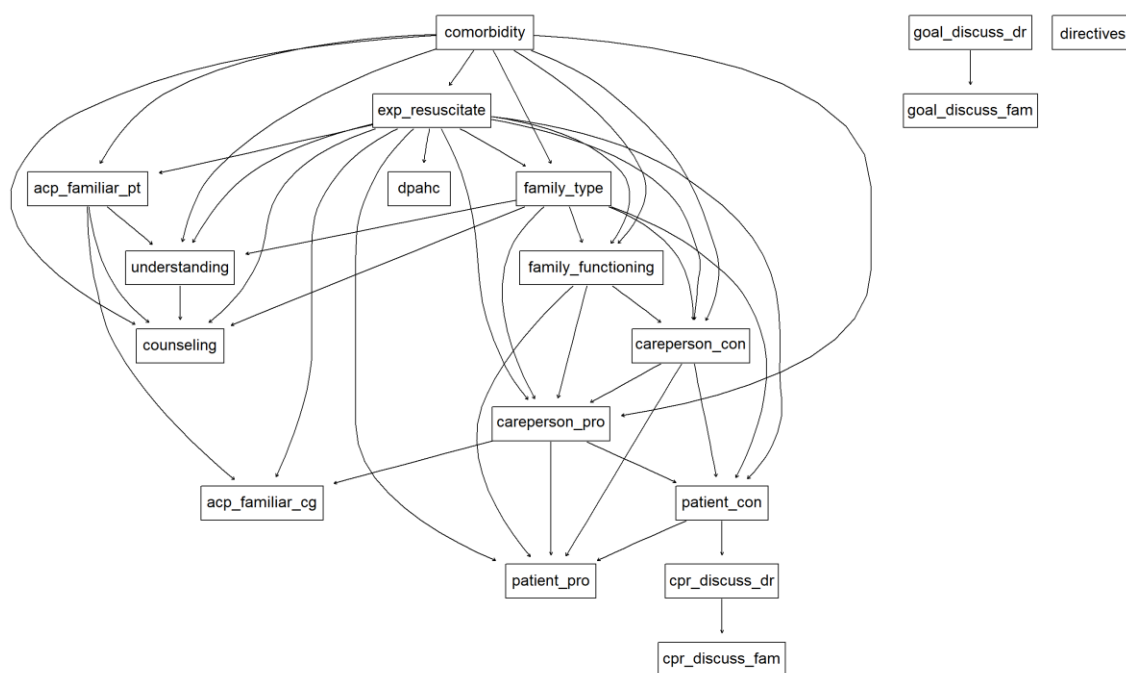
Supplemental figure 3 Learned network structure from Hill-Climbing algorithm plus mandatory arcs



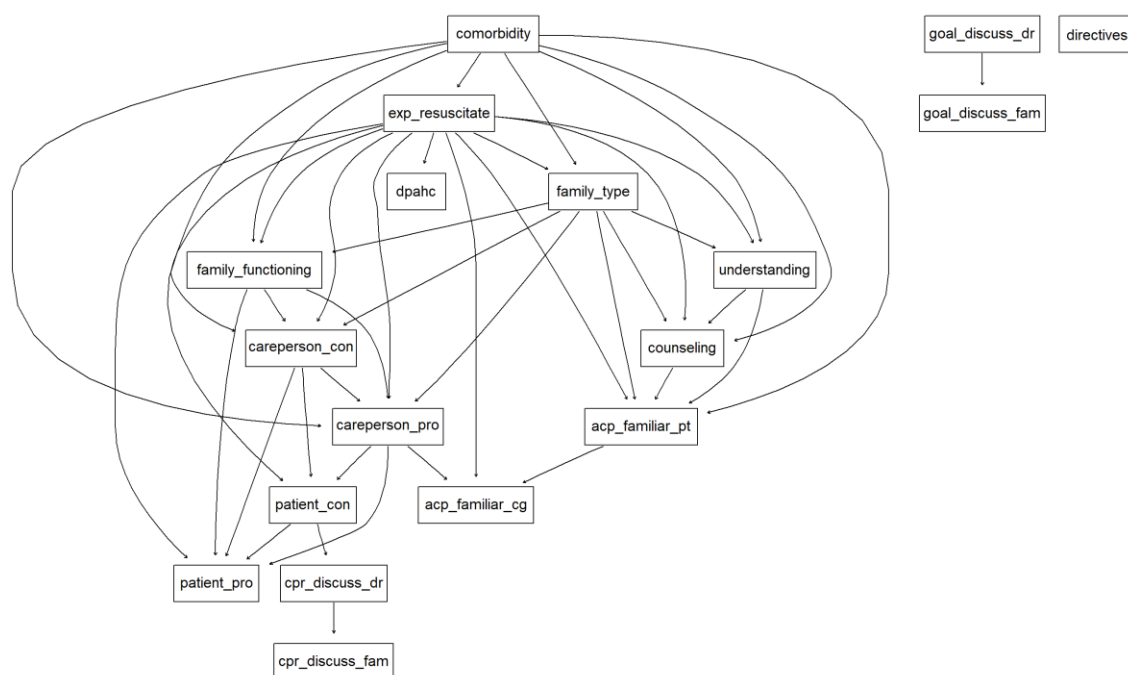
Supplemental figure 4 Learned network structure from Greedy Search algorithm



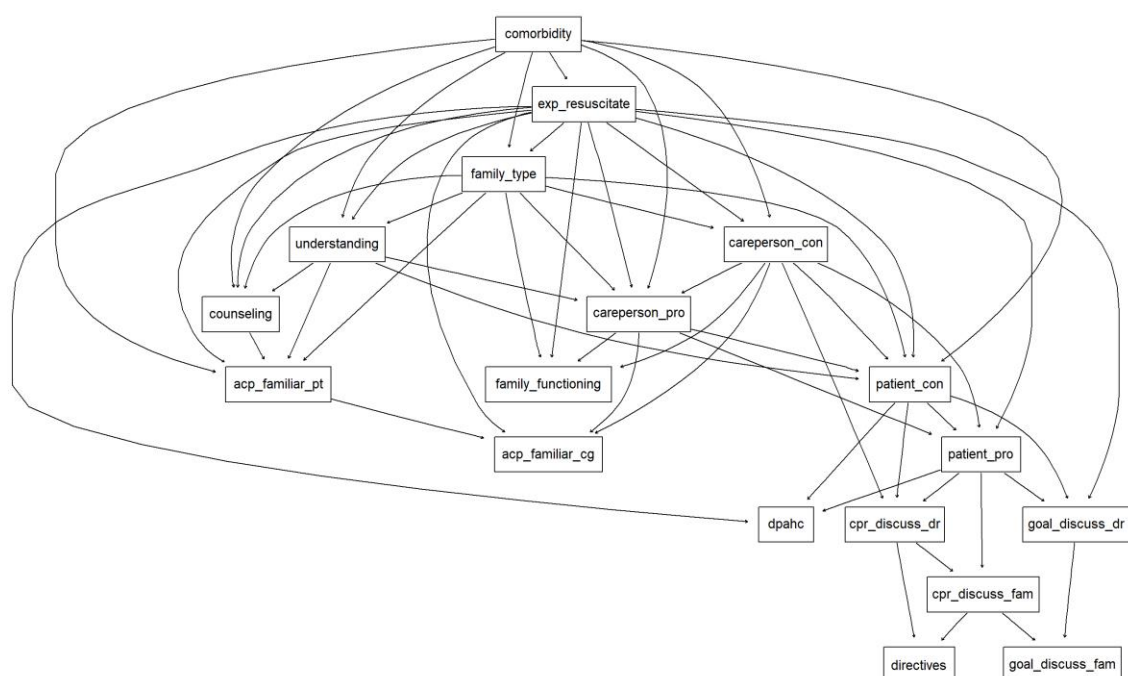
Supplemental figure 5 Learned network structure from Greedy Search algorithm plus mandatory arcs



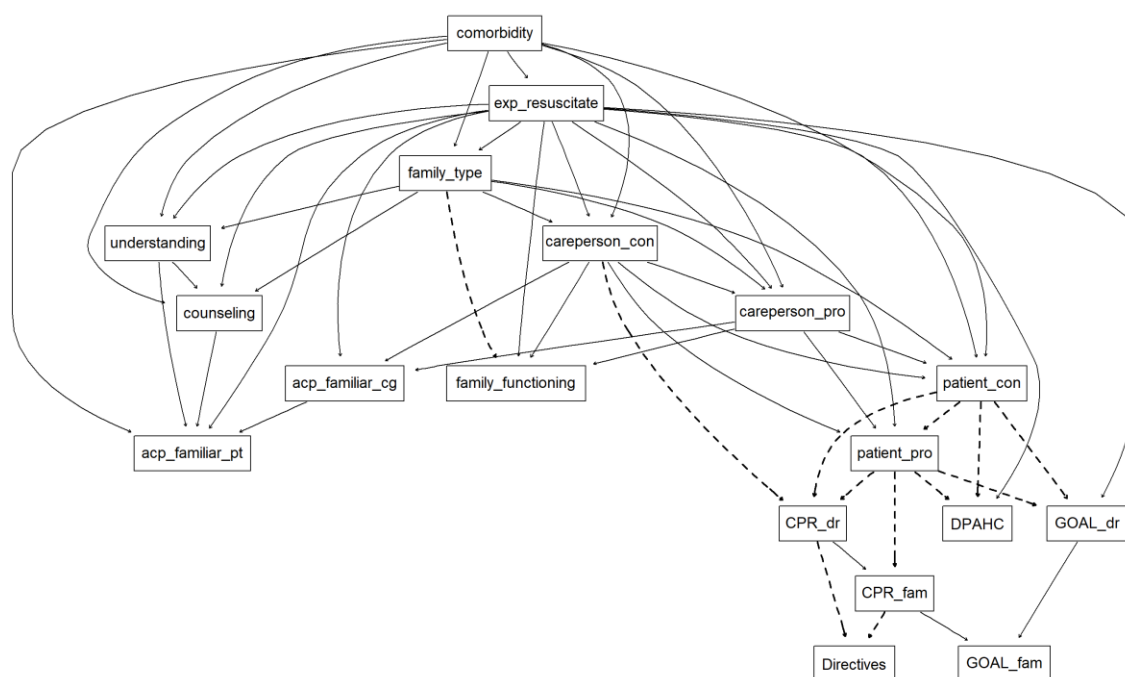
Supplemental figure 6 Learned network structure from Model Averaging (Hill-Climbing algorithm)



Supplemental figure 7 Learned network structure from Model Averaging (Greedy Search algorithm)



Supplemental figure 8 Learned network structure from Model Averaging (Greedy Search algorithm plus mandatory arcs)



Supplemental figure 9 Learned network structure from Model Averaging (Hill-climbing algorithm plus mandatory arcs – final model), dashed line representing the expert suggested arcs

Appendix 13. Distributions of perceptions regarding ACP

Variable	Caregiver						Patient				
	Totally disagree	Disagree	Neutral	Agree	Totally agree	N/A	Totally disagree	Disagree	Neutral	Agree	Totally agree
ATATIM	74 (26.5)	111 (39.8)	35 (12.5)	38 (13.6)	10 (3.6)	11 (3.9)	64 (22.9)	76 (27.2)	27 (9.7)	89 (31.9)	23 (8.2)
CAREFL	3 (1.1)	2 (0.7)	16 (5.7)	127 (45.5)	122 (43.7)	9 (3.2)	3 (1.1)	6 (2.2)	15 (5.4)	142 (50.9)	113 (40.5)
CONTRL	2 (0.7)	11 (3.9)	31 (11.1)	145 (52.0)	81 (29.0)	9 (3.2)	3 (1.1)	7 (2.5)	56 (20.1)	139 (49.8)	74 (26.5)
DESTIN	81 (29)	114 (40.9)	18 (6.5)	38 (13.6)	19 (6.8)	9 (3.2)	84 (30.1)	84 (30.1)	18 (6.5)	68 (24.4)	25 (9.0)
DOCBUS	41 (14.7)	99 (35.5)	65 (23.3)	36 (12.9)	27 (9.7)	11 (3.9)	30 (10.8)	92 (33.0)	23 (8.2)	93 (33.3)	41 (14.7)
DOCKNO	39 (14.0)	84 (30.1)	42 (15.1)	71 (25.4)	31 (11.1)	12 (4.3)	32 (11.5)	51 (18.3)	57 (20.4)	104 (37.3)	35 (12.5)
EASECG	3 (1.1)	3 (1.1)	10 (3.6)	144 (51.6)	112 (40.1)	7 (2.5)	1 (0.4)	9 (3.2)	34 (12.2)	111 (39.8)	124 (44.4)
EASEDM	4 (1.4)	6 (2.2)	9 (3.2)	131 (47.0)	118 (42.3)	11 (3.9)	2 (0.7)	10 (3.6)	43 (15.4)	100 (35.8)	124 (44.4)
ENSURE	3 (1.1)	9 (3.2)	36 (12.9)	141 (50.5)	83 (29.7)	7 (2.5)	6 (2.2)	11 (3.9)	83 (29.7)	120 (43.0)	59 (21.1)
FUTILE	21 (7.5)	48 (17.2)	40 (14.3)	92 (33.0)	65 (23.3)	13 (4.7)	5 (1.8)	20 (7.2)	19 (6.8)	128 (45.9)	107 (38.4)
HEAVY	63 (22.6)	106 (38)	39 (14.0)	47 (16.8)	15 (5.4)	9 (3.2)	113 (40.5)	90 (32.3)	14 (5.0)	50 (17.9)	12 (4.3)
HRMONY	5 (1.8)	9 (3.2)	21 (7.5)	149 (53.4)	87 (31.2)	8 (2.9)	3 (1.1)	14 (5.0)	61 (21.9)	107 (38.4)	94 (33.7)
INFPOS	41 (14.7)	78 (28.0)	79 (28.3)	61 (21.9)	12 (4.3)	8 (2.9)	81 (29.0)	88 (31.5)	13 (4.7)	83 (29.7)	14 (5.0)
LOWSTD	51 (18.3)	64 (22.9)	73 (26.2)	62 (22.2)	22 (7.9)	7 (2.5)	125 (44.8)	88 (31.5)	29 (10.4)	26 (9.3)	11 (3.9)
RELIEF	3 (1.1)	3 (1.1)	18 (6.5)	132 (47.3)	114 (40.9)	9 (3.2)	2 (0.7)	12 (4.3)	37 (13.3)	126 (45.2)	102 (36.6)
SADTALK	64 (22.9)	96 (34.4)	42 (15.1)	49 (17.6)	18 (6.5)	10 (3.6)	96 (34.4)	119 (42.7)	21 (7.5)	39 (14.0)	4 (1.4)
SICKER	47 (16.8)	93 (33.3)	35 (12.5)	72 (25.8)	21 (7.5)	11 (3.9)	78 (28.0)	104 (37.3)	31 (11.1)	57 (20.4)	9 (3.2)
TOOFAR	50 (17.9)	120 (43.0)	55 (19.7)	38 (13.6)	7 (2.5)	9 (3.2)	73 (26.2)	91 (32.6)	15 (5.4)	79 (28.3)	21 (7.5)
TOSTOP	66 (23.7)	68 (24.4)	45 (16.1)	56 (20.1)	32 (11.5)	12 (4.3)	143 (51.3)	76 (27.2)	28 (10.0)	27 (9.7)	5 (1.8)

UNSTABL	32 (11.5)	96 (34.4)	68 (24.4)	62 (22.2)	13 (4.7)	8 (2.9)	50 (17.9)	54 (19.4)	61 (21.9)	96 (34.4)	18 (6.5)
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Appendix 14. Expert ratings form for mandatory arcs

A template of the expert knowledge query form is provided below (an example of question variable (i.e., patient's con) is only shown, meaning that it can be replaced by any of the remaining variables in the choice variables). This electronic form was sent to the invited experts.

Instruction

Please provide your opinion on whether **the factor in the question is the potential cause of the factors in the options**

1. Question variable: Patient's perception of ACP in terms of harm changes (increases/decreases)

Choice	Disagree	Uncertain	Agree
Patient's perception of ACP in terms of benefits changes (increases/decreases)			
Caregiver's perception of ACP in terms of benefits changes (increases/decreases)			
Caregiver's perception of ACP in terms of harm changes (increases/decreases)			
Occurs/Does not occur: Family discussion on treatment goals			
Occurs/Does not occur: Discussion on treatment goals with the treating physician			
Occurs/Does not occur: Discussion about tube CPR with family members			
Occurs/Does not occur: Discussion about tube CPR with the treating physician			
Occurs/Does not occur: Assignment of a surrogate			

Appendix 15. Manuscript 1

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RESEARCH

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Advantages, barriers, and cues to advance care planning engagement in elderly patients with cancer and family members in Southern Thailand: a qualitative study

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Abstract

Background Older cancer patients are vulnerable to poorer health outcomes during cancer treatment. Although the Thai elderly had their own preferences towards future medical care and advance care planning (ACP) could help cancer patients make informed decisions, Thai physicians report a low ACP engagement rate. Thus, this study aimed to explore the perceptions of older cancer patients and their families towards ACP engagement.

Method We used a qualitative approach to explore the perceptions of non-haematological cancer patients aged ≥ 60 years old and their primary caregivers. The study was conducted at the Oncology Radiotherapy Referral Center, Songklanagarind Hospital in Southern Thailand. Semi-structured in-depth interviews were conducted with the patients and their caregivers. Thematic analysis was used to identify and analyze recurring patterns and themes of perceptions regarding ACP engagement within the interview transcripts.

Results Among the 138 families approached, 32 interviews were conducted. Three themes were found: (1) Advantageous opportunity: the patients believed ACP would help them realize their life values, and ensure that their preference would be respected; (2) contemplation and barriers to ACP: ACP is unfamiliar and unnecessary, might have low utility, worry patients and family members, take away optimism, would not be a proper activity for the patient at the current health situation; and (3) Cues for ACP initiation: perceived conformity with one's religion, awareness of the current cancer state, having multiple comorbidity or experience suffering related with medical care, wishing not to burden family, having close family members, and trust in physicians.

Conclusion ACP engagement could be hindered or promoted by perceptions of older patients and/ or their family members, as well as the communication skills of the care providers. Care professionals who aim to initiate ACP should minimize the potential barriers, make the ACP benefits salient, and watch for cues indicating a propitious time to start the ACP conversation.

Keywords Advance care planning, Elderly, Cancer, Oncology, Behavior change, Determinants, Qualitative research

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Introduction

Palliative care is specialized care which aims to reduce suffering and improve the quality of life for people who have life-threatening or life-limiting illnesses, and it has been recognized in many countries as a basic health right [1]. Palliative care functions through thorough assessments and comprehensive care, which are person-centered and goal-oriented [1]. Advance care planning (ACP) is a voluntary process of communication between a doctor, the patient, and the patient's relatives which is important in gaining a clear understanding of the individual's values and goals of care over time [2, 3]. ACP can help improve the quality of the palliative care the individual receives as it helps ensure that the individuals receive care that is consistent with their values, goals, and preferences [4]. ACP ranges from speaking with the patient to help understand the patient's values, and if there are preferred or non-preferred options for care, to preparing legal documents such as a power of attorney stating the legal decision maker(s) for the patient if or when they become incapacitated [2, 5]. Previous studies reported that ACP helped individuals to have peace of mind [6], reduced psychological distress among surviving family members [7], improved the patient's satisfaction and quality of life [8], and lead to fewer hospitalizations and more hospice use, which in turn helped reduce healthcare costs [9–11]. Nevertheless, applications and recognition of ACP varied across countries [12].

The World Health Organization reported that 56.8 million people globally require palliative care, however, only fourteen per cent are receiving it [13]. The main barriers to high-quality palliative care include a lack of health system provision and awareness, misconceptions about palliative care eligibility and opioid use, and cultural and social barriers to communications involving death and dying [13]. In recent decades in Thailand, palliative care has been advocated by the Ministry of Public Health (MOPH) and non-government organizations [14, 15], and a living will has been recognized as legally binding in the National Health Act, section 12, since 2007. However, their use and the concepts of ACP have not been widely recognized by either general Thai citizens or most healthcare professionals. The Thai government started to actively promote ACP through a National Steering Committee and cooperation agreements with the Thai Palliative Care Society (THAPS) and other civil society organizations [16], and Thai standards for advance care planning were later published in 2022. The provision of ACP was also supported under the Thai national health system by national health policies, resulting in continuous training for palliative care providers and service reimbursement for government hospitals [14]. Despite these efforts, care providers found that ACP has not yet been commonly adopted by Thai families [14, 17] and

it was uncommon for conversations about ACP to be directed by a physician or the patient's family [14, 18]. This phenomenon could result from the members prioritizing seniority and respect for elders, and older family members are treated as saints in the family [12, 14, 18]. Nevertheless, the elderly might have missed the important chance to say if they would like to stay at home for the final years, and do not wish to be admitted to a hospital for burdensome treatments if the chance of survival is low [19].

Cancer is a group of diseases of which the incidences commonly peaks in older adults and the patients likely experience an acute decline in health when their cancer advances [20, 21]. Also, the elderly are an age group in which the persons are susceptible to multiple morbidities and ageing changes; even those without significant morbidities could experience fragility and functional impairment as they age [21]. When the elderly get cancer, they are more likely to experience poorer cancer outcomes compared with younger patients, for example, they tend to have higher mortality and are at risk of adverse reactions resulting from chemotherapy and radiotherapy [22–25]. ACP is an important element in cancer care since it helps cancer patients establish informed decisions for their future cancer treatment [26–28]. However, it is common for cancer patients to refuse to consider ACP [28, 29].

A systematic review evaluating the ACP context in cancer care in several Western countries summarized that ACP had a bidirectional relationship between patient and family, as well as health professionals; it can provoke fear and distress due to the timing of initiation and the person who initiates talking about the decision for the end of life. In addition, there were also complexities in views of autonomy and institutional effects on ACP, and knowledge in ACP and experience towards end-of-life care [29]. More locally, a previous study in Thailand showed that older cancer patients preferred to be told the full truth about their illness, to have their family fully informed, and to pass away at home [30]. However, it appears consistently that Thai physicians and families do not normally engage the patients in conversations regarding treatments and prognoses owing to a lack of confidence to convey the messages, fears of negative psychological consequences to the patients and their beliefs that talking about bad things would make them happen [14, 17]. However, we could expect these ACP engagement modifiers to differ across settings even in the same country. The South of Thailand is an area where people have multicultural backgrounds [31], and we still have had a low level of understanding of ACP engagement in older patients and their families in this part of Thailand. Thus, the current study aimed to explore the perceptions and attitudes of older cancer patients in Southern

Thailand and their caregiving family members towards ACP engagement.

Methods

Our study applied a qualitative approach to explore the perceptions and attitudes of older patients with cancer and their caregiving family members towards advance care planning, and applied content analysis as recommended in the thematic analysis framework [32].

Informant selection

We purposively selected patients who were 60 years of age or older, with non-haematological cancer, and able to understand and communicate in Thai and their caregiving family members who were 18 years old or older and had contributed the highest number of hours (compared with the other family members) for the patient's care. Such criteria were applied to identify and select patients who potentially had rich information to describe the patient's perceptions towards ACP in older people with a solid tumor, of which the cancer types share similar disease trajectories [33, 34]. Patients who could not tolerate the interview, had obvious cognitive impairment or mental problems, had moderate to severe pain, or had brain lesions were excluded. Patients who had regular radiotherapy sessions and were having a follow-up visit were considered potential study informants. After the routine care, potential informants were preliminarily informed about the study by the registered nurses who were knowledgeable of the selection criteria. If the potential participants seemed amenable, the nurse then informed the researcher. SS invited interested patients and their caregivers to the consultation room for a face-to-face discussion to provide full information on the study. The patients and caregivers who agreed to participate were then asked to sign an informed consent form and arrange an appointment for an in-depth interview.

Setting

The study was conducted from January 2023 – April 2023 at the Oncology Radiology Clinic, Songklanagarind Hospital, the major referral center for cancer patients in Southern Thailand.

Data collection

The interview guide was first developed by the research team, incorporating questions from a previous study [6] and suggestions from local palliative care consultants. Due to a concern of unfamiliarity with the concept of ACP in some of the informants, we designed our interview guide to let the interviewer provide basic information about the ACP concepts. The additional files show interview guides for patients and caregivers in more detail (see Additional file 1 and 2). We pilot-tested the

interview guide with 3 patients who had the same features as the formal informants to evaluate the comprehensibility of the questions. SS (previously trained in qualitative research methods and currently working as a palliative care physician at the study center) conducted all the semi-structured in-depth interviews with each informant. The interview took place at a consultation room to ensure that we could effectively address any potential mental or physical issues, such as psychological reactions, that might arise. While we were carrying on with our data collection, a few questions were later added to capture more detailed data based on what the interviewer learned from the previous interviews. To be aware of potential sensitive points about and avoid difficult areas of questioning, the caregivers were interviewed first and then the older patients. The interviews took approximately 45 min per session and the interviewer had not known the informants before the interviews. Each session was audio recorded and field notes were used to make notes of body language input or unclear words. In the case where the informant's answer was not clear the interviewer would ask further questions to clarify the meaning at each point by a validation question, for example, "Am I understanding correctly that you are feeling/thinking ...?" The audiotapes were transcribed verbatim into the Thai language. Saturation of the data was discussed among the researchers, including one experienced palliative care nurse and one oncology nurse, to decide no emerging data and whether the collected data was sufficient to exemplify the study theoretical concept [35].

Data analysis

We applied a thematic analysis framework [32] and several approaches to ensure trustworthiness, credibility and transferability of the data [36]. Credibility was established through investigator triangulation and peer debriefing. Transferability was established through thick descriptions of the data. The first four transcripts, including the field note data, were given to two coders, SS and PL. The coders first familiarized themselves with the data by going through the transcripts line by line. The initial codes were compared, critically discussed, and initially agreed upon by the two coders. SS continued to code the remaining transcripts and record emerging codes in a form of coding dictionary. Additions or modifications of the codes and their dictionary were logged on a daily basis for subsequent auditing. Broader meanings of the codes were identified in terms of themes after examining the whole dataset. The components of the Health Belief Model (HBM) [37] were identified a priori as a beneficial approach to theming the informants' thoughts. The HBM framework encompasses beliefs and perceptions which could potentially modify the readiness of a patient to engage in advance care planning. The themes and

Table 1 Characteristics of the informants

Characteristic	Patients	Family caregiver
Gender		
Female	5	16
Male	11	0
Age group		
60–69	10	8
70–79	4	1
80 or more	2	7
Religion		
Buddhist	13	13
Islam	3	3
Occupation		
Agriculture/fishery	2	2
State officer	5	6
Private employee	1	1
Retired officer	2	0
Self-employed	4	3
Unemployed	2	4
Marital status		
Married, with children	15	12
Married, no children	1	1
Single	0	3
Education		
> Bachelor's degree	2	0
Bachelor's degree	3	6
Diploma	0	1
High school	5	5
Primary school	6	4

Table 2 Characteristics of the cancers

Characteristic	N (total = 16)
Type of primary cancer	
Breast	2
Colon	1
Esophagus	2
Head and neck	3
Lung	1
Prostate	3
Rectum	2
> 1 type	2
Metastatic cancer	4
Years after cancer diagnosis	
< 1 year	8
1–3 years	3
> 3 years	5
Performance status	
ECOG 1	8
ECOG 2	3
ECOG 3	5

subthemes were debriefed with PL and RK to ensure solid interpretations and conclusions. The data were managed and analyzed by Microsoft Excel and R software. Themes and subthemes are provided with descriptions and examples of the relevant verbatim quotes.

Results

We invited 138 patients for an interview. One hundred and six (76.8%) declined to participate and ten (7.2%) did not come to the scheduled interviews. The common reasons for non-participation were that the interview took too long thus did not suit their travel plan to their accommodation (87 patients), they were busy with several ongoing treatments at the time (16 patients), and were uncomfortable with discussing their situation (13 patients). Finally, we conducted in-depth interviews with sixteen patients and sixteen caregiving family members (Table 1). Thirteen families were Buddhist. Five patients and six caregivers had a bachelor's degree or higher. The median family size was 4 (range 2–10) people. Fifteen patients were married and currently staying with their children.

Head and neck cancer and prostate cancer were the two most common primary cancer types (Table 2). Two patients had two primary cancer sites. Metastasis was present in four patients. Most of the patients were recently diagnosed with cancer (less than one year) and were undergoing cancer treatment. In general, the informants were well-functioning (Eastern Cooperative Oncology Group grade 1; ECOG1).

Themes

We found three themes reflecting perceptions and attitudes of the informant towards ACP. First, the older patients and families saw ACP as an advantageous opportunity for their medical care. Secondly, there were certain beliefs or quality which reflect contemplation and hinderances of ACP engagement. And finally, a third group could be defines as cues to ACP initiation also emerged from the interviews, in which different situations or qualities can be observed to decide timely ACP discussions. Table 3 summarizes themes and subthemes found in our study.

Theme 1: advantageous opportunity

Many individuals believed that ACP had significant benefits. The informants saw ACP as fostering introspection about their life values, and ensuring the preservation of their dignity when life-sustaining decisions arose.

Introspection of life values through invited communications

It was uncommon for older patients with cancer to feel that writing down their preferences would be a good idea. However, some patients saw ACP as exercise to

Table 3 Themes and subthemes

Theme	Subtheme
1. Advantageous opportunity	1. Introspection of life values through invited communications 2. Conveying one's will to trustable others while still capable
2. Contemplation and barriers to ACP	1. Perceived potential low utility of ACP 2. Rely on capable others 3. Perceived functional gap 4. Unfamiliarity of advance directives and living wills 5. Maintaining optimism by avoiding bad news 6. Prioritizing the family decision making authority over one's own
3. Cues for ACP initiation	1. Perceived conformity with religious principles 2. Multiple health conditions 3. Awareness of a low chance for recovery 4. Experience suffering from medical treatments 5. Not wishing to burden the family 6. Having a close caretaker 7. Trusting doctor-patient relationship

contemplate one's values and beliefs, in terms of medical care preferences.

"They (healthy persons) should be able to think about what they would want at the end of life, and thus be able to do it (write a living will). Eventually, persons who become sick and have troublesome symptoms would be aware of what treatments were about to be given to them." (Male, 78, prostate cancer).

When timing is appropriate, an invitation to ACP would help them consider what they wished to have and wished not to have, ahead of time:

"I would be feeling neutral if my doctor started the conversation. I think we (the patient and the doctor) should always discuss this. The first time is when a patient is still healthy. Second, the discussion should be done when the patient has or is informed of some abnormal symptoms. Third, it should be done when the symptoms worsen. (Male, 60, prostate cancer)

His wife also expressed the same feeling:

"It is sensible that 'If we did this, it would somewhat affect something else'. It is the same as general prescriptions which sometimes affect the liver or the kidney then it requires us to decide whether or not we want to refuse the treatment to save the organs... It is better to have information so we can decide what we want. I am not negative about this; at least we can choose for ourselves. It would be beneficial because I would be knowledgeable about how to take care of him." (Female, 60, caregiver – wife).

Conveying one's will to trustable others while still capable

ACP was perceived as a process to convey messages regarding one's preferences to family members and their doctors. Some informants felt that taking part in ACP meant a thoughtful act to express their values at a time when they were still well-functioning and to link their values with future potential changes in their health, especially if it started to deteriorate.

*"If she (the daughter) thinks I should be intubated, I should follow her. This is an actual plan made in advance. If any bad things happen, this thing (the document indicating the surrogate) can authorize her for decision-making." (Female, 66, breast cancer).
"It is good because I can leave my instructions for my doctor to follow. Those punctures, those resuscitations, are not preferred." (Female, 96, advanced rectal cancer).*

Another informant, who was a soldier, shared that living will could carry his preferences to ensure that his dignity would be preserved while he could also do good things for other people.

"The doctor would help me to see which state is a life without quality, meaning that I am at a time I cannot either serve this country or enjoy eating or traveling. We should not end up in a bed in an ICU, should we? Let the younger and healthier people use the facility." (Male, 64, advanced lung cancer).

Theme 2: contemplation and barriers to ACP

In some cases, the patients and their families had different perceptions of the value of ACP. These expressed their concerns regarding ACP, in which some caretakers felt they could contemplate being in the patient's situation. Apart from someone else trying to understand their feelings, the patients expressed concerns related to how the family caregivers would be affected by the patient's decisions.

Perceived potential low utility of ACP

ACP utility was contemplated on its currency and the chance of being applied. One informant expressed concerns regarding the currency of advance directives and living wills despite their potential benefits.

"The document (living will) can instruct the families clearly, but we cannot be sure if they are up to date. However, if there is no document at all, the communication would be limited to 'at the present', so we cannot understand much about what the patient's preferences are. Most people would easily say some-

thing like he/she could face the end of life and not require any resuscitations. But if they severely suffered from such conditions, they might instead ask for full medical support." (Male, 60, prostate cancer).

In addition, although the directives could be helpful at the time death is approaching and/or the doctor is going to put them on long-term machine dependence, a patient might think such conditions have a very low chance of occurring in most people's treatments; such individuals can speak for themselves until the very last minute.

"(Advance directives) would not be useful if they were still able to speak for themselves. In my experience, some people can speak until their last breaths. For me, I think I need some time to think if the documentation suited me. I think I better not do it (document the will) at this time because there would be a small chance for general patients to apply this. Let's say, I have never seen or heard of them being applied." (Male, 64, nasopharyngeal cancer).

Rely on capable others

It was not uncommon that advance decisions in some elderly patients with cancer were transferred to some important others. Some patients thought that they had a limited capacity to decide on medical treatments, unlike their physician or their children, who had more knowledge and a better understanding of the topic.

"It is up to my doctor how the treatment would be chosen ... It is up to my kids. These or those treatments are all up to them, all of them. I am used to relying on them. I am incapable of deciding about these things (medical treatments)." (Male, 83, rectal cancer).

Another patient said that she would always agree with what was advised by the clinicians.

"If the doctor advises me to receive any treatments, I will follow her advice. That's it. It is unnecessary to tell her. She just does her job, so do I ... she does her job; I follow her advice, this and that. That's all, nothing more than that." (Female, 60, cervical cancer).

Perceived functional gap

Some patients perceived that health deterioration was too far ahead to be worth considering at the moment while they were generally well-functioning; thinking about potential treatments received while the patient was

living almost normally did not sound reasonable. This interpretation of the current situation led to the conclusion that advance care decisions should not be made too early.

"(A living will) is suitable for people who are already sick. Some people cannot devise this kind of thing because they are currently active, and they might be still ignorant of the chance of becoming ill." (Male, 63, advanced nasopharyngeal cancer).

His wife also shared similar thoughts.

"We are worried about what has not arrived yet. Thinking about having him (the patient) intubated is [briefly silent]. We are still at the point that he is still capable of eating. If it is already the time, we must make up our minds and let the physician do their work." (Female, 62, caregiver – wife).

Unfamiliarity of advance directives and living wills

Living wills and advance directives were new to fifteen dyads. After such terms were introduced, some of the informants misunderstood that it was the same as the will to arrange individual's properties, as they were more familiar with the term 'general will'.

"Living will ... I haven't heard about that, only the will for the property that I have heard about." (Female patient, 66, breast cancer).

Only one family had knowledge about living wills and advance directives. In this family, most of the patient's children were well-educated and had high-income jobs. The patient shared that the document had functioned well in her son's (who was a clinician) case when he was severely ill.

"When Doc (her son) was alive, he also instructed us (via his advance directives), no more pain and no further procedures." (Female, 96, advanced rectal cancer).

Maintaining optimism by avoiding bad news

Some of the participants were uncomfortable with ACP as they tried to maintain an optimistic caring environment for both the patient and the family. They focused on fostering hope for a cure for themselves (cancer patients) or their patients (family members), while discussing values and preferences for medical care seemed to be all about handling incurableness and dying.

"I preferred not to talk with my family about this (advance decisions) because my mom is quite old. She does not seem prepared for this. We often mention pleasant stuff and rarely talk about something that could be stressful. My wife might be ok to plan for stuff like this, but it could also be another story because she is still young, and we don't have kids. She is scared that she will lose me ... I think we should not discuss about this... because sometimes it feels like cursing myself." (Male, 62, advanced nasopharyngeal cancer).

A family member of a 96-year-old cancer patient also shared similar thoughts.

"I have never asked the physician if the cancer is at what stage. Whether she could ... she could live for how long further; I have never asked because I thought it would create pressure in the atmosphere. I know it is close. It is surely about to happen ... We, her kids, never asked something like that because we have prepared ourselves for things that would occur to our mother. But it is better not to learn about it." (Female, 68, caregiver – daughter).

Sometimes, family members and the clinician might conspire to withhold actual information disclosure and prevent the patient from participating in ACP discussions.

"At the hospital, the doctor let only me know the information. She said 'It is inoperable. It is far gone, and the risk (of surgery) is too high to take'. The doctor only told me, and I would take the information to my brothers, but not my mom ... The doctor said 'You (the patient) don't need to go into the room. You must be tired because of getting the X-ray so you can wait in front of the room'. Although the patient was very willing to learn about the results, we avoided telling her the major ones." (Female, 24, caregiver – daughter).

Prioritizing the family's decision-making authority over one's own

An advance directive was seen as a document which can help communicate the patient's wishes for future care, especially when there are no immediate relatives. However, some patients expressed a concern about conflicts in views in the family despite a clear understanding about the rationale, owing to differences in values.

"If the family is multi-generational, I think this kind of document (advance directive) has limited benefits because at that time it could be used, there could be

husband or wife, their kids, or even their parents for some patients thus the document could create conflicts among people. Suppose I wrote it in my way, but my kids instead say, 'It is worthwhile to just add one minute to my life', and then the document is there forcing them to follow it. These troubles would not happen to a writer like me, but the families could feel guilty for what they have decided." (Male, 60, prostate cancer).

Similarly, a patient who had spent 18 years as a monk expressed that his experience made him feel his wife might see things differently so what he wanted might not be accepted. Such contemplation had kept his willingness to share his preferences with his wife quiet until the present.

"I could have donated my body to the hospital already if I was not considerate of my wife. We have never talked about this, but this is what I have been thinking about ... It has been 2 years since she has been involved in the treatments and everything, so it is somewhat difficult. If I do not tell her, there could be quarrels." (Male, 63, nasopharyngeal cancer).

Theme 3: cues for ACP initiation

Both patient and caregiver informants shared some patients' qualities which might have prompted a patient to participate in ACP communications with loved ones or with the treating physicians. These qualities convey the sense of a patient being ready for end-of-life care decisions or appointing a surrogate decision maker for healthcare.

Perceived conformity with religious principles

ACP is analogous with an important religious principle in both Buddhism and Islam, which is to always be aware of uncertainty in life and be prepared for it.

"I have no problem because I am aware that our time will soon come. We should not be ignorant (about uncertainties in health). Such ignorance ... it is not acceptable in Islam. Ignorance of the uncertainties in life and health is like a living person putting oneself into the grave. God would not forgive ignorant persons." (Female, 66, breast cancer).

Her daughter also expressed similar thoughts:

"It (deterioration of health) could be expected at some point for everyone. She is, in my opinion, a kind of religious person...She always says something like loss is certain for us; we are born, grow, fall ill,

and die... It is good to let her know that she could plan for herself if (the cancer) is incurable [lowering voice]. (Female, 34, caregiver – daughter)

Multiple health conditions

One cancer patient had been thinking about uncertainty in health due to multiple comorbidities. The patient's contemplation might have prompted him to share his wishes with his family members.

"He (the patient) looked depressed at that time. For me, his reaction was understandable because he was old and had multiple conditions. He might feel uncertain about what would happen in the future, so I think we must start talking [quietly subdued laughter]. We must talk and prepare; I ask him "What do you think about that?"; we talk about this kind of stuff. He is a person who is already aware of the uncertainty, I think." (Female, 60, caregiver – wife).

Awareness of a low chance for recovery

When there are certain possibilities for irreversible or aggressive cancer, some patients understand that medical treatments will be ineffective or only try to prolong life. And when they decide to share such thoughts with the care providers, prognosis statements and discussions for palliative care could be initiated at an appropriate time.

"If I was aware that there would be only a small chance for a person to survive the cancer, I would tell the doctor to let him/her go instead of trying to cut something out of him/her. Aggressive treatment would only create unnecessary pain and likely be ineffective." (Female, 66, breast cancer).

Another informant thought similarly; she added that there was no value in putting patients who are at the end of life on a life-sustaining machine.

"I mean if I am aware that it is very likely that I am going to die in a short period of time and the doctor will keep resuscitating me for nothing, or on the other hand, there are some conditions for which the doctor would possibly put me on a long-term machine, I would choose neither of them." (Female, 73, advanced ovarian and colon cancer).

Experience suffering from medical treatments

Most informants had heard of or had indirect experience of invasive medical procedures, and some of the patients had had direct experience of such procedures. These

experiences prompted engagement in ACP by being unwilling to let themselves or their loved ones experience the same thing again.

"I told my doctor, if the disease is severe and untreatable, or whatever, to not do anything to me. The time when I was intubated made me aware of how much I hate my life being under that condition. Even though I was moved to the post-surgery ward (after the surgery), the tube was still with me keeping my mouth open. I was aware that I was sick, but I was so thirsty, and drinking was prohibited. I was in real pain having a tube in my mouth." (Female, 73, ovarian and colon cancer).

Some caregivers could understand how it would be to have a tube in the mouth. One informant also expressed similar thoughts.

"Some patients ... they are exhausted; they want to sleep. If a treatment causes suffering, they would prefer not to receive it because they have suffered enough. To get intubated is real suffering. It would be all dried up, the throat. I can remember the moment my mom struggled to say "water", then I cried." (Female, 65, caregiver – wife).

Not wishing to burden the family

While discussing care plans, a patient may express his/her wishes not to be a totally care-dependent such that it would greatly cause a great burden for the family. Some patients could imagine how life-sustaining treatments could burden their own body and its consequences for their children. These thoughts were found in both patients who were recently retired and the oldest-old.

"Everyone will arrive at that point. I think I would like to pass painlessly, which is to be managed in any way to be pain-free. If I am about to pass, I and my kids agreed that we would choose not to undergo any burdensome treatments like surgery... The kids were worried about me being paralyzed and bed bound. They said they could handle it if it happens... I said I preferred not to burden my kids, let them live their lives. It cannot be stopped when I have to go." (Female, 66, breast cancer).

Another patient shared his awareness towards creating a chronic burden to the family as a result of putting a patient on a long-term life sustaining machine, and commented on his perceived benefits of a living will together with a family-related dilemma.

"If it (the use of a life sustaining machine) is not too long, like 45 days, I think it is acceptable ... But, it is difficult to tell (if other people would see a living will as beneficial) because people have different beliefs. Some relatives are attached to the patients. They might insist on sustaining the patient's life to be as long as possible. But for me, I reaffirm what I said." (Male, 64, advanced lung cancer).

Having a close caretaker

Having a family member with a close relationship with the patient could help the patient identify a surrogate decision maker for healthcare.

"No discomfort here, I confirm that. I can write (her daughter's) name as my surrogate decision maker. It is exactly her because she is the one closest to me and knows a lot about my health." (Female, 66, breast cancer).

Trusting doctor-patient relationships

Many informants expressed the opinion that trust in their physician would help them feel comfortable with what was suggested by the physician, including an invitation to take part in ACP. One of them compared trust in their physician and adhering to their advice with her adherence to religious principles.

"Allah gives us the capability to think and consider things using our brain... We have always adhered to religious principles, but when it comes to diseases and their treatment, we trust our physician as our number one resource. (Female, 54, caregiver – daughter)

One caregiver shared that good communication experiences could make them feel more relaxed for further discussions.

"When we were with the doctor, I had several questions. After the doctor addressed them and explained them to us clearly, we felt more hopeful. At first, we had, let's say, 10% of hope." (Female, 47, caregiver – daughter).

On the other hand, a family could be greatly discouraged by traumatizing messages from the physician, and thus further ACP discussions could be difficult.

"The first time she saw a doctor at the provincial hospital, the doctor shouted out, "Your cancer is gigantic!" She went back home, and she became drained.

She did not cook or do housework as usual. I could see that she was clearly discouraged." (Female, 34, caregiver – daughter).

Discussion

This qualitative study explored how elderly patients with cancer and their caregiving family members think about ACP. Our study included both patients and the caregiving family members of those patients who had various types of cancer, including metastatic cancer. The study families had various socioeconomic features, and they commonly had more than one generation in the family. The caregivers who agreed to participate in the interviews were all females. Three concepts of thought towards ACP engagement were identified as behavioral modifiers. The families' behaviors regarding the ACP concept were generally formulated through the lens of the combination of perceived benefits and barriers to ACP engagement, and the cues they experienced through their life or cancer treatment course. We found that the barriers and cues to ACP engagement had a range of opinions, to some extent depending on whether the interviewee was a patient or caregiver similarly to the concepts identified in previous studies investigating the engagement of ACP in elderly [29, 38].

ACP as an advantageous opportunity

Some informants indicated their beliefs that ACP could enable cancer patients to receive their preferred treatment through authorizing their surrogate to follow their preferences. This perceived benefit was consistent with what has been reported by elderly patients in general and in older individuals with chronic diseases [39–41]. Earlier research also showed that ACP helped increase the sense of control for end-of-life care for many terminal patients [42, 43]. Additionally, ACP was seen as an opportunity to examine one's own preferences and share what one values with the family and care professionals. This conformed with another study in South Korea [44], which found that the ability to exercise his/her own will towards medical care was the major reason (38.9%) to proceed with ACP.

Barriers to ACP engagement

The acceptance of ACP could be impeded by several factors involving any of the patients, family and/or care professionals [3]. According to prior systematic reviews [12, 29], care professionals need to tackle several patient-related barriers, including lack of knowledge and understanding of their diseases and ACP, influences from their beliefs, and perceptions towards medical care and of the role of ACP. It has been over a decade since living wills have been officially accepted in Thai law, and various forms of this document have been developed

and distributed by different groups to help patients who might wish to follow this path [17], for example, the Bao Jai (means relieving) book and Thai standard forms for ACP. However, most of our informants were not aware that these types of documents existed. This possibly complicated undisclosed end-of-life wishes in Thailand since older people tend to have their own preferred end-of-life care [19].

ACP has been perceived by some people as a form of communication delivering unfavorable information, potentially causing stress or demotivation among patients, families, and even healthcare practitioners [3, 45–47]. The current study found that concerns in delivering bad news could be another important barrier to ACP engagement. Some families might be concerned about distress and discouragements if their loved ones participated in ACP and that they could lose their willpower and could not be able to tolerate the cancer treatment. These underlying thoughts appeared to motivate them to avoid starting values discussions and talking about end-of-life care with their elderly relative or even concurring with the healthcare provider to withhold unfavorable news and limit the patient's involvement in the discourse [17]. Complicating matters further, older cancer patients might also be considerate of their family and therefore reluctant to express wishes that they think could worry their family. This type of cultural sensitivity has been hypothesized in an earlier study in Asian families [12]. Amidst this intertwined unexpressed preferences in a family, clinicians can play significant roles in delivering honest information and mediating the family dynamics. Previous study found that 87% of general cancer patients [48] and 95% of metastatic cancer patients [30, 49] preferred to receive information about their cancer from their attending physician.

Cues for ACP initiation

Although there are no standard guidelines concerning when ACP should be initiated, in earlier studies specialists have recommended that the person who is willing to initiate an ACP conversation should observe if there are patient-centered cues, for instance, when the patient initiates the conversation, after the patient is diagnosed with a new life-limiting disease, or when there is a change in the patient's circumstances [3, 50]. In the current study, we identified cues in which interpersonal relationships were intertwined. The cues cover signals in which the patient's perceptions were directed toward his/her own experience or concerns, for instance, having multiple comorbidities or becoming aware of an unfavorable prognosis, and interpersonal qualities such as trusting relationship with their physician. There could be an opportunity for care providers who can assess if such cues are present, even if not, establishing trust with

cancer patients and their families allowed the provider to initiate ACP discussions.

Study limitations and further studies

Our qualitative descriptions were derived from non-hematological cancer patients and their family caregivers in the south of Thailand who required radiotherapy, and thus the findings of this study might have limited generalizability to older cancer patients in other settings. Also, we had a relatively low response rate. The high refusal rate to participate might have reflected the unfamiliarity with ACP of most Thai families or perhaps be partly attributable to our strict protocol, which required all informants to participate in our consultation room. In addition, only female caregiving family members agreed to participate in our interviews, and thus the data of the caregivers' thoughts could be biased towards gender-related experiences. However, in order to clarify this potential bias, we consulted two debriefers to obtain their more experienced views concerning palliative care and oncology to confirm whether the saturation of the qualitative information was sufficient to draw at least tentative conclusions regarding a better understanding of the patients' attitudes towards ACP [35]. Future studies should include other cancer types and have a better balance of male-female caregivers to acquire more in-depth perceptions from male-related family members.

Conclusions and implications

Although ACP perceived as an advantageous opportunity for many of our participants, there were also concerns about it raising uncomfortable questions. During general consultations, care professionals might first observe if there are any cues indicating the patients are ready for ACP, then introduce the ACP benefits through personalized instances, emphasizing that ACP would help the patients to receive their preferred treatment via their trusted doctors or surrogate decision makers. Such timely initiation and personalizing the advantages could make ACP more acceptable [51]. Nevertheless, several barriers such as a perceived low utility of ACP or family efforts to maintain an optimistic atmosphere should not be overlooked [2, 3, 52]. These intertwining patient-family-provider relationships on the contemplation of ACP engagement should always be considered when a successful ACP for Thai older cancer patients is desired.

Abbreviations

ACP	Advance care planning
AD	Advance directives
ECOG	Eastern Cooperative Oncology Group

Supplementary Information

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Appendix 16. Manuscript 2 (under review)



Dyadic Perspectives of Advance Care Planning's Pros and Cons among Families of Older Cancer Patients: A Cross-Sectional Validation Study

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10 **Keywords:** older cancer patient, caregiver, advance care planning, palliative care,
11 transtheoretical model, Thailand, confirmatory factor analysis.

12 **Number of words:** 3498

13 **Number of figures and tables:** 8

14 **Abstract**

15 **Background:** Older adults are vulnerable to poor cancer outcomes. Advanced care planning (ACP)
16 is integrated into cancer care as a process of communication among clinicians, patients, and family
17 members to ensure respect for patients' preferences. ACP engagement in families of older cancer
18 patients may be motivated by dyadic perceptions of ACP's pros and cons.

19 **Objective:** This study aims to confirm the decisional balance configuration regarding ACP's pros
20 and cons and compare relevant measures among patients and their caregivers.

21 **Methods:** This cross-sectional study was conducted in an oncology radiotherapy clinic,
22 Songklanagarind Hospital, Thailand, between August 2023 and June 2024. We cross-culturally
23 adapted the original pros and cons questionnaire for use by Thai patient-caregiver dyads. Further, we
24 performed confirmatory factor analysis and applied factor invariance models. We examined model
25 fits using the following model statistics: the root-mean-square error of approximation (RMSEA),
26 standardized root-mean-square residual (SRMR), comparative fit index (CFI), and Tucker-Lewis
27 Index (TLI). Differences in chi-square fit statistics ($\Delta\chi^2$, Δdf) were applied to determine significant
28 weak and strong factor invariance within nested configural invariance, metric invariance, and scalar
29 invariance models.

30 **Results:** This study considered a sample of 177 families. Pros and cons were negatively correlated
31 (correlation coefficient = -0.53 and -0.25 in patients and caregivers, respectively), and a 13-item two-
32 factor single-order configuration was found to comparably fit both patients and caregivers. However,

33 strong invariance (i.e., comparable factor mean) between patient and caregiver models could not be
34 concluded.

35 **Conclusions:** The Thai 13-item decisional balance instrument can help anyone quantify the pros and
36 cons of a family dyad. However, the instrument cannot compare the means of pros and cons between
37 patients and caregivers because it does not conclude a strong invariance of pros and cons between
38 dyads.

39 **1 Introduction**

40 Globally, cancer is a major health burden and cause of death, with severity second only to
41 cardiovascular disease (1). Aging causes several biological changes that complicate cancer treatment.
42 As the prevalence of these noncommunicable diseases increases with age, multimorbidity commonly
43 presents (51.0%) after the age of 60 years (2). Several studies indicate that multimorbidity is an
44 independent risk factor for cancer (3, 4). For instance, patients with diabetes (with or without other
45 cardiovascular risks) are at risk of developing cardiac complications from 5-fluoruracil treatment (3).
46 Further, frailty is a geriatric syndrome that affects an individual's reserve and resistance to external
47 stressors (5, 6). According to earlier studies, 30.4% and 43.5% of older adults and older cancer
48 patients, respectively, were frail (7, 8). Older cancer patients with geriatric syndrome and frailty are
49 three and seven times, respectively, at risk of toxicity from carboplatin and paclitaxel (9) and tend to
50 live with poor health-related quality of life (HRQoL) even after the completion of their cancer
51 treatments (7).

52 Advance care planning (ACP) is a communication strategy that is applied along the cancer treatment
53 pathway (10). It encompasses various key behaviors, including sharing the meanings of life and
54 illness, talking about life-sustaining treatments, appointing surrogate decision-makers, and writing
55 advance directives or living wills (11). ACP enables the care team to understand and respect cancer
56 patients' wishes and preferences (12) and provide satisfactory care while preserving the patient's
57 HRQoL (13). Moreover, ACP reduces the duration of hospitalization and enhances hospice use,
58 thereby reducing medical care costs (14–16). While participating in ACP, clinicians may invite
59 patients and their families to clarify the patients' understanding of the illness, examine their
60 perceptions regarding relevant treatments, and further define patient-centered goal of care. In
61 addition to the professionals who provide care, family members play important roles in care planning
62 by initiating within-family discussions or enabling the patients to share future medical care plans and
63 determine potential surrogates by themselves (17, 18).

64 In general, Thai families encompass multiple generations of individuals (19). Generally, younger
65 members respect their elders and tend to act supportively toward the latter (20). By initiating ACP,
66 the family members of older patients who are aware of the patients' health deterioration may prepare
67 the family for subsidies and be willing to learn the patients' wishes to ensure respect for their
68 autonomy (21). However, there are circumstances in which the families of older Thai patients do not
69 engage in ACP behaviors. Families tend to be concerned about patients' fear and distress regarding
70 their prognosis on ACP initiation and their involvement in the ACP process ; hence, they attempt to
71 separate the patient from the ACP discussion (22, 23). Apart from causing low ACP initiation, this
72 fear can create problems because one-third of older patients' decisions regarding future medical care
73 differ from their families' decisions (24).

74 Older patients' ACP engagement may be influenced by individual perceptions (25). ACP's benefits
75 and barriers, as perceived by both patients and their caregivers, are intertwined in ACP engagement

mechanisms (17). The caregivers' tendency to initiate ACP discussions with patients, or vice versa, is affected by the extent to which they perceive ACP's benefits and barriers. According to the transtheoretical model (TTM) (26), the likelihood of behavioral change depends on the extent to which individuals perceive the pros (i.e., benefits) and cons (i.e., barriers) of such an action. Therefore, their perception of a high level of pros and a low level of cons for ACP can motivate individuals to engage in ACP. However, to date, research does not clarify how the pros and cons of ACP are assessed among Thai people. Hence, we develop a questionnaire to assess the decisional balance in Thai cancer patients' families, confirm the questionnaire construct in accordance with the perceived pros and cons of ACP, and compare the decisional balance between patients and their caregivers by considering the stages of readiness for ACP engagement.

2 Methods

2.1 Study Design and Setting

We conducted our cross-sectional study in an oncology radiotherapy clinic at Songklanagarind Hospital, Songkhla, Thailand. Investigations included interviews and a self-reported survey of older patients with cancer and their caregivers, respectively, who visited the clinic for oncological interventions. Data were collected between August 1, 2023, and June 30, 2024. The study site was a university-affiliated referral center for cancer care located to the south of Thailand; it facilitated cross-regional referral (under the national Cancer Anywhere scheme), as well. Usually, the hospital serves approximately 4,000 outpatients per day and has 800 inpatient beds. Further, Songklanagarind employs multidisciplinary cancer specialists, including four oncologists and seven oncology radiotherapists. The oncology radiotherapy clinic's daily services encompass both in- and outpatient consultations and handle approximately 200 cases per day.

2.2 Participant Selection

We invited eligible subjects to participate in the study in the form of dyad. The required sample size for confirmatory factor analysis (CFA) was 135 patients and caregivers. A 5:10 ratio of observations per free parameter in the predefined two-factor 13-item CFA (which required the estimation of 27 parameters) was adopted. (27) Once patients completed their oncology clinic visits, the clinic staff preliminarily informed all the eligible patients and sent the interested dyads to the investigator to obtain the participants' informed consent. Due to our concerns regarding Thai people's unfamiliarity with ACP, the procedure to procure informed consent included explanations of ACP based on Thai ACP standards (28). The study considered all the patients visiting the study clinic who were 60 or more years old, diagnosed with nonhematological cancer, and accompanied by an informal (family) caregiver who primarily provided care (i.e., the highest time contribution in terms of patient care). Caregivers were eligible if they were 18 years or older, willing to participate in the study, or capable of communicating with others. Patients with brain diseases (e.g., brain tumors and dementia), communication difficulties (i.e., difficulty in hearing or speaking), moderate to severe pain, psychological problems (e.g., a depression or anxiety diagnosis), and physical incapacity and those with caregivers who were unwilling to participate were excluded from the study. The patients responded to the translated ACP questionnaire through a structured interview and, simultaneously, the caregivers self-responded to the questionnaire. The questionnaire additionally queried familial demographic characteristics for caregivers alone. Subsequently, the patients' demographic information was checked against their electronic medical records (EMRs). Moreover, the patients' diagnoses, comorbidities, and times of cancer-associated visits were collected from the EMRs.

2.3 Variables and Study Instruments

120 The study considered the following variables:

121 1) Decisional balance: The decisional balance questionnaire is a five-level Likert scale
 122 questionnaire, in which item ratings range from “totally disagree” to “totally agree” (1 to 5).
 123 The questionnaire was developed using the TTM framework pertaining to decisional balance
 124 (29). We acquired permission to adapt the questionnaire to our study’s characteristics, and we
 125 applied the World Health Organization guidelines for cross-cultural adaptation (30, 31). The
 126 question wording and corresponding codes (for compact presentation) are summarized in
 127 table 1. We modified the questionnaire into two versions—the patient and caregiver versions—
 128 by incorporating our earlier qualitative findings (32). Both versions allowed the respondent
 129 (patient or caregiver) to assess the extent of perceived pros and cons of ACP engagement in
 130 the index case (i.e., the patient). Accordingly, patients assessed the pros and cons of all ACP
 131 activities that involved themselves, whereas caregivers assessed whether the activities
 132 involved the patients in their care. This approach enabled us to evaluate the dyadic
 133 perspectives in patients’ ACP engagement. Our panel of investigators assessed the quality of
 134 initially translated questionnaires to maintain cultural and semantic equivalence. The panel
 135 included three palliative care physicians. A Thai native English instructor specializing in
 136 international collaboration performed a backtranslation of the questionnaire to assess the
 137 consistency between the English and Thai versions. Further, three external experts in
 138 palliative care evaluated the content validity of the final version of the questionnaire. They
 139 applied the item-objective congruence index, for which the optimal cutoff point was 0.5
 140 (range: 0.67–1). A pilot test involving 17 homebound older patients and 13 caregivers
 141 thoroughly evaluated the questionnaire’s usability. The time taken to complete the
 142 questionnaire was approximately 10 minutes and, overall, items were rated “mostly
 143 understandable” or “all understandable.” The questionnaire’s internal consistency had reached
 144 an acceptable level (Cronbach’s alpha values of 0.83 and 0.71 for pros and cons,
 145 respectively). Figure 1 summarizes the adaptation process of the decisional balance
 146 questionnaire.

147 <Insert Figure 1 here>

148 2) Stages of readiness for ACP engagement: The interview-guide instrument contains stepwise
 149 questions about ACP engagement behaviors. Using this instrument, the interviewer asks 5–16
 150 questions per respondent to categorize the respondents into precontemplation (PC),
 151 contemplation (C), preparation (P), and action/ maintenance (AC/M) groups based on six
 152 ACP behaviors involving both families and treating clinicians (33). The adaptation of the
 153 original interview guide was conducted using the World Health Organization process (30) to
 154 our study involving Thai patients. In this study, we presented only the (1) importance of
 155 quality of life versus living as long as possible (meaning of life and illness, MoL) and (2) use
 156 of life-sustaining treatment (LST). Responses were categorized into AC/M (if one had already
 157 engaged in ACP), P (if one felt prepared to engage in ACP within the next 30 days), and
 158 PC/C (if one was uninterested in or was contemplating ACP engagement in the next 6
 159 months).

160 3) Prior awareness of ACP: A single question was used (for both interviews and self-
 161 completions by patients and caregivers) to inquire about prior knowledge of any types of
 162 ACP. This includes discussions about values and preferences, discussions about life-
 163 sustaining treatment use, advance directives or living wills, and durable powers of attorney
 164 for health care.

165 4) Participants' demographic characteristics, including age, sex, occupation, monthly income of
 166 the family, education, family type, and nominated family head (i.e., the absence of any legal
 167 document, such as the durable power of attorney for healthcare), were included in the self-
 168 reported questionnaires completed by caregivers.

169 2.4 Statistical analysis

170 Our analysis consists of two parts: CFA and descriptive analyses. Prior to conducting formal
 171 analyses, we excluded all respondents systematically missing decisional balance data (i.e., the
 172 absence of all decisional balance data). Other missing (categorical) data in which missing at random
 173 was assumed were imputed by the nonparametric random forest method using the missForest
 174 package. Such imputations were set in the unsupervised mode, with 100 trees per forest and four
 175 candidate decisional balance variables per split. The imputations' performance was considered good
 176 and poor when the proportion of falsely classified entries (PFC) was close to 0 and 1, respectively
 177 (34). Further, we performed CFA to examine whether seven items could be explained by pros and the
 178 remaining six could be explained by cons. We used the 13-item two-factor single-order model to
 179 represent the pros and cons for each set of patient and caregiver items. A correlated structure between
 180 the pros and cons was assumed, and the variance of a factor was set to 1. The model fit was assessed
 181 using the root-mean-square error of approximation (RMSEA), standardized root-mean-square
 182 residual (SRMR), comparative fit index (CFI), and Tucker–Lewis Index (TLI), with acceptable
 183 values set at less than 0.06, 0.09, 0.90, and 0.90, respectively (35). The factors, item codes, and
 184 relevant measures are shown by diagrams. Further, factor invariance between the two-factor models
 185 applied in patient and caregiver groups was tested for 1) weak invariance, that is, the presence of
 186 significant chi-square difference ($\Delta\chi^2$) between the nested configural and metric invariance models
 187 (since the loadings were constrained to be equal between the groups), and 2) strong invariance, that
 188 is, $\Delta\chi^2$ between the nested metric and scalar (constrained loadings and intercepts) invariance models.
 189 The weak and strong invariance tests enable the assessment of whether the loadings and means of the
 190 factors (i.e., pro and con), respectively, can be compared between patients and caregivers. Finally, we
 191 followed an earlier recommendation on presenting model invariance (37) and established significant
 192 invariance at $p < 0.05$. All CFAs were performed with R software and the lavaan package (37).

193 Moreover, we described the variations in pros and cons for different stages of ACP readiness for
 194 MoL and LST discussions. For this illustration, “totally disagree,” “disagree,” “neutral/uncertain,”
 195 “agree,” and “totally agree” were converted to a score range of 1–5 in that order. Based on the
 196 original studies (26, 29), the scores were summed within pro and con items, and T-score was applied
 197 to quantify the pros and cons in the equivalent numerical range. The operation included multiplying
 198 the standardized (z) score by 10 and adding 50 points, with the scores' mean and standard deviation
 199 (SD) being standardized to 50 and 10, respectively.

200 3 Results

201 This study examined 354 patients, in total. Further, 48 families were excluded based on patient
 202 criteria, including being unable to communicate, not being accompanied by a caregiver, having brain
 203 disease, having a psychological diagnosis, and being included in multiple research projects.
 204 Subsequently, 129 caregivers declined to participate because they were uncomfortable with the topic,
 205 felt uninterested, or were too busy with other appointments. Finally, 177 families, comprising 177
 206 patients and 177 family caregivers, participated in the study (Figure 2).

207 <Insert Figure 2 here>

208

209 Table 2 summarizes the demographic characteristics of the participants. Many of the patients were
 210 between 60 to 79 years old (median age 68.5 years), and several were women (82.5%) or married
 211 (69.5%). The majority of the older adults (54.2%) were not actively working; they were retired
 212 officers or unemployed. However, most of the caregivers were actively working (83.5%). The
 213 monthly income of the participating families was mostly below 30,000 THB (53.6%). Only one-fifth
 214 of the families had multiple generations. In other words, families comprising older adults (patients
 215 living with their spouses or with only their children, not their grandchildren) alone were common
 216 (75.7%). The patients were the perceived heads of almost half of the families (48.6%), and
 217 approximately half of the caregivers were unofficially authorized as surrogate decision-makers
 218 (51.4%). Approximately one-tenth and one-third of the patients and their family members,
 219 respectively, had heard of any type of ACP.

220 The participants had various types of cancer (table 3). Approximately half of them had
 221 gastrointestinal tract cancers (24.3%), breast cancer (22.0%), head and neck cancer (18.1%), or male
 222 genital organ cancers (10.7%). A small proportion of the participants (7.3%) had at least two primary
 223 cancers, and almost a quarter had metastatic cancer. The median number of participant cancer visits
 224 was 8.

225 Only some of the decisional balance variables (i.e., pros or cons) of the caregivers (3.7% of the
 226 decisional balance data) had missing data and were imputed (PFC = 0.44). Pros and cons were
 227 structured as two factors explaining the 13 items in each patient (n = 177) and caregiver (n = 173)
 228 group. The correlation for each item was generally low (r = 0.001 to 0.218) between the groups.
 229 Figure 3 illustrates the configuration of factors and observed variables in the patient and caregiver
 230 groups. Standardized factor loadings ranged from 0.36 to 0.81 and 0.32 to 0.78 in the patient and
 231 caregiver groups, respectively. Further, pros and cons were more negatively correlated in the
 232 patients' group than in the caregivers' group (correlation coefficients were -0.53 and -0.25,
 233 respectively). As seen in table 4, the model's structure was found to comparably fit both groups (CFI
 234 = 0.937, TFI = 0.924, RMSEA = 0.058, and SRMR = 0.055 in the configural invariance model). The
 235 model's loadings were not significantly different between patients and caregivers ($\Delta\chi^2 = 12.946$, Δdf
 236 = 11, p-value = 0.2968). However, the scalar invariance model demonstrated poor fit statistics and
 237 significant model fit deviation from the metric variance model ($\Delta\chi^2 = 78.147$, $\Delta df = 11$, p-value <
 238 0.001); therefore, the means of pros and cons should not be directly compared between patients and
 239 caregivers.

240 <Insert Figure 3 here>

241 Figure 4 illustrates the changes in the mean T-score per stage of readiness in MoL and LST
 242 discussions. In patients, unlike cons, pros were found to increase with preparedness. However, the
 243 methods used to balance pros and cons were relatively different between MoL and LST discussions.
 244 At the preparation stage, the gap between pros and cons was greater in LST than in MoL discussions,
 245 and no substantial changes in the gap were found in the AC/M stage. By contrast, the gaps between
 246 the pros and cons among caregivers were relatively smaller than those among patients at all stages. In
 247 addition, whereas the pros remained higher than the cons from P to AC/M, the scores dropped
 248 slightly in AC/M.

249 <Insert Figure 4 here>

250 4 Discussion

Our cross-sectional study demonstrated the decisional balance of ACP among older patients with cancer and their family caregivers in Southern Thailand. Whereas the numbers of male and female participating patients were relatively balanced, the caregivers were mostly women. Approximately one-third of the participants indicated a bachelor's degree education. Head and neck cancer was the most common cancer type, and one-fourth of the patients had metastatic cancer. In general, the patients' types of cancer were similar to the center's general cancer population, although the former had a relatively smaller proportion of lung cancer (4.5% vs. 10.3%) (38). A quarter of the families were multigenerational, and approximately half of the caregiver respondents were the nominated informal surrogate decision-makers of their families. Only 10% of the patients had ACP awareness, whereas as much as one-third of the caregivers had heard of ACP.

The decisional balance questionnaire configured by seven pro and six con items had weak invariance between patient and caregiver groups. In other words, the constrained loadings that were equal between patients and caregivers demonstrated insignificant deviation from the configural invariance model and, further, the fit indices (e.g., CFI, RMSEA, and SRMR) did not differ substantially between configural and metric invariance models (i.e., the difference did not exceed -0.01, -0.015, and -0.030 for CFI, RMSEA, and SRMR, respectively) (39). However, our scalar invariance model showed a significant deviation in fit from the metric invariance model. Therefore, strong invariance cannot be concluded, and the means of pros and cons should not be compared across groups. In other words, we could not conclude that patients and caregivers perceived the same levels of pros and cons despite having identical item responses. We clarify that it is reasonable to expect incomparable pros and cons because the patients and their family members have potentially different baseline perceptions. In an earlier study, the perceived advantages of and barriers to ACP differed between patients with mild dementia and their caregivers, and the caregivers expressed more barriers than the patients (40). Hence, we clarify that such differential ACP perceptions among our participants were likely based on their baseline experiences as a patient or caregiver; whereas the patients had direct experiences of their own disease but never heard about ACP (since only 11% were reportedly aware of ACP), the caregivers' views could have resulted from their caring experience and higher prior ACP knowledge.

Our results support the idea that decisional balance configurations have convergent validity (41). We clarified the variations in ACP pros and cons by discussing the readiness stages for ACP engagement. In MoL and LST discussions, families tended to perceive high cons and low pros for ACP; inversely, pros were found to be higher than cons when they were at the preparation stage. The decisional balance pattern conforms with the hypothesized relationship between pros and cons through stages of behavioral changes in the TTM (26), in which crossing over between pros and cons was expected at the preparation stage and pros were expected to become higher than cons at the action stage. Nevertheless, although the pros were higher than the cons after the preparation stage, a slight drop in pros was observed in MoL and LST discussions among caregivers and LST discussions among patients. TTM provides an explanation for this variation, as well. Individuals tend to progress through stages as follows: Those who are in precontemplation progress to preparation; through cognitive processes (that increase consciousness), affective processes (i.e., feelings of significant relief on ACP engagement), and evaluative processes (e.g., self-revaluation), they perceive the higher pros of ACP. In later stages, individuals tend to rely on contingency and commitment to maintain their actions and proceed by perceiving the lower cons of a behavior (26).

To the best of our knowledge, this study is the first to develop and validate a decisional balance questionnaire using a cross-cultural adaptation process in patient-caregiver dyads. Our findings provide insights into the assessment of decisional balance in ACP engagement and promotion in

future research, as well as clinical settings. However, this study has several limitations. First, we validated the questionnaire for use in Thai families of older cancer patients by incorporating our qualitative findings into the refinement of items (32). Accordingly, the questionnaire's content is contextually specific to the Thai population and has limited generalizability. Second, the application of our factor invariance testing reveals only the equivalence of the configured structure and the loadings specific to older cancer patients' families in Thailand. Hence, care should be taken while generalizing these findings to other populations. Third, we asked the patients about their stage of change in MoL and LST discussions. Therefore, we cannot exclude the possibility that caregivers were willing to participate but this willingness was not perceived by the patient.

5 Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

6 Author Contributions

SS and SA conceptualized the study. SS, WS, SA, PV, RK, PL, and OF were responsible for designing the study. SS, PL, and OF were the instrument development panel members. SS conducted interviews and collected data. SS, WS, PV, PL, and OF analyzed the collected data. SS wrote the first draft of the manuscript. All the authors have read, revised, and approved the manuscript for publication.

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441 10 Data Availability Statement

442 All available data are within the paper and its supporting information files.

443

444 **11 Tables**445 **Table 1** Details of decisional balance questionnaire.

Code	Question wording*
HRMO	Health care proxy appointment will make the decision-making on [patient] future medical care among the family members easier.
CONT	ACP will help [patient] control what will happen to [patient] when [patient] become unable to make decisions.
RELI	[patient] feel at ease if [patient] plan and inform [patient] physician and family members about [patient] ACP.
ENSU	[patient] is sure that [patient] will receive preferred medical care when [patient] are unable to make decisions if [patient] physician and family members acknowledge about [patient] medical care preferences in advance.
EASEC	ACP will help family members make decisions about [patient] medical care more easily.
EASED	ACP will help [patient] make future decisions more easily if [patient] become seriously ill.
CARE	Making an advance care plan means not to be careless for any potential changes in health
LOWS	It is possible that [patient] would not receive standard clinical care if [patient] decide to accept or refuse some treatment ahead of time.
SADT	ACP for [patient] future medical care makes [patient] feel that [patient] may live shorter life with [patient] family.
UNST	It is not necessary for me to make an ACP since [patient] preference may change in the future.
TOO	ACP is not suitable for [patient] because [patient] make decisions day by day.
INFP	ACP is difficult because there are too many issues related to [patient] future medical care to think about.

HEAV	ACP seems difficult because [patient] do not like to think about when [patient] health is deteriorating.
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*[patient] refer to the index patient whom the question refers to; if the respondent is the patient, this bracket will be replaced by “you”; and if the respondent is the caregiver, this bracket will be replaced by “the patient”.

Table 2 Participant and family characteristics.

Characteristic	Patient (n = 177)	Caregiver (n = 177)
Age (median, Q1–Q3)*	68.5 (64.2–73.2)	48.3 (40.1–58.5)
Women (n, %)	79 (44.6)	146 (82.5)
Marital status		
Married, with or without kids	147 (83.1)	123 (69.5)
Widowed/single (n, %)	30 (16.9)	54 (30.5)
Occupation (n, %)		
Government officer (or retired)	43 (24.3)	60 (33.9)
Self-employed	53 (29.9)	88 (49.6)
Unemployed/housewife	81 (45.8)	26 (16.4)
Buddhist (n, %)	146 (82.5)	148 (83.6)
Possession of bachelor’s degree or higher (n, %)	52 (29.4)	77 (43.5)
Head of the family (n, %)	86 (48.6)	18 (10.2)
Prior awareness of any ACP types (n, %)	19 (10.7)	57 (32.2)
Family’s monthly income (n, %)		
<30,000 Baht	95 (53.6)	

30,000–50,000 Baht	52 (29.4)
More than 50,000 Baht	50 (16.9)
Expanded family (n, %)	43 (24.3)
Caregiver being the informal surrogate decision-maker (n, %)	91 (51.4)

*Q1 = first quartile, Q3 = third quartile

451

452 **Table 3** Clinical characteristics of patients.

Characteristic	
Cancer type (n, %)	
Gastrointestinal tract	43 (24.3)
Breast	39 (22.0)
Head and neck	32 (18.1)
Male genital organ	19 (10.7)
Lung	12 (6.8)
Female genital organ	11 (6.2)
Thyroid	3 (1.7)
Other	15 (8.4)
Two or more primary types	3 (1.7)
Metastatic cancer (n, %)	42 (23.7)
Number of cancer clinic visits (median, Q1–Q3)	8 (2–24)

*Q1 = first quartile, Q3 = third quartile

454

455 **Table 4** Measurement for factor invariance models between groups (patient and caregiver).

Model	CFI	TLI	RMSEA	SRMR	χ^2 (df)	$\Delta\chi^2$ (Δ df)	p-value*
Model 1: Configural invariance	0.938	0.925	0.057	0.053	201.34 (128)	—	—

Model 2: Metric invariance	0.936	0.928	0.056	0.062	214.86 (139)	13.522 (11)	0.2606
Model 3: Scalar invariance	0.875	0.870	0.075	0.077	298.93 (150)	84.070 (11)	<0.001

456 CFI = comparative fit index, TLI = Tucker–Lewis index, RMSEA = root-mean-square error of
 457 approximation, SRMR = standardized root-mean squared residual, χ^2 = chi-square statistics, df =
 458 degree of freedom.

459 *Significance by chi-square statistics.

460

461

462 **12 Figure captions**

463 **Figure 1** Adaptation process of the decisional balance questionnaire.

464 **Figure 2** Participant recruitment process.

465 **Figure 3** Confirmatory factor analysis results of the configural invariance model for decisional
466 balance scales: the patient (A) and family caregiver (B) groups.

467 Rectangle = observed variable; oval = factor; values amid arrows = standardized factor loadings; the
468 curved two-headed arrows represent the correlations between factors; p and f indicate patient and
469 family caregiver items, respectively.

470 **Figure 4** Mean T-scores of pros and cons for stages of change in the advance care planning (ACP)
471 engagement of patients and family caregivers.

472 PC/C, pre-contemplation/contemplation; P, preparation; AC/M, action/maintenance; error bars
473 indicate SD.

474

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