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Journal

BMJ Supportive & Palliative Care, 12(2)

Authors

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Publication Date

2022-06-01

DOI

10.1136/bmjspcare-2021-003313

Peer reviewed



HHS Public Access

Author manuscript

BMJ Support Palliat Care. Author manuscript; available in PMC 2022 June 01.

Published in final edited form as:

BMJ Support Palliat Care. 2022 June; 12(2): 167–177. doi:10.1136/bmjspcare-2021-003313.

Prognostic disclosure in oncology - current communication models: a scoping review

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Abstract

Background—Prognostic disclosure is essential to informed decision making in oncology, yet many oncologists are unsure how to successfully facilitate this discussion. This scoping review determines what prognostic communication models exist, compares and contrasts these models, and explores the supporting evidence.

Method—A protocol was created for this study using the Preferred Reporting Items for Systematic Reviews and Meta-analyses Protocols extension for Scoping Reviews. Comprehensive literature searches of electronic databases MEDLINE, EMBASE, PsycINFO and Cochrane CENTRAL were executed to identify relevant publications between 1971 and 2020.

Results—In total, 1532 articles were identified, of which 78 met inclusion criteria and contained 5 communication models. Three of these have been validated in randomised controlled trials (the Serious Illness Conversation Guide, the Four Habits Model and the ADAPT acronym) and have demonstrated improved objective communication measures and patient reported outcomes. All three models emphasise the importance of exploring patients' illness understanding and treatment preferences, communicating prognosis and responding to emotion.

Conclusion—Communicating prognostic estimates is a core competency skill in advanced cancer care. This scoping review highlights available communication models and identifies areas in need of further assessment. Such areas include how to maintain learnt communication skills for lifelong practice, how to assess patient and caregiver understanding during and after these conversations, and how to best scale these protocols at the institutional and national levels.

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Contributors JRB conceived and designed the analysis, collected data, performed the analysis, wrote scientific paper and oversaw submission process; she is guarantor of overall content. DCM collected data, performed analysis, and was responsible for critical review of the manuscript. CR-R assisted in the review of data and critical review of the manuscript. EM assisted in scoping review analysis, concept design, and manuscript review. JAJ assisted in scoping review analysis and editing of manuscript. KVD assisted in overall concept refinement and manuscript review.

Competing interests None declared.

Ethics approval This study does not involve human participants.

INTRODUCTION

The communication of prognosis—the likelihood that a given clinical state or outcome will occur within a specified period of time—is essential to informed, shared decision making in oncology. Often equated with life expectancy, the definition of prognosis comprises a range of other anticipated outcomes such as changes in functional independence, symptom burden or patient reported quality of life. Prognostic awareness is associated with: increased delivery of goal-concordant care; improved patient mental health, patient quality of life and caregiver bereavement; decreased healthcare costs and fewer non-beneficial end-of-life measures. Yet it is estimated that only half of all patients with advanced cancer are aware of their prognosis, even as they approach the end of life. 6-8

Oncologists are often hesitant to engage patients in discussions about predicted survival and the expected outcomes of treatment.^{6 9 10} Multiple barriers to prognostic disclosure in oncology have been identified and can be considered in terms of barriers to establishing a prognostic estimate and barriers to communicating the prognostic estimate.¹¹

Barriers to estimating prognosis

There is inherent uncertainty in prognostication due to two phenomena: aleatory uncertainty and epistemic uncertainty. Aleatory uncertainty addresses the inherent randomness of future outcomes; epistemic uncertainty stems from the lack of existing data on the probability of outcomes. The latter is particularly relevant in oncology, in part due to evolving treatments such as personalised medicine and immunotherapy, increased use of multimodal interventions, and advancements in existing systemic therapy, radiation therapy and surgical technique. Clinicians may use prognostic indices, available data, prior experience and clinical judgement to reduce this uncertainty, and are overall more successful in prognostication with regards to estimates of life expectancy than they perceive.

Barriers to communicating prognosis

Many oncologists feel ill equipped to communicate prognostic estimates due, in part, to lack of training. 14-17 Historically, there had been debate as to whether an oncologist should inform a patient of her prognosis; the focus has since shifted to *how* prognostic information should be delivered. 13 18-22

Consensus guidelines have been created specifically for patient-clinician communication to help promote the importance of, and make clinicians more comfortable with, prognostic disclosure.²³ These internationally recognised guidelines identify several main areas of focus: (1) core communication skills, including responding with empathy to patients' emotions; (2) discussion of goals of care and prognosis; (3) discussing treatment options and clinical trials; (4) discussing end-of-life care (5) using communication to facilitate family involvement in care; (6) communicating effectively when there are barriers to communication; (7) discussing cost of care; (8) meeting the needs of underserved populations; and, finally, (9) clinician training in communication skills.

Our objective is to review the available communication models with respect to prognostic disclosure in oncology. A scoping review is conducted to systematically map research in this

area. The following research question was formulated: What models exist to aid clinicians in having successful conversations about prognosis with their oncology patient? We aim to synthesise evidence of successful communication techniques in oncology and highlight the importance of balancing both content and skill to deliver the message appropriately and effectively.

METHODS

We conducted a scoping review of models for discussing prognosis with oncology patients in order to provide clinicians with evidence-based practices. The scoping review aims to answer three main questions: (1) what guidelines exist to aid clinicians in having successful conversations of prognostic disclosure; (2) between these guidelines, what commonalities and dissimilarities exist and (3) finally, of these guidelines, which have been validated in the clinical setting?

Search strategy and selection criteria

With the guidance of an institutional medical librarian, search terms were generated and preliminary searches were used to refine the search strategy. A protocol was created for this study using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols extension for Scoping Reviews (PRISMA-ScR), and was registered in the Open Science Framework database (https://osf.io/bmjzw/).²⁴

Comprehensive literature searches of electronic databases MEDLINE, EMBASE, PsycINFO and Cochrane CENTRAL were executed by the medical librarian and research team as a sensitive search strategy. The preliminary search strategy included combinations of specific terms referencing to cancer, communication, prognostication and guidelines. Searches were conducted using keywords, Medical Subject Headings (MeSH) and MeSH Entry; Boolean operations were used to search by different combinations of words (supplemental figure 1). Peer-reviewed articles published between 1971 and October 2020 were included in addition to relevant papers found with searching the grey literature. Inclusion criteria included: peer-reviewed articles including retrospective cohort studies, prospective cohort studies, randomised controlled trials, observational studies, expert opinions, protocols, editorials, book chapters and symposium of national expert conclusion articles; topic: communication and prognostic disclosure as it pertains to the oncology patient population, all languages were included. Exclusion criteria included: study populations of interest outside of the general oncology populations (eg, only studying paediatric patients or patients with breast cancer). Articles that evaluated communication skills specific to a certain type of cancer were excluded due to the possibility that these techniques may be uniquely tailored to the specific disease site.

Two reviewers (JRB and DCM) independently screened all titles/abstracts retrieved by the search strategy according to the scoping nature of this review. In cases of disagreement, a third reviewer (CR-R) was required. After initial screening, full text was obtained for further assessment. A standardised data extraction form was employed including authors, year of publication, title, article type, population, aims, methodology, outcomes and important results. Quality of qualitative publications was assessed using the National Institute of

Health Quality Assessment Tools for the appropriate category.²⁵ Formal risk of bias assessment was not applicable for this scoping review, consistent with methodological guidance for scoping reviews.²⁶ ²⁷

Finally, communication guidelines extracted during this scoping review were synthesised in table format, analysed for similarities, differences and limitations with the aim to consolidate key themes among all retrieved guidelines. The final report was created in accordance with the PRISMA-ScR.²⁴

RESULTS

The search strategy generated 1532 results, of which 78 papers were deemed relevant on critical appraisal (figure 1). These include: 26 observational studies, 14 expert opinions, 10 randomised clinical trials, 8 systematic reviews, 6 proposed consensus guidelines, 6 non-systematic reviews, 4 protocols, 3 non-randomised studies on intervention effects and 1 case study (supplemental table 1). Within the included articles, we identified, reviewed and synthesised five communication models for discussing prognosis: the Serious Illness Conversation Guide (SICG)²⁸; the VitalTalk ADAPT acronym²⁹ the PREPARED protocol³⁰; the SPIKES protocol³¹; the Four Habits Model (table 1).³²

Communication guidelines

The Serious Illness Care Program, created by palliative care experts at Ariadne Labs out of at the Dana-Farber Cancer Institute, first published in 2012, is a multicomponent, structured communication intervention, developed with the goal for every ill patient to have more frequent, earlier, and higher quality conversations with her clinician about her goals, values and priorities that may inform future care. 33 Based on literature review, pilot work and consultation with a national advisory group, a structured guide emphasising seven key elements was created. The guide recommends to: elicit illness understanding, elicit decisionmaking preferences, share prognostic information according to preference, understand goals and fears, explore views on trade-offs and impaired function, and understand desire for family involvement (table 1).³³ Additionally, as part of the programme, letters are provided to patients prior to the clinician encounter to prepare them for the discussion, and a family communication guide is provided to facilitate further discussion of the patient's values and goals. The Serious Illness Conversation Guide (SICG) appeared in 8 of the 78 included articles, including validated by randomised controlled trials.³³⁻³⁸ The creation of this programme was supported by Charina Endowment Fund, Partners Healthcare and the Margaret T. Morris Foundation.

VitalTalk, developed in 2012 by US palliative care physicians based on research initially funded by the National Institute of Health, aims to equip clinicians with skills to communicate effectively and empathetically.²⁹ Their chapter, *Offer Prognostic Information: How to Balance Hope and Realism*, emphasises two points: first, 'understand if the patient might make a different choice if she understood her prognosis more explicitly' and, second, determine how much the patient wants to know and in what method she wishes to acquire this knowledge.³⁹ VitalTalk's ADAPT talking guide provides a five-step approach

to discussing prognosis (table 1). Within the literature, VitalkTalk appeared in five articles, including a randomised controlled trial. ³⁹⁻⁴³

The SPIKES protocol was developed by clinicians at MD Anderson, first presented in 2000.³¹ The need for formal education on how to best 'discuss bad news' stemmed from the authors' survey at the 1998 American Society of Clinical Oncology conference. While 88% of clinicians felt that a strategy or approach to breaking bad news would be helpful, only 18.4% had formal training on breaking bad news.³¹ This protocol attempts to achieve four essential goals: gathering information from the patient; provide intelligible information in accordance with the patient's needs and desires; support the patient by employing skills to reduce emotional impact and isolation; finally, develop a strategy in the form of treatment plan with the patient's input and cooperation. This model emphasises the expression of empathy and patient-centred discussion as essential aspects of prognostic disclosure (table 1). Eleven of the included papers referenced the SPIKES protocol.¹⁹ ³¹ ⁴⁰ ⁴²⁻⁴⁹

The PREPARED protocol was created out of an Australian and New Zealand expert advisory group, first published in 2007, with special concentration on how to discuss progressive life-limiting illness with patients and their families. The protocol was created based on systematic literature reviews, reviews of previous guidelines and expert opinions, and refining of guidelines by expert personnel (table 1).³⁰ The PREPARED protocol was mentioned in one consensus guideline during the scoping review.

Finally, the Four Habits Model was created by investigators at Kaiser Permanente, first published in 1995, to outline a cohesive structure to enable clinicians to communicate effectively and efficiently (table 1).³² The model was created out of the clinical–patient communication programme, started in 1990 as a day-long workshop and led to the development of the communication consultant programme, ranging from one-on-one coaching (listening to audiotapes of visits, problem-solving difficult encounters, observing and debriefing patient visits) to departmental presentations, courses, newsletters and lunchtime discussions.^{32 50} Personalised sessions within the course focus on a single habit, such as making empathic statements or testing for patient comprehension. The Four Habits Model was included in three of the 78 incorporated articles, and validated in a randomised control trial.⁵¹

Across the models, several themes arise: preparing for and introducing the conversation; exploring patient understanding and preferences; communicating prognosis; responding to emotion; clarifying goals and concluding the discussion (table 1). Each framework emphasises varying points. For example, the PREPARED protocol and the Four Habits Model recognise the need to establish rapport with the patient. ³⁰ ³² The PREPARED protocol delves into ways the clinician can acknowledge cultural and contextual factors influencing patient preferences. In comparison, the SPIKES tool emphasises connecting with the patient and minimising outside distractions or interruptions. ³¹ The frameworks provide varied levels of detail, leaving certain aspects of employing the communication strategy up to the interpretation of the user, for example, how to develop rapport.

There are three core components that each framework includes: assessing patients' illness understanding and preferences, communicating prognosis and responding to emotion. Several models offer specific language to aid in prognostic disclosure. For example, the SICG offers pairing 'wish/hope' and 'worry' statements to initiate difficult conversations. ²⁸ 'It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly and I think it is important to prepare for that possibility.' Or, expressed in terms of life expectancy, 'I wish we were not in this situation, but I am worried that time may be as short as months to a year.'

Each framework emphasises exploring and acknowledging patients' emotions. Several models recommend naming the specific emotion: 'I can see that this news comes as quite a shock.' Nuances exist between the models. For example, allowing for silence is emphasised in the SICG,²⁸ versus fostering realistic hope with the PREPARED protocol,³⁰ and, finally, demonstrating empathy is explicitly stated within the SPIKES protocol and the Four Habits Model.^{31 32} While each of these frameworks have been applied and studied to different extents, their overarching goal is to build the clinician's self-awareness in relation to the patient's emotion, perspective and situation.

Models for discussing prognosis applied in the clinical setting

Of the five models, the SICG and the ADAPT acronym have been studied and validated in randomised control trials. Implementation of the Serious Illness Care Program in a randomised clinical trial demonstrated that clinicians in the intervention group were more likely to have significantly higher-quality prognosis discussions as measured by patient-centredness, comprehensiveness and a focus on values or goals.³³ Clinicians in the intervention group initiated these conversations earlier in the patients' disease trajectory.³⁴ ³⁵

Application of these models has been used in combination with structured education for patients. When clinicians completed VitalTalk communication skills training and patients received preconversation communication-priming interventions, patients reported higher quality communication.³⁹ In a randomised study, prior to meeting with the clinician, patients received questionnaires evaluating if they had previously thought about end-of-life care, code status, and barriers and facilitators to talking about future plans. Similarly, the Values and Options In Cancer Care (VOICE) study combined oncologist skill-based training and a 1-hour patient and caregiver coaching session to help prepare patients to voice their greatest concerns.^{52 53} In this randomised controlled trial, communication scores of the intervention group showed a significant improvement compared with the control group indicating improved patient-centred communication.⁵³ Specifically, in conversations of the intervention group, there were more engaging statements and responses to emotion.

Further, a qualitative analysis of audiorecorded serious illness conversations demonstrated that after clinicians underwent communication skills training, measurable changes including supportive dialogue and openness to discuss emotionally challenging topics were increasingly noted among clinicians assigned to the intervention arm.⁵⁴ This dialogue and openness was often prompted by SICG dialogue. Additionally, the study noted that physicians frequently discussed prognosis framing it through varying treatment lenses,

as opposed to an overarching prognosis, consistent with the practice in other audiotaped oncology conversations. ⁵⁵ ⁵⁶ Clinicians were noted to have difficulty in responding to emotional or ambiguous statements, especially when patients expressed emotional distress or uncertainty about their current or future health status. Although a small sample size, this study reflects that while there are tangible benefits from the 2.5-hour SICG training and Serious Illness Care Program, something more is needed. The tendency for excessive optimism, focus on treatments as a way to communicate prognosis, and use of vague language to avoid patients' (and possibly clinicians') distress was prevalent. ⁵⁵

In addition to the guidelines provided to clinicians to aid in the conversation of prognostic disclosure, several studies employed a question prompt list to prepare both clinicians and patients for discussion. ⁵² ⁵⁷⁻⁵⁹ In one systematic review, question prompt lists and patient reported outcomes were the most effective tools incorporated to facilitate physician–patient communication. ⁵⁸ Employment of the question prompt lists was associated with caregivers and patients asking more prognostic questions, and had fewer unmet needs about the future. ⁶⁰ Pre-consultation exposure to certain questions can encourage improved communication, shared decision making and facilitate familiarity in communication of vulnerable discussions, a known barrier to prognostic communication. ⁶¹ ⁶²

DISCUSSION

Skillful communication of prognosis is a core competency in oncology and, importantly, one that can be taught, learnt, and retained. Yet despite its importance to clinical practice, the most effective method of training oncologists to effectively communicate prognosis has not yet been established or widely disseminated. This scoping review analyses five communication guidelines to aid clinicians in successful prognostic disclosure. While slight variations and differing points of emphasis exist between the guidelines, strong commonalities are seen throughout, including: assessing patients' illness understanding and preferences, verbally communicating prognosis and responding to emotion.

An emphasis on empathy

Responding to patients' emotions with empathy is arguably one of the most fundamental communication skills, yet physicians find exploring patients' emotions and expressing empathy to be among the most difficult aspects of their conversations. ¹⁴ Studies demonstrate that patients prefer honest and clear dialogue and that there is great value in active listening and facilitating silence when discussing prognosis. ¹⁵ ²² ⁵⁴ ⁶³⁻⁷¹ The five frameworks identified in this scoping review underscore the value in exploring a patient's emotion and emphasise the importance of empathic communication. These guidelines provide a solution to the challenge of expressing empathy by providing a concrete framework of verbiage and phrases to aid in empathic communication.

While not specific to the discussion of prognosis, as appeared during the data gathering portion, VitalTalk provides a specific guideline for responding to emotion, articulating empathy using Naming Understanding Respecting Supporting Exploring (NURSE) statements. 40 41 44 45 47 72 73 VitalTalk prompted the development of Oncotalk that started as a communication skills workshop designed for oncology fellows as a 4-day

intensive skills course addressing eight communication skills, the most important of which, according to one of the developers, was responding to patients' emotion. ⁴⁰ Central to the Oncotalk philosophy is that successful communication skills can be learnt and harnessed the same way any medical procedure is established: through practice and constructive feedback. ^{40 41} The programme emphasises 'asking before telling,' letting the patient lead the conversation, attending to patients' emotions, and giving information in simple language based on patients' needs. In a preintervention and postintervention cohort study, after the Oncotalk workshop, a group of medical oncology fellows exhibited tangible changes in their communication skills. ⁷⁴

Researchers wanted to investigate whether these skills were teachable over a condensed timeframe. In a randomised controlled trial, medical, radiation and gynaecological oncologists were randomised to complete an interactive hour-long training computer programme on how to respond to patients' negative emotions, which included feedback provided on oncologists' own recorded conversations. 72 Oncologists in the intervention group used more empathic statements and were 200% more likely to respond empathically to negative emotions compared with those in the control group. Patients in the intervention group perceived greater empathy from their oncologists and felt the oncologists' communication was more impactful. Empathic statements were defined as any of five behaviours consistent with the NURSE framework; empathic opportunities were defined as 'continuers' which facilitated NURSE or 'I wish' statements. Lastly, 95% of oncologists in the intervention group believed the tutorial influenced change in their practice.

Scaling up: can communication models be implemented at the institutional level?

Beyond the *how* and *what* we can say to communicate prognosis effectively, a large issue remains: how can we scale these practices to the institutional level? Varying models have been shown to be effective when implemented on an systems-wide level. 51 75-78 The longitudinal case study completed by Kaiser Permanente over 16 years demonstrated that clinician–patient communication training is attainable on a large-scale and improves clinicians' communication skills and clinicians' confidence in having difficult discussions. 32 79 Critical success factors of education and development sessions included using experiential learning format and voluntary attendance. 32 Over 16 years, the programme took on many facets; what started as a 1-day course gave rise to a communication consultant programme, which included one-on-one coaching; smaller sessions, termed clinician–patient interaction courses, were held two to three times per year at each hospital primarily for new hires and sometimes were a required component of orientation.

Those at Ariadne Labs conducted an evaluation of an educational programme 'train-the-trainer' model where they trained 22 trainers within three systems using the Serious Illness Care Program who then trained 297 clinicians total. ⁷⁶ Overall, clinicians across multiple disciplines demonstrated statistically significant improvement in self-rated skills including how to share prognosis; specifically clinicians reported benefits of having concrete language and framework. This 'train-the-trainer' model is an example of a scalable way to educate

clinicians across varying disciples. Further objective measures must assess the benefit of these types of programmes and their long-term durability.

CONCLUSION

The ability to skillfully communicate prognostic estimates is essential to the delivery of high-quality cancer care and is currently a high priority in the medical community on an international level. In this scoping review, we identified five models to guide oncologists through prognostic disclosure. Several of these tools have been applied to clinical practice and studies suggest that interventions for clinicians' and/or patients can promote more successful, patient-centred dialogue. This review is unique in that we identify communication models aimed at improving the quality of the patient—oncologist discussion including a variety of sources from randomised controlled trials to prospective studies. We compare and contrast similarities and differences of these models in hopes to underscore the key components that make these studied models successful.

There are important methodological limitations of this review. The broad nature of this topic made it difficult to conduct a specific, well-defined search and we may have inadvertently excluded publications that were not captured by the selected databases. Further, there are potential limitations associated with comparing and contrasting the identified communication models as only some of them have been validated with randomised controlled trials. Lastly, as with any publication, the dates of our search criteria fail to acknowledge recently published literature such as a study by Epstein *et al* exploring a newly conceived communication intervention, Oncolo-GIST, designed to enhance oncologists' ability to convey prognostic information clearly.⁸⁰

Evidence-based approaches to communication skills training in oncology are needed, as are strong efforts to implement these approaches in the clinical training. Further studies are needed to evaluate how communication skills can be best retained over time, how to evaluate prognostic understanding among patients and caregivers especially in response to employed protocols, and how to scale protocols within and among institutions. Several proposals have been suggested with regards to how to retain skills over time including: workshops followed by interval videoconferences; maintenance of certification courses for continuing education credits; incorporating specific documentation within a dedicated electronic medical record section to prompt and/or track clinicians' activities; and, combined interventions targeting both physicians and patients such as a pre-conversation questionnaire, phone application or workshop. 81 82 The Alliance of Dedicated Cancer Centers, composed of the USA's leading cancer centres, has recently supported a programme named the Improving Goal-Concordant Care initiative, which includes training in prognosis communication and structured documentation of such conversations on large, institution-level, scales.⁸³ More system-wide programmes should be initiated to better understand how to scale these programmes successfully while still encouraging personal learning experiences with careerlasting, durable effects.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding

The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

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Key message

What was already known?

 Several communication models exist to aid clinicians in their approach to prognostic disclosure with the patient.

What are the new findings?

- Three communication models have been validated in randomised controlled trials. These demonstrate improved objective communication measures and patient reported outcomes.
- All three models emphasise the importance of exploring patients' illness understanding and treatment preferences, communicating prognosis and responding to emotion.

What is their significance?

- A) Prognostic disclosure communication models have tangible effects on successful communication employed in clinic; varying strategies including the method of learnt communication, and intervention for both the patient and clinician may benefit patient-centered prognostic communication
- B) Further research is needed to understand how to: evaluate the effect of
 prognostic awareness of patients, maintain successful communication skills
 for lifelong practice, and, lastly, scale this skill at the institutional and national
 levels.

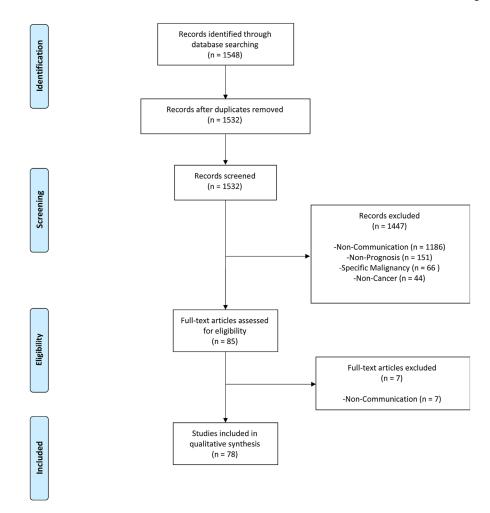


Figure 1. Search strategy flow diagram.

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Table 1

Communication models for discussing prognosis

Communication model	Serious Illness Conversation Guide ²⁸	ADAPT ²⁹	PREPARED ³⁰	SPIKES ³¹	The four habits model ³²
Components	Set up the conversation Assess understanding and preference Share prognosis Explore key topics Close the conversation Document your conversation Communication with key clinicians	Ask what the patient knows, Discover what information about the future would be useful Anticipate ambivalence ambivalence information Track emotion	Prepare for the discussion Relate to the person Elicit patient and caregiver preferences Provide information tailored to needs of patients and their families Acknowledge emotions and concems (Foster) Realistic hope Encourage questions Document	Setting Perception Invitation or Information Knowledge Empathy Summarize or Strategize	Invest in the beginning Elicit the patient's perspective Demonstrate empathy Invest in the end
Created/ sponsored by	Ariadne Labs-MGH, National Advisory Group, United States, 2012	VitalTalk National Institutes of Health funding, 2012	Expert Advisory Panel, New Zealand, Australia, 2007	MD Anderson physicians, 2000	Kaiser Permanente, 1995
Introduction/	Set up the conversation		Prepare for the discussion	Setting up the Interview	Invest in the Beginning
environinent	• Introduce purpose		Confirm pathological diagnosis and investigation	Arrange for some	Create rapport
	 Prepare for future decisions 		tragnosis and investigation results before initiating discussion	• Involve significant	questsElicit the patient's
	• Act normicalon			others	concerns
	normani da Asaran		Iry to ensure privacy and uninterrupted time for discussion	Sit down, make connection with the nation	Plan the visit with the patient
			Negotiate who should be present	Manage time constraints and interruptions	forCould you tell me more about that?" – "What else?"
			Relate to the person		
			Develop rapport		
			Show empathy, care and compassion during the entire consultation		
Patient's	Assess understanding and	Ask what the	Elicit patient and caregiver preferences	Assessing the patient's perspective	Elicit the patient's perspective
understanding and preference	preferences	patient knows, what they want to know Discover what information	Identify reason for consultation and elicit patient's expectation	Before you tell, ask' Obtaining the Patient's Invitation	Ask for the patient's ideas Elicit specific
		about the future would be useful for the patient	ctain y unecstaining and establish how much detail they want to know		Explore the impact on the patient's life

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Communication model	Serious Illness Conversation Guide ²⁸	${ m ADAPT}^{29}$	PREPARED ³⁰	SPIKES ³¹	The four habits model ³²
		(statistics vs living to a particular date) Anticipate ambivalence	Consider cultural and contextual factors influencing information preferences	How much information and in what manner would you like it	
Prognosis	Share prognosis Share prognosis tailored to information preferences Frame as a 'wish worry', 'hope worry' statement	Provide information in the form the patient wants	Provide information tailored to individual needs of both patients and their families • What to expect • Use clear, jargon-free language • Explain uncertainty, limitations and unreliability of prognostic and end-of-life information • Consider caregiver's distinct information needs	Giving Knowledge and Information to the Patient • Prepare that you are giving bad news • Start at the level of comprehension and vocabulary of the patient; use nontechnical words • Don't use excessive bluntness • Give information in small chunks and check periodically as to the patient's understanding	Invest in the end • Deliver diagnostic information frame in terms of patient's original concerns • Provide education
Respond to patient's emotion	Allow silence, explore emotion	Track emotion	Acknowledge emotions and concems patient's and caregiver's fears and concerns and their emotional reaction to the discussion Respond to distress (Foster) Realistic hope Be honest without being blunt Do not give misleading or false information to try to positively influence patient's hope Reassure support, treatments and resources are available to control pain and other symptoms	Addressing the patient's emotions with empathic responses • Observe for any emotion (tearfulness, sadness, silence, shock) • Identify the emotion (name it), use open ended questions • Identify the reason for the emotion • Let the patient know that you have connected the emotion with the reason for the emotion	Be open to the patient's emotions Make an empathic statement Convey empathy nonverbally
Goals	Explore key topics Goals		(Foster) Realistic hope • Explore and facilitate	Strategy • Clear plan for the	Elicit the patient's perspective Explore the impact
	• Fears and worries		realistic goals and ways	future	on the patient's life

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Communication model	Serious Illness Conversation Guide ²⁸	${ m ADAPT}^{29}$	PREPARED ³⁰		SPIKES ³¹	The four habits ${ m model}^{32}$
	Sources of strength Critical abilities Tradeoff's	th	0.0	of coping on a day-to-day basis	Shared decision making Understand important specific goals	Invest in the end Involve the patient in making decisions
	• Family					
Conclusion	Close the conversation		Encourage questions	stions	Summarize	Complete the visit
	Summarise		•	Check understanding and if		Summarise
	Make a		II 68	information meets patient's and caregiver's needs		Review next steps
	Check in with patient	ient	•	Leave door open for topics to be discussed again in		Ask for additional questions
	Affirm commitment	ant	£.	future		Assess satisfaction
After encounter	Documentation		Document			
	Document your conversation			Write a summary of what has been discussed		
	Future plans Communicate with key clinicians	h	•	Speak or write to other key healthcare clinicians involved in patient's care		
Validation	RCT ^{34 35}	$ m RCT^{39}$	Not validated		Observational study ⁴⁰	RCT ⁵¹

RCT, randomised controlled trial.