

Review Article

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The experiences of health professionals, patients, and families with truth disclosure when breaking bad news in palliative care: A qualitative meta-synthesis

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Abstract

Objective. Disclosing the truth when breaking bad news continues to be difficult for health professionals, yet it is essential for patients when making informed decisions about their treatment and end-of-life care. This literature review aimed to explore and examine how health professionals, patients, and families experience truth disclosure during the delivery of bad news in the inpatient/outpatient palliative care setting.

Methods. A systemized search for peer-reviewed, published papers between 2013 and 2020 was undertaken in September 2020 using the CINAHL, Medline, and PsycInfo databases. The keywords and MeSH terms (“truth disclosure”) AND (“palliative care or end-of-life care or terminal care or dying”) were used. The search was repeated using (“bad news”) AND (“palliative care or end-of-life care or terminal care or dying”) terms. A meta-synthesis was undertaken to synthesize the findings from the eight papers.

Results. Eight papers were included in the meta-synthesis and were represented by five Western countries. Following the synthesis process, two concepts were identified: “Enablers in breaking bad news” and “Truth avoidance/disclosure.” Several elements formed the concept of Enablers for breaking bad news, such as the therapeutic relationship, reading cues, acknowledgment, language/delivery, time/place, and qualities. A conceptual model was developed to illustrate the findings of the synthesis.

Significance of results. The conceptual model demonstrates a unique way to look at communication dynamics around truth disclosure and avoidance when breaking bad news. Informed decision-making requires an understanding of the whole truth, and therefore truth disclosure is an essential part of breaking bad news.

Introduction

A life-limiting diagnosis is devastating for the patient and their family to receive. Yet the advantage of timely truth disclosure regarding a life-limiting illness enables a patient and their family to be involved in informed decision-making and physically, mentally, and spiritually prepare for the end-of-life (Kogan et al., 2013; Becker et al., 2015). The health professional needs to explain bad news in language that the patient and family can understand while considering the impact of cultural and spiritual preferences (Mostafazadeh-Bora and Zarghami, 2017). Such a conversation requires empathy, tact, intuition, and skill (Bousquet et al., 2015) and can be one of the most challenging tasks for health professionals to undertake (Berkey et al., 2018).

Difficulty in breaking bad news may result from the doctor’s fear of emotional responses from patients and families, a lack of time for detailed dialogue, inadequate training in end-of-life discussions, or not being comfortable with prognostication (Berkey et al., 2018; Johnston and Beckman, 2019). Patients’ or family members’ reactions to bad news may be intensified by various factors such as age and family responsibilities (Ptacek and Eberhardt, 1996), faith, culture, past experiences, and symptoms of the disease (Mostafazadeh-Bora and Zarghami, 2017).

Receiving bad news in a healthcare context refers to any information which will negatively alter a person’s view of their future, yet the definition of “bad” is proportionate to the patient’s understanding of the life-limiting illness and may differ from the reality as understood by the health professional (Buckman, 2005).

The shift away from a paternalistic medical culture to patient autonomy in which a patient has the right to know about their diagnosis and prognosis has become a legal and ethical requirement in Western countries (Goldberg, 1984; Bousquet et al., 2015), yet in practice, the truth can be withheld, distorted, and manipulated by health professionals for various

reasons (Fallowfield et al., 2002; Sarafis et al., 2014). Health professionals are faced with ethical dilemmas of “do no harm” at the same time as respecting patients’ autonomy (Beste, 2005) especially when patients are unable to contribute to decision-making due to their physical or emotional state (Sarafis et al., 2014).

Although there is literature discussing the delivery of bad news and various communication models to assist health professionals, examining truth disclosure within bad news is not as prolific. Therefore, this qualitative meta-synthesis aimed to explore and examine how health professionals, patients, and families experience truth disclosure when delivering or receiving bad news in the inpatient/outpatient palliative care setting.

Methods

Like the meta-ethnography technique described by Noblit and Hare (1988), the meta-synthesis aims to use an inductive and interpretive methodology to synthesize and combine the included papers with going beyond the original interpretations (Britten et al., 2002; Thomas and Harden, 2008). The meta-synthesis was undertaken in three phases: a systemized search, quality appraisal, and synthesis.

Search strategy

A systemized search was undertaken in September 2020 following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Liberati et al., 2009). With the aid of a librarian, a scoping search was undertaken using (life limit* OR life threatening OR fatal OR terminal) diagnosis OR prognosis AND disclosure of information and repeated using (communication). Of the papers that matched the selection criteria and the paper’s aim, the keyword “truth disclosure” appeared as a commonality among the papers. With that in mind, the search process was recommenced using a combination of keywords and MeSH terms using the CINAHL, MEDLINE, and PsycInfo databases. MeSH terms of (“truth disclosure”) were used with CINAHL and Medline and (“truth”) with PsycInfo. Keywords included (“palliative care or end-of-life care or terminal care or dying”) NOT (“children or adolescents or youth or child or teenager”) NOT (“ICU or intensive care unit”) NOT (“emergency department or emergency room or accident and emergency or a&e or a & e”). Restrictors were set to retrieve peer-reviewed articles written in English and published between 2013 and 2020. An age restrictor for “adults” was also added. The search was repeated, combining the three databases and the terms (“bad news”) with the keywords and restrictors. In addition to searching the databases, a comprehensive hand search of the

available literature was conducted by looking at reference lists. A total of 212 articles were retrieved, including two hand-searched articles, and once duplicates were excluded ($n = 156$), all three authors screened 56 articles for relevance by reading titles and abstracts and excluded 12 articles. The remaining 44 articles were then read in full and assessed against the inclusion/exclusion criteria (see Table 1), with the final eight papers being eligible for a quality assessment. Figure 1 outlines this process. The rationale for limiting the search to the above keywords, period, cohort, paradigm, and hospital department was to examine the latest papers discussing truth disclosure during a bad news conversation within a restricted environment, looking at a specific behavior.

Quality appraisal

The Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item Checklist for Interviews and Focus Groups (Tong et al., 2007) was used to assist the authors in examining the papers’ rigor and methodological designs. Within the Research Team and Reflexivity domain, there was limited information regarding the researchers’ characteristics, and none of the eight papers clearly disclosed the researchers’ relationship to the participants. This was also reflected for each paper when assessed using the Critical Appraisal Skills Programme (CASP, 2020), and as a result, each paper scored $\geq 90\%$. While some inadequate methodological reporting was evident, no paper was discarded on this basis as all papers yielded important findings and provided in-depth analysis and discussion of their findings (Dixon-Woods et al., 2004). Table 2 details each paper’s characteristics.

Synthesis

The purpose of a meta-synthesis is to develop new concepts by going beyond the findings of the original papers (Britten et al., 2002; Thorne et al., 2004; Thomas and Harden, 2008). The papers were synthesized based on Noblit and Hare’s (1988) phases of conducting a meta-ethnography. The first author circled pertinent words, drew links between them, and annotated phrases throughout the Findings and Discussion sections of each paper. This became an iterant process in which concepts or third-order constructs were developed, as per the adaptation for health research by Britten et al. (2002) and detailed in Table 3. Following the terminology of meta-ethnography (Noblit and Hare, 1988), first-order constructs are the participants’ quotes, second-order constructs are the themes generated by the original authors, and third-order constructs are the development of new concepts as a result of translating the papers into one another. The second and third authors examined the development of the third-order

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
Patients with a terminal diagnosis and their families	Residential aged care facilities, homes, hospices, and community settings
Health professionals providing palliative care within an in/outpatient setting	ICU or emergency departments
Papers written in the English language	Psychiatric, maternity wards or units
Adults over the age of 18 years	Dementia or intellectual disability
Primary research	Education, communication tools, or evaluations
Papers published between 2013 and 2020	End-of-life decisions, advance care plans, or referrals to palliative care; voluntary assisted dying
Focusing on truth disclosure, truth-telling, and the delivery of bad news	Doctor/patient relationships or quality of care post-diagnosis
Qualitative	Literature reviews, editorials, discussion papers, and other grey matter
	Quantitative, mixed methods

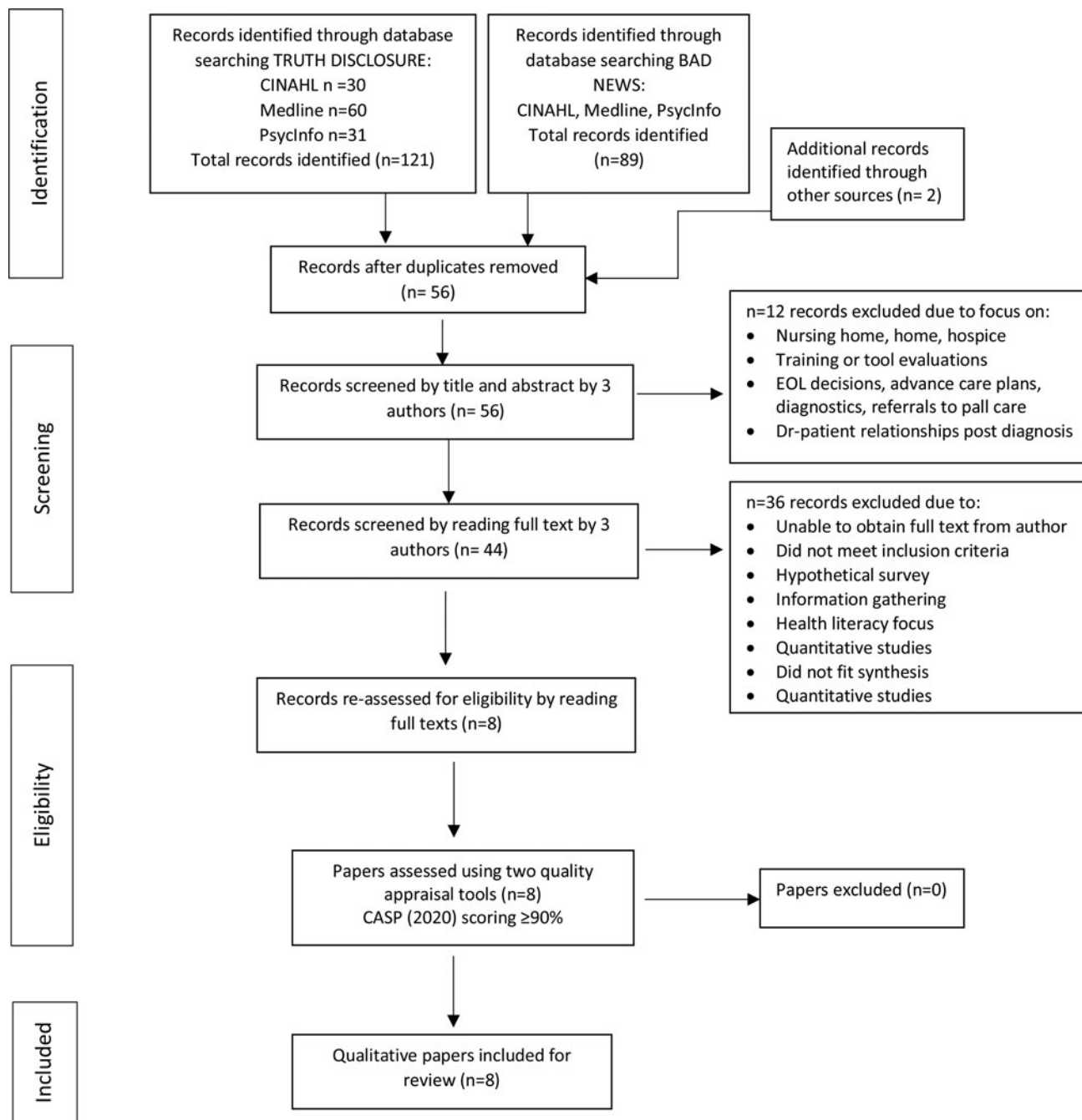


Fig. 1. PRISMA flow diagram.

constructs and pursuant concepts until agreement and consensus were reached.

Results

Description of included papers

Eight papers were included in the meta-synthesis and were represented by five Western countries being Sweden ($n = 2$), UK ($n = 2$), USA ($n = 2$), Canada ($n = 1$), and The Netherlands ($n = 1$). Data collection arose from semi-structured interviews with patients ($n = 2$), nurses ($n = 2$), doctors ($n = 1$), recorded consultations

between doctors and patients ($n = 2$) in which only one included the patients' voices in the data, open-ended questions from a survey with nurses ($n = 1$), and focus groups (FGs) followed by semi-structured interviews with doctors, nurses, and dieticians ($n = 1$). The first FG consisted of ($n = 1$) dietician, ($n = 2$) nurses, and ($n = 1$) specialist palliative care nurse. The second FG consisted of ($n = 2$) nurses, ($n = 1$) dietician, ($n = 1$) specialist palliative care nurse, and ($n = 1$) doctor. Twenty-five individual semi-structured interviews then followed with ($n = 10$) nurses, ($n = 5$) specialist palliative care nurses, ($n = 3$) dieticians, and ($n = 7$) doctors. Settings included outpatient chemotherapy clinics, general medical wards, stroke units, and oncology centers across 11

Table 2. Characteristics of included papers

Author & country	Aims	Sample and setting	Methodology/ paradigm	Data collection	Data analysis	Limitations
Bergqvist and Strang (2019) Sweden	Explore breast cancer patients' preferences and perceptions of patient-doctor communication regarding continuous late lines of palliative chemotherapy	20 women with incurable breast cancer (aged 40–80 years) on a minimum of 2nd line of palliative chemotherapy Outpatient chemotherapy clinic at Karolinska University Hospital Solna, Sweden Sampling method not stated	Not stated	Semi-structured face-to-face interviews	Qualitative conventional content analysis	Patients' retrospective experiences may have changed over time Single-site limiting generalizability
Mishelmovich et al. (2016) UK	Explore specialist cancer and palliative care nurses experience of delivering significant news to patients with advanced cancer	Clinical nurse specialists in cancer and palliative care ($n = 10$, female) One acute NHS hospital Purposeful sampling	Heideggerian hermeneutic phenomenology	Individual semi-structured interviews	Not stated	Single-site and all-female participants which may not be generalizable across all populations or settings
Abdul-Razzak et al. (2014) Canada	To understand patients' preferences for physician behaviors during end-of-life communication	Seriously ill inpatients with either CHF, severe COPD, liver cirrhosis, medical patients >80 years ($n = 5$), or active metastatic cancer ($n = 11$) Total patients ($n = 16$) female ($n = 11$) male ($n = 5$) General medical wards in three Canadian academic tertiary hospitals in Alberta, Canada Purposive, maximum variation sampling	Interpretive description Taken from a larger mixed-method study; quantitative data published separately	Individual face-to-face interviews Field notes were taken of observation occurring during interviews	Constant comparative	Patients' retrospective experiences may have changed over time Only Caucasians included which may not be generalizable across cultures Different settings may yield different results
Anderson et al. (2013) USA	To describe initial communications about serious illness between hospitalists and patients and to identify patterns that led to sensitive and honest discussions of death and dying even at a first meeting	Hospitalists ($n = 23$) who interviewed seriously ill patients ($n = 39$) Two hospitals comprising the medical service at an academic medical center Sampling method not stated	Grounded theory	Audio recorded encounters between hospitalists and patients in the absence of the researcher ($n = 39$)	Dimensional analysis	Did not capture other conversations with other providers while admitted; family members were mostly not present; single-site limiting generalizability
Henselmans et al. (2017) The Netherlands	To examine how communication about life expectancy is initiated in consultations about palliative chemotherapy and what prognostic information is presented	Medical oncologists ($n = 6$); oncologists-in-training ($n = 7$); advanced cancer patients with <1-year prognosis ($n = 41$) Academic Medical Center Amsterdam, Netherlands Sampling method not stated	Design not stated Prospective observational follow-up study	Audio-recorded consultations ($n = 62$) Data were derived from a previously published prospective observational study	Content analysis stated in the original study; Maxqda10 software used	Single-site limiting generalizability Cultural differences may prevent generalization across populations
Rejnö et al. (2017) Sweden	To deepen the understanding of stroke team members' reasoning about truth-telling in EOL care due to acute stroke with reduced consciousness	Stroke team members ($n = 15$): physicians ($n = 4$), RNs ($n = 7$), ENs ($n = 4$) Stroke units in two county hospitals in Western Sweden	Design not stated Follow-up study	Individual interviews	Inductive and deductive qualitative content analysis	Participants' beliefs and experiences were examined which may be different from data collected in field settings; stroke patient context may not be generalizable to other disease contexts

(Continued)

Table 2. (Continued.)

Author & country	Aims	Sample and setting	Methodology/ paradigm	Data collection	Data analysis	Limitations
Millar et al. (2013) UK	To examine the relationship between physician's approaches to communication about terminal prognosis and other healthcare professionals' approaches to communicating with patients and their families about cachexia	Registered nurses, dieticians, specialist nurses, and medical staff working in the cancer center ($n = 34$) Cancer center of a large teaching hospital in Northern Ireland, UK	Symbolic interactionism Part of a wider study	Two focus groups ($n = 4; 5$) and individual semi-structured interviews ($n = 25$)	Content analysis and constant comparative method	Participants' beliefs and experiences were examined which may be different from data collected in field settings; single-site limiting generalizability
McLennon et al. (2013) USA	To describe the frequency and types of ethical dilemmas experienced by oncology nurses caring for advanced cancer patients and to summarize their written comments about prognosis-related communications	Registered nurses practicing in oncology settings who were members of the Oncology Nursing Society ($n = 137$) Sampling method not stated	Design not stated The original study used a cross-sectional design	Narrative comments from two open-ended questions were taken from a mailed survey	Content analysis	Participants' beliefs and experiences were examined which may be different from data collected in field settings Data were drawn from a survey tool that was not formally validated; the survey was mailed to Oncology Nursing Society members which may not be representative of all oncology nurses

sites. Five of the eight studies were either follow-up or part of wider studies. See Table 2.

Participant characteristics

Overall, ($n = 77$) patient voices were heard ($n = 11$) with non-cancer diagnoses. The first group of patient participants included ($n = 20$) women aged between 40 and 80 years with incurable breast cancer, undergoing outpatient palliative chemotherapy. These participants preferred only to hear good news, handed over decision-making to others, and used treatment as a form of denial. A second group of patient participants were aged between 55 and over 89 years and included ($n = 5$) patients with cancers and ($n = 11$) with CHF, severe COPD, liver cirrhosis, or other medical issues and were inpatients in medical wards. As most of these participants had chronic disease, they had built therapeutic relationships, valued being known, and understood the importance of open diagnostic and prognostic conversations when they were ready. The final group of ($n = 41$) cancer patient participants were undergoing palliative chemotherapy and had an estimated <1 year to live. They expressed their desire for prognostic information overtly or covertly but only 30% of the time this was addressed.

Of the ($n = 235$) health professionals whose voices were heard, the nursing cohort consisted of ($n = 167$) oncology nurses, ($n = 11$) stroke unit nurses, and ($n = 12$) palliative care specialists. Of the physician cohort ($n = 19$) were oncologists, ($n = 23$) were generalists, ($n = 4$) were stroke specialists, and ($n = 2$) palliative consultants. Within the dietician cohort, ($n = 3$) were in oncology and ($n = 2$) in palliative care.

Specialist palliative care nurses and consultants were confident and experienced in conducting diagnostic, prognostic, and end-of-life conversations. They highlighted the need to establish relationships to develop trust before delivering bad news and the importance of shared decision-making. On the other hand, the majority of health professional participants in the synthesis were generalists, oncologists, stroke experts, or medical/oncology nurses who were not comfortable delivering diagnostic or prognostic bad news. Most waited for prompting or acknowledgment by the patient, used vague terminology or overly optimistic forecasting while others avoided it through fear, to protect the patient/family, or believed it was not their job. The majority believed they needed further education about how to deliver bad news and some nurses wanted better collaboration among the team.

Description of the conceptual model

Two concepts were identified following the synthesis process: "Enablers in breaking bad news" and "Truth avoidance." Several elements formed the concept of Enablers for breaking bad news, such as the therapeutic relationship, reading cues, acknowledgment, language/delivery, time/place, and qualities that will be discussed separately. Figure 2 illustrates how the Enablers create an environment within which to deliver bad news, leading to a crossroad, even if momentarily and unconsciously, of whether bad news will be shared or avoided. At the crossroads, a decision is also made as to the level of truth disclosure which is affected by personal barriers which maybe fear, and anxiety felt by the health professional and is discussed in Truth avoidance. The process is

Table 3. Summary of emerging concepts

Fourth-order constructs	Third-order constructs	Second-order constructs (original themes)	Description of first- and second-order constructs	Source
Enablers: • Reading cues Truth avoidance	Patients working at controlling and living in their death avoidance = coping mechanism Partial/selective truths Pleasing others Treatment = hope Activities for denial Patients handed over decision-making	1. Communication (doctor–patient) • Partial/selective truths • Patient’s will to please the doctor 2. Hope • Patient–doctor communication • Patient–family interaction 3. Doctor • The expert • Positive characteristics • Negative characteristics	Communication changed over time. Patients prefer vague prognoses. Women want to please the doctor & family. All involved are playing a game of “Common collusion” — doctor takes the path of least resistance; family playing the game of death avoidance. Treatment was used as an activity for denial & put off the concept of death. The patient handed over decision-making. Patient happy when good news presented = good doctor. Bad news delivered = bad doctor	Bergqvist and Strang (2019)
Enablers: • Therapeutic relationship • Experience	The relationship allows sensitive delivery of bad news. Identifying with patients How to break bad news Confidence and ability develop with experience and self-reflection	1. Importance of relationships (establishing trust) 2. Perspective-taking (nurse–patient) 3. Ways to break significant news 4. Feeling prepared and putting yourself forward (nurse)	A therapeutic relationship with the patient forms the basis of trust, enabling the breaking of significant news. Easier to talk to older patients, less risk of personal identification. Forming partnership with the patient to listen, empower, & assist decision-making. Experience increased confidence in delivering significant news. Clinical Nurse Supervisors use guidelines flexibly to guide their conversations.	Mishelmovich et al. (2016)
Enablers: • Therapeutic relationship • Reading cues • Language	Relationship (including patient–family unit) allows sensitive delivery of bad news How to break bad news	1. Knowing me • Acknowledging family roles • Respecting one’s background 2. Conditional candor • Assessing readiness • Being invited to the conversation • Appropriate delivery of information	As the family forms the support network and future decision-making, treat the patient and family as one “unit.” Long-term patient/doctor relationship allowed a deeper understanding of patient’s wishes, values, & needs. Open discussion of diagnosis & prognosis was wanted when the patient was ready, but the doctor had to gauge this. The context needs to be considered as well as the delivery style.	Abdul-Razzak et al. (2014)
Enablers: • Therapeutic relationship • Reading cues • Language • Acknowledgment Truth avoidance	Open acknowledgment of possible death was needed for EOL discussions (including prognostication) to occur How to break bad news (assessing readiness) The possibility of dying was not raised by the doctor first	1. Context: A seriously ill patient’s hospital admission 2. Conditions: Patient and physician actions • Conditions facilitating acknowledgment of the possibility of dying • Conditions directing the conversation away from serious illness and prognosis 3. Process: Continuum of acknowledging the possibility of dying • Acknowledging • Not acknowledging 4. Consequences: Addressing EOL issues	Meaningful conversations took place about EOL issues after open acknowledgment about the possibility of dying took place, otherwise the doctor/patient conversation only involved treatment of the immediate issue. Open acknowledgment equates to Glaser & Strauss’s (1965) term “open awareness.”	Anderson et al. (2013)
Enablers: • Reading cues • Language Truth avoidance	Patient/family requested prognostic information — never volunteered by the oncologist	1. Taking the initiative 2. Information presented • Tailoring • Life expectancy information 3. Incorporating uncertainty	Patients requested prognostic information overtly or covertly, but it was not volunteered by the oncologist. Few oncologists probed for the clarification of information needs. Time was discussed in averages and in terms of “years” to “months” and tended to be optimistic. Only 19 of 62 consultations were life expectancy addressed.	Henselmans et al. (2017)
Enablers: • Therapeutic relationship • Reading cues • Language Truth avoidance	Truth-telling builds a relationship of trust = deeper discussions How to break bad news (timing) Partial/selective truths	1. Truth above all • A value in itself • To establish trust 2. Hide truth to protect • Not add extra burden in the sorrow • Awaiting the timely moment	People have a right to be told the truth which should be delivered in a simple, straightforward manner. Truth helps build a relationship based on trust, enabling a deeper conversation about EOL issues. Yet at times, staff chose to withhold truth to NOK to protect them	Rejno et al. (2017)

(Continued)

Table 3. (Continued.)

Fourth-order constructs	Third-order constructs	Second-order constructs (original themes)	Description of first- and second-order constructs	Source
		<ul style="list-style-type: none"> • Not being a messenger of bad news 	from added sorrow, unhelpful or unconfirmed information, or avoid emotional outbursts. Nurses practiced avoidance strategies to avoid lying.	
Enablers: <ul style="list-style-type: none"> • Therapeutic relationship • Reading cues • Time • Qualities Truth avoidance	Relationship needed for hard conversations to take place Truth avoidance Wanted education Not nurse's role	1. Physicians' approaches to truth-telling about terminal prognosis 2. Nurses and dieticians' approaches to discussions about weight loss	Many oncologists tended to avoid truth-telling about a terminal diagnosis or refractory cachexia due to time constraints, lack of relationship, and desire not to take away patient's hope. Some oncologists preferred physical interventions rather than providing psychological support. Nurses and dieticians tended to avoid truth-telling (despite the situation being obvious) due to lack of education, confidence, and such discussions leading to EOL discussions. Nurses believed it was not their role to prognosticate so remained guarded and practiced avoidance strategies.	Millar et al. (2013)
Enablers: <ul style="list-style-type: none"> • Language • Qualities Truth avoidance	Truth avoidance makes a nurse's role harder and creates an ethical conflict Collaboration provides better care Doctors and nurses need education around EOL and prognostic issues	1. Ethical Dilemmas <ul style="list-style-type: none"> • Truth-telling • Conflicting obligations • Futility 2. Prognosis-related communications <ul style="list-style-type: none"> • Who should talk about it? • Nurses role • Nurses advice • What do nurses need? • Why is it important? 	Oncology nurses faced multiple ethical dilemmas when providing care when truth-telling was avoided, vague, or patients/families were given false hope or mislead. Nurses became conflicted with cultural, language, or religious barriers and preferences or futile treatments that reduced the quality of life. A collaborative team provided the best care, and NPs and experienced nurses were comfortable discussing EOL issues. Nurses acted as advocates, facilitators, and support agents. Some nurses believed that prognostic information should only be addressed by the doctor, while other nurses initiated conversations to move patients toward acceptance and EOL planning. Some nurses stated they would like more communication between professionals about the patient's status and more education about how to address prognostic-related questions.	McLennon et al. (2013)

circular as conversations need to be repeated. There are consequences for both courses of action.

Enablers in breaking bad news

Several elements assisted in the sensitive delivery of bad news, such as the development of a therapeutic relationship, reading cues, language/delivery, appropriate time/place, and qualities.

Therapeutic relationship. The importance of a therapeutic relationship between the health professional and the patient/family unit emerged as an important factor in creating a conducive environment for the delivery of bad news in five of the eight papers (McLennon et al., 2013; Millar et al., 2013; Abdul-Razzak et al., 2014; Mishelmovich et al., 2016; Rejnö et al., 2017). In the palliative care setting, health professionals were able to understand the patient's preferences, history, culture, religion, and health literacy and learn how to phrase conversations tailored to their preferences (Millar et al., 2013; Abdul-Razzak et al., 2014;

Mishelmovich et al., 2016). A relationship fostered through good listening skills facilitated the development of familiarity, security, and trust and enabled open and honest discussions around diagnosis and prognosis (Abdul-Razzak et al., 2014; Mishelmovich et al., 2016; Rejnö et al., 2017).

“Well there's sort of a bond or connection between you. If you know someone fairly well it's easier to do things with them, work out plans. But if you're more like a stranger, um they really don't know what you might like or what's best for you and you don't really understand them.” (Patient in Abdul-Razzak et al., 2014, p. 4)

Working in partnership with the patient/family by involving them in end-of-life discussions gave them control in decision-making which reflected person-centered care and attenuated paternalism (McLennon et al., 2013; Millar et al., 2013; Abdul-Razzak et al., 2014; Mishelmovich et al., 2016). Involving the family in discussions was important, as they were pivotal in providing

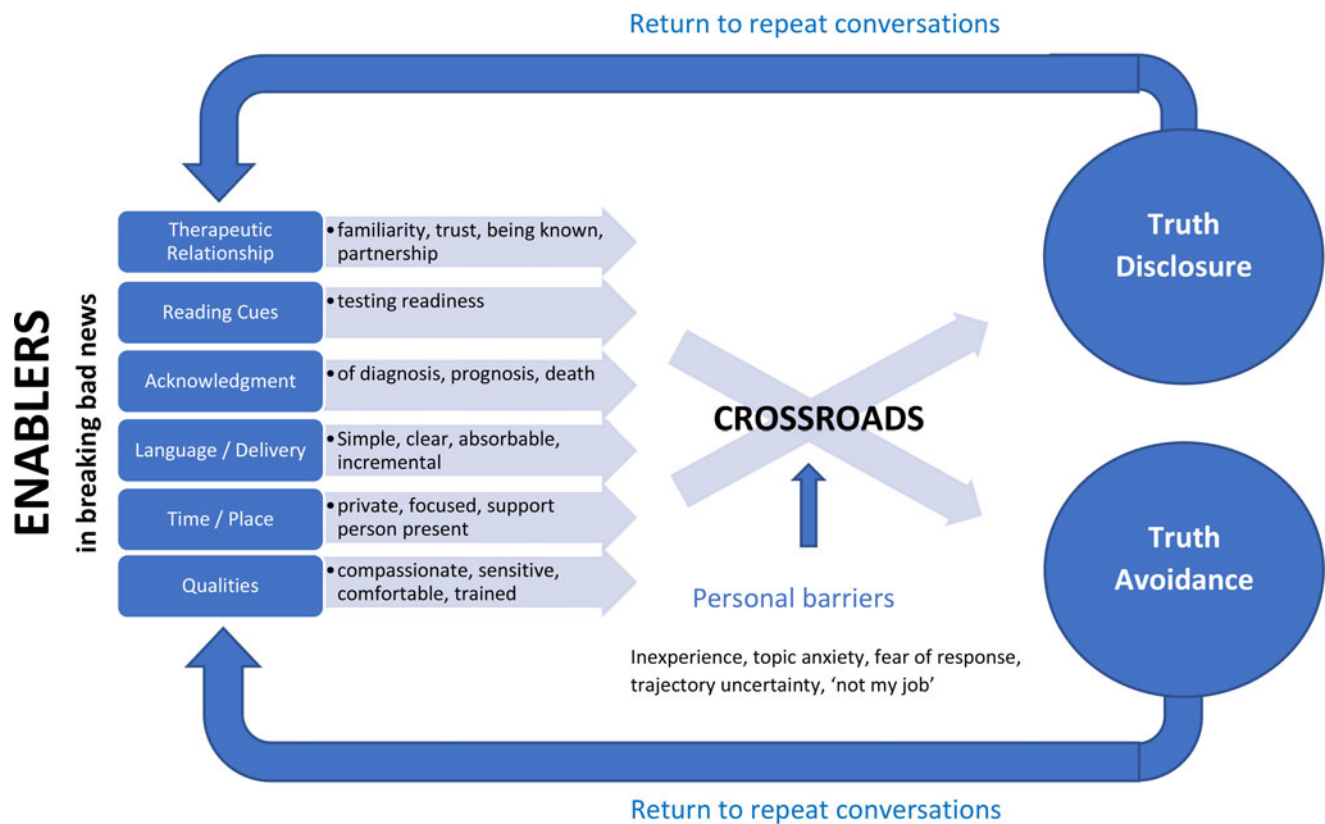


Fig. 2. Enabling truth disclosure model.

physical and emotional support to the patient and were potential future decision-makers (Millar et al., 2013; Abdul-Razzak et al., 2014).

Where a prior relationship did not exist, the generalist doctors relied on testing the patient's current knowledge of their illness to frame the direction of the conversation and did not disclose any prognostic information or discuss the severity of the illness without a direct request from the patient (Anderson et al., 2013).

Reading cues. Whether or not to break the bad news to patients often depended on whether patients gave cues about their readiness to know more (Mishelovich et al., 2016). Requests for further information or acknowledgment of dying took the form of overt verbal requests (Anderson et al., 2013; McLennon et al., 2013; Millar et al., 2013; Henselmans et al., 2017), vague comments or euphemisms (Anderson et al., 2013; Henselmans et al., 2017), or non-verbal cues such as a "look" (Mishelovich et al., 2016). Other times, patients expressed their emotional distress which if explored further by the doctor enabled the patient to acknowledge the terminal illness, opening the door to an end-of-life conversation (Anderson et al., 2013; Millar et al., 2013).

At times health professionals needed to cast out their cues to test patients' readiness for the diagnostic, prognostic, or deeper end-of-life discussions, sometimes referred to as giving a "warning shot" (Anderson et al., 2013; McLennon et al., 2013; Mishelovich et al., 2016). Patients felt the doctor had a difficult task looking for and understanding cues for readiness, and suggested the doctor simply put out their cues to test the patient's response. Despite overt requests for further information by patients/families, some doctors practiced avoidance and dismissed

or deflected their requests (Anderson et al., 2013; Henselmans et al., 2017). When neither doctor nor patient initiated cues, then the truth was not disclosed and opportunities for end-of-life discussions were missed (Henselmans et al., 2017). Breaking bad news before the patient was ready was considered to be potentially emotionally harmful and risked damage to the doctor-patient relationship (Abdul-Razzak et al., 2014) yet had to be balanced against urgency (Rejnö et al., 2017).

Alternatively, patients gave cues about their unwillingness to enter conversations about end-of-life issues or worsening news and while within the patient's rights caused dilemmas for health professionals at times (Henselmans et al., 2017; Bergqvist and Strang, 2019). This is explored further under the heading of Truth avoidance.

Acknowledgment. Without a prior relationship, the generalist doctor addressed the end-of-life issues after patients acknowledged their terminal diagnosis and the possibility of dying, otherwise no doctor moved conversations forward without recognizing the patient's readiness (Anderson et al., 2013; Henselmans et al., 2017). Acknowledging the terminal illness was not the same as the patient acknowledging its full gravity (Millar et al., 2013) or that they were dying from it (Anderson et al., 2013). Yet at other times after bad news was delivered, the patient then requested prognostic information around life expectancy (Henselmans et al., 2017).

Language/delivery. Requesting the patient to describe in their own words what they knew about their illness allowed the doctor to assess the patient's knowledge, health literacy, and language style (Anderson et al., 2013). Simple, straightforward language

without medical jargon or “sugar coating” was expressed by some patients and health professionals (Abdul-Razzak et al., 2014; Mishelmovich et al., 2016; Rejnö et al., 2017) as being important and is illustrated by this remark: “He [the doctor] was very open and very clear about what he was telling me. He didn’t sort of hide away from it or pull punches” (male patient in Abdul-Razzak et al., 2014, p. 4). Yet not all patients were in agreement as illustrated by this patient’s comments: “But she said there are metastases here and in the lung and ... I thought ... if I may say so, that she was brutal ... Should you hand it out like that?” (female patient in Bergqvist and Strang, 2019, p. 750).

Contradictory beliefs from different patients reinforce the dilemma health practitioners are faced with and confirm the importance of the therapeutic relationship and reading cues. Tailoring the information presented to the patient with the information being requested also required skill on behalf of the health professional (McLennon et al., 2013; Henselmans et al., 2017). Incremental disclosure of information allowed better absorption of bad news (Millar et al., 2013); thus, ongoing conversations were important (McLennon et al., 2013; Millar et al., 2013).

The impartation of suitable and absorbable knowledge by the health professional to a level of understanding by the patient/family was essential. Unfortunately, nurses observed that some patients did not understand what was being said to them concerning treatment, or were aware of the extensiveness of their terminal illness, due to poor health literacy, general education, or dementia (McLennon et al., 2013; Millar et al., 2013).

When doctors used vague terminology, there was the risk that some patients would create a false hope by focusing on certain positively worded phrases (McLennon et al., 2013). When doctors avoided using the words “death or near dying,” patients/families did not develop full awareness and remained unprepared (McLennon et al., 2013). Doctors who conveyed overly optimistic prognoses allowed patients/families to set unrealistic expectations, which made follow-up conversations difficult for nurses (McLennon et al., 2013).

Language can present a barrier to effective end-of-life conversations for non-English speaking patients and families (McLennon et al., 2013). While simple body language and mobile phone translation apps assisted with nursing tasks and care, in-depth prognosis-related conversations could not safely be undertaken without an interpreter present, which diminished impromptu conversations (McLennon et al., 2013).

Appropriate time/place. The timing for the delivery of bad news depended on contexts such as the urgency of the consultation, in the case of stroke (Rejnö et al., 2017), or whether the doctor would be visiting the patient daily (Mishelmovich et al., 2016) and could deliver news in increments (Millar et al., 2013; Mishelmovich et al., 2016). At other times, the doctor delayed the delivery of bad news, so the family could be present (Rejnö et al., 2017).

The appropriate location to deliver bad news was only mentioned in one paper and took the form of a complaint (Abdul-Razzak et al., 2014). Not only was discussing end-of-life issues during the doctors’ rounds in the presence of a multitude of interns an example of lack of privacy and sensitivity, but patients also felt pounced on and unprepared (Abdul-Razzak et al., 2014).

Qualities. Certain personal qualities were expected in the health professional such as being compassionate, empathetic, non-

judgmental, sensitive, kind, and comfortable in exploring the patient’s fears and distress (Anderson et al., 2013; Millar et al., 2013; Mishelmovich et al., 2016). Palliative care/oncology nurse practitioners saw themselves as qualified and experienced to deliver bad news and with experience gained over time, clinical nurse specialists believed they gained confidence and were, therefore, more willing to partake in breaking bad news and providing support to patients and families (Mishelmovich et al., 2016). Yet many nurses felt inadequately trained and believed all health professionals should be well educated in the art of delivering bad news (McLennon et al., 2013; Millar et al., 2013). Nurses tended to use communication guidelines flexibly and with experience developed their own style (Mishelmovich et al., 2016). In contrast, other nurses claimed being placed in this position was against their workplace norms and practices and it was the role of the doctors to engage in diagnostic, prognostic, and in-depth end-of-life discussions (McLennon et al., 2013; Millar et al., 2013; Mishelmovich et al., 2016; Rejnö et al., 2017).

Collaboration among staff was essential for the smooth running of the department, mutual support, and presenting a united front to the patient/family (McLennon et al., 2013). Timely sharing of information and prompt completion of the doctor’s notes assisted nurses to know exactly what the doctor had told the patient, so they could assist with translating meanings and treatments and provide emotional support after the news was broken (McLennon et al., 2013).

Truth avoidance

Truth Avoidance was evidenced in six of the eight papers (Anderson et al., 2013; McLennon et al., 2013; Millar et al., 2013; Henselmans et al., 2017; Rejnö et al., 2017; Bergqvist and Strang, 2019) and is a broad concept incorporating reasons why the disclosure of the truth was avoided and its consequences.

Some patients and families used denial as a defense mechanism to disassociate themselves from the seriousness of their condition which took the form of only seeking positive news or reducing the information they sought in case bad news was broached (Bergqvist and Strang, 2019). Some patient’s perception of a good doctor was one who only presented good news (Henselmans et al., 2017; Bergqvist and Strang, 2019) and likewise in their view a bad doctor presented bad news. While internet searching was undertaken, patients chose to look for vague diagnoses or isolated symptoms which enabled them to disassociate themselves from the seriousness of their condition (Bergqvist and Strang, 2019).

A game of “common collusion” was played out between doctors, patients, family, and friends, all avoiding the reality of approaching death (Bergqvist and Strang, 2019). Instead of having open and honest discussions about end-of-life preferences or treatment options, futile treatment continued (Bergqvist and Strang, 2019). Over time, patients relinquished their autonomy and handed over decision-making to others, often expressed in a desire to please the doctor, friends, and family (McLennon et al., 2013; Bergqvist and Strang, 2019). Despite some patients already aged in their 90s with weeks to live, treatment continued, causing poorer quality of life than the patient could enjoy had they been told the truth and accepted their prognosis (McLennon et al., 2013).

Some generalist doctors during hospital admission, despite direct information requests from the patient, also deflected end-of-life conversations. Truth avoidance occurred by claiming it was not their role as there were other more qualified specialists such as oncologists or their primary care doctor that the patient should be discussing such topics with (Anderson et al., 2013)

and opportunities were lost. Oncologists were either vague with their time estimates, overly optimistic, spoke of life expectancy in years rather than in months, or avoided prognostication altogether (Henselmans *et al.*, 2017). Sometimes this was due to a patient's request, other times it was despite it (Henselmans *et al.*, 2017). Nurses who prognosticated tended to be more realistic with their time estimates, although their qualifications and experience were not stated (McLennon *et al.*, 2013).

Idealism versus reality was evident wherein health professionals described truth-telling as virtuous, to be practiced at all costs despite the consequences, yet at other times truth disclosure was handled with caution and was selective, being withheld to protect the family from perceived emotional outbursts or to protect themselves (nurses) from an uncomfortable task (Rejnö *et al.*, 2017). Doctors also acknowledged lying to the family or acting more optimistic to give the family hope, while the patient was still alive (Rejnö *et al.*, 2017). Most nurses told "half-lies, white lies or outright lies" to avoid truth disclosure to family while waiting for tests to be confirmed or the right timing to do so (Rejnö *et al.*, 2017). Alternatively, to avoid lying, nurses justified any delays in truth disclosure by purposefully not checking results (Rejnö *et al.*, 2017).

Nurses and dieticians avoided discussing cachexia in cancer patients due to lack of confidence, education, and experience and wanted to avoid the subsequent distress this might cause to the patient/family (Millar *et al.*, 2013). A more pressing issue in truth avoidance for these staff members was knowing such conversations would invariably lead toward the patient asking about prognostic questions, the result of which they did not believe was their duty to divulge (Millar *et al.*, 2013). The consequences were the patient/family remained uninformed of the seriousness of their illness until the doctor had these important conversations with them. Another consequence of this avoidance affected the collegiality of the team. Nurses were reluctant to have end-of-life conversations with the patients when they did not know what the doctor had told them for fear of giving conflicting information or divulging too much (McLennon *et al.*, 2013).

Truth avoidance was practiced by doctors due to many factors, some being a lack of time especially when conversations needed to be delivered incrementally and repeated or not having an established doctor-patient relationship (Millar *et al.*, 2013). The result is the patient is sent away under a pretense of false hope and the doctor and patient both avoid facing reality and any emotional outburst (Millar *et al.*, 2013). Another reason for some doctors' reluctance stemmed from a "fix-it culture" in preference to providing psychological support (Millar *et al.*, 2013).

Nurses faced ethical dilemmas in truth disclosure when the family wanted information withheld from the patient or overrode the wishes of the patient by insisting on continuing unwanted treatment (McLennon *et al.*, 2013). Patient's cultural and religious preferences also impacted whether nurses could have end-of-life discussions with the patient and created dilemmas in whose wishes the nurse was obliged to adhere to, or accepting the patient's right to wait for a miracle instead of commencing end-of-life preparations (Anderson *et al.*, 2013; McLennon *et al.*, 2013).

Discussion

The qualitative meta-synthesis explored the views and experiences of health professionals and patients and families with truth disclosure during the delivery or receipt of bad news in palliative care. While family voices were not directly obtained, their opinions and behaviors were discussed in the papers. Each Enabler of breaking

bad news was believed to be an important factor in the development of a conducive environment in which to improve the success of the delivery of bad news but were not always achieved. The development of a therapeutic relationship, for example, in the person-centered care model, was recognized as an important mechanism in which to care, build trust, and communicate to patients and families and it follows that bad news should be more readily received and accepted within this environment (Beste, 2005; Mishelovich *et al.*, 2016). Nurses are in a unique position to discuss end-of-life issues with patients, as they spend concentrated time with the patient and family (Pontin and Jordan, 2013). Yet not all patients may want to take control of their health or be responsible for decision-making as found in this review (Gaston and Mitchell, 2005; Bergqvist and Strang, 2019).

Other than the patient group mentioned above, most of the patients in the synthesis valued openness and honesty and understood the benefit of having a prior relationship with their doctor (Abdul-Razzak *et al.*, 2014). They imagined the stress the doctor felt while waiting for patients to cue readiness and suggested the doctor just send out testing phrases and gauge patient responses (Abdul-Razzak *et al.*, 2014). Regarding ongoing treatment, if patients are to participate in shared decision-making, they need to understand their medical condition, treatment options, side effects, and how the benefits outweigh the risks, which is part of the consenting process (Sarafis *et al.*, 2014) — this is easier said than done (Wilson *et al.*, 2014). Not all patients will have full cognitive ability (McLennon *et al.*, 2013; Sarafis *et al.*, 2014), highlighting the need for early discussions in the disease trajectory and the completion of advance care directives. Informed patients with "realistic" hope can decide whether tolerating treatment with unpleasant side effects is worth the trade-off against quality time with loved ones. Through open and honest end-of-life conversations, patients may avoid futile treatment resulting in cost savings (Zhang *et al.*, 2009), improved the quality of life for themselves and their bereaved carers (Selman *et al.*, 2017), tie up their financial affairs, complete their bucket list, and plan for end-of-life. Therefore, truth-telling is a vitally important aspect for achieving quality outcomes for palliative patients and their families.

Communicating bad news in palliative care is not linear but a circular process (Duke and Bailey, 2008) and requires returning frequently to the facilitating factors (as depicted in Figure 2.), not only as the disease trajectory unfolds, but in daily follow-up conversations. Just because truth disclosure has taken place once, the patient's receipt of the bad news or comprehension of it may not be fully realized (if at all) and the process will need to start again. When closing a consultation where bad news was given, it was essential to assess the understanding of the patient/family confirming that the message has been received and understood, as patients can take on a completely different meaning than the health professional intended (Fried *et al.*, 2003; Xafis and Wilkinson, 2019).

The findings demonstrate how difficult the task is for health professionals to break bad news while being fully truthful in the process. What is perceived as a straightforward, honest, and open disclosure of bad news by one patient is perceived as blunt, rude, and inappropriate by another, proving the need for careful individual tailoring of communicating information by health professionals (Abdul-Razzak *et al.*, 2014; Bergqvist and Strang, 2019). Assessing readiness or reading the patient's cues for further information indicates to the health professional there is some degree of receptivity on the patient's part. Yet for patients

afraid or not sure how to ask, topics may not be broached, thus robbing the patient of time to put their affairs in order (Henselmans et al., 2017) or continue with futile treatment. Emotional numbness caused by the shock of receiving bad news may create difficulties in paying attention and retaining information which may also be a factor for the patient not pursuing end-of-life discussions (Maciejewski and Prigerson, 2013), yet this does not negate gentle ongoing conversations to help move the patient forward.

The crossroads in the conceptual model illustrate how the health professional is faced with the need to decide whether or not to disclose the truth which may be influenced by personal issues. These personal issues include stress and anxiety when having to deliver bad news due to inexperience, personal fears with illness and death, concerns about how the news would impact the patient/family, discomfort in handling emotional outbursts, uncertainty about the illness trajectory, or family requesting the withholding of information (Hagerty et al., 2005; Hancock et al., 2007; Kogan et al., 2013; Sarafis et al., 2014; Johnston and Beckman, 2019).

Health professionals may err on the side of caution in truth disclosure for fear of taking away the patient's hope (Beste, 2005; Sarafis et al., 2014). However, hope can be fostered by honesty and support developed during a therapeutic relationship (Beste, 2005), assuring the patient that they will not be abandoned by the health professional as they transition in palliative care (van Vliet et al., 2013), setting goals other than seeking a cure (Clayton et al., 2008), or having prognostic information framed in "hope for the best and expect the worst" case scenarios (Kiely et al., 2011). Trying to protect patients by withholding the truth from them will eventually increase anxiety and confusion, as the patient's condition deteriorates and is not in the patient's best interests (Fallowfield et al., 2002; Clayton et al., 2008). Enzinger et al. (2015) found that doctor–patient relationship ratings were not negatively affected, nor did the patients show an increase in sadness or anxiety due to truthful prognostication.

Only papers written in the English language and representing Western culture were included in this synthesis which may have produced different results. A strength of the findings of this meta-synthesis stemmed from the examination of the voices of patients; overall, ($n = 77$) patients were interviewed together with ($n = 235$) health professionals with broad experience and qualifications. Families were referred to by participants, but they were not directly interviewed in any of the included papers.

Conclusion

Breaking bad news truthfully is a difficult task and requires forethought, skill, and time. Creating a conducive environment using the Enablers described in the conceptual model leads the health professional to decide whether to disclose the truth or avoid it. Personal issues such as fear and anxiety impact decision-making at this point and can become a barrier. It is a circular process and requires the Enablers to be revisited in recurring conversations throughout the illness trajectory. The truth about the patient's illness status needs to be disclosed openly and honestly, and the patient's understanding confirmed, for them to exercise their autonomy and make informed decisions about their treatment and end-of-life goals.

Author contributions.

The first author designed the project, searched, and screened the literature, coded, analyzed, synthesized, and wrote the manuscript. The second and third authors assisted

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