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Research Report

A prospective cross-sectional survey comparing patient and provider expectations regarding ovarian cancer prognosis

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ABSTRACT

Introduction: There is limited data comparing patient and physician expectations regarding ovarian cancer prognosis. Our primary objective was to compare physician and patient estimates of survival to 6 months, 1 year, and 5 years; secondary objectives included comparing provider and patient responses on the likelihood of requiring future treatments and categorizing patient and provider preferences regarding communication about prognosis.

Methods: A prospective cross-sectional survey was delivered to 10 gynecologic oncology providers and 50 adult ovarian cancer patients from November 2015-April 2016 at one institution. Descriptive statistics were used to categorize survey answers and compare survey answers between patients and providers; multivariable logistic regression evaluated patient survey responses.

Results: All providers (100%) believed treating providers should discuss prognosis and 90% reported having prognostic conversations with patients, compared to 63%, 37%, and 4% of patients who reported discussing prognosis, living wills/advance directives, and palliative care/hospice services, respectively, with their provider. Compared to their provider, patients gave significantly lower estimations of requiring any future therapy (mean score 84.6 vs 74, p <.001) and future chemotherapy (mean score 84.1 vs 69.8, p <.001) and significantly higher estimations of requiring future surgery (mean score 23.3 vs 40, p <.001), achieving remission (mean score 33.5 vs 47.5, p =.009), survival to 1 year (mean score 77.1 vs 86.4, p =.002), and survival to 5 years (mean score 40.5 vs 61.3, p <.001).

Conclusions: Although gynecologic oncology providers believe it is important to discuss prognosis and end-of-life care, there are gaps in communication, knowledge, and expectations between providers and ovarian cancer patients.

1. Introduction

In the United States, ovarian cancer is the most lethal gynecologic malignancy, with a 5-year relative survival of 48.6% (SEER, 2021). In order to provide optimal cancer care, physicians must be able to clearly convey information about diagnoses, prognoses, and treatment options to their patients (Fallowfield and Jenkins, 1999). This information is especially relevant for diseases such as ovarian cancer, when assessing treatment options and planning for future care can have significant consequences on quality of life, morbidity, and mortality.

Unfortunately, cancer patients and their providers often have discordant perceptions of disease and expected treatment and survival (Hancock et al., 2007; Mackillop et al., 1988; Quirt et al., 1997; Gramling et al., ; Herzog et al., 2014). Patients may underestimate the nature of their disease (Quirt et al., 1997; Eidinger and Schapira, 1984; Temel et al., 2011), the intent of treatment (Mackillop et al., 1988; Quirt et al., 1997), the probability of clinical remission or benefit (Mackillop et al., 1988; Quirt et al., 1997; Herzog et al., 2014; Eidinger and Schapira, 1984), and the likelihood of survival (Gramling et al., ; Herzog et al., 2014), and physicians may be unaware of their patients' misconceptions

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(Mackillop et al., 1988). Although studies comparing patient and physician expectations regarding prognosis have been undertaken in other cancers (Hancock et al., 2007; Mackillop et al., 1988; Quirt et al., 1997; Gramling et al), there are no similar studies evaluating whether discrepancies between patients and providers exist surrounding ovarian cancer prognosis.

The primary objective of this study was to compare physician and patient estimates of survival to 6 months, 1 year, and 5 years at one academic institution. Secondary objectives included comparing provider and patient responses on the likelihood of requiring future treatments and categorizing patient and provider preferences regarding communication about ovarian cancer prognosis.

2. Materials and methods

We performed a prospectively administered cross-sectional survey study from November 2015-April 2016 of gynecologic oncology providers and their ovarian cancer patients. Written informed consent was obtained for all providers and patients completing the survey and approval was obtained prior to study initiation through the University of Pennsylvania institutional review board (#823737).

All gynecologic oncology physicians and advanced practice providers within the University of Pennsylvania Gynecologic Oncology division were eligible for inclusion. Eligible patients were identified from the patient censuses of enrolled providers from record review and approached on the date of appointments with those providers. Patients were eligible for inclusion if they were at least 18 years old; had biopsy-confirmed ovarian, primary peritoneal, or Fallopian tube carcinoma; had established gynecologic oncologic care at the University of Pennsylvania; and were scheduled for a chemotherapy or return patient visit on the date of enrollment. Exclusion criteria included current or prior enrollment in hospice care programs; current palliative care or treatment; a secondary primary malignancy within the last five years (excluding non-melanoma skin cancer); illiteracy or lack of English proficiency; lack of decision-making capacity; and/or presentation for a new patient appointment or initial consultation.

Enrolled providers completed an initial survey with both multiple-choice and open-ended questions about their communication style regarding prognosis and end-of-life care with ovarian cancer patients. The survey was designed via an iterative process with input from the Division of Gynecologic Oncology providers. Enrolled patients completed a 19-question survey on the day of enrollment. The survey included multiple-choice questions about their previous treatment, prior treatment or disease-related complications, and sources of information about cancer prognosis; three-option ("yes / no / unsure") questions on whether they had received information on advanced care planning or palliative/hospice care from their provider; and 10 questions that utilized a continuous scale from 0 to 100% regarding their perceived likelihood of future treatment or hospitalization, future treatment or disease related complications, and survival to 6 months, 1 year, and 5 years. For each patient who completed a survey, their visit provider filled out a matched survey with the same 10 questions that utilized a continuous rating scale from 0 to 100% (Fig. 1). Providers were blinded to their patients' answers.

Demographic and clinical information of patient participants was obtained from chart review including age, race, religion, marital status, prior medical history, presence of an advance directive, International Federation of Gynecology and Obstetrics (FIGO) cancer stage, treatment history, and major cancer complications including venous thromboembolism, bowel obstruction, malnutrition requiring total parenteral nutrition, ascites, pleural effusion, anemia requiring transfusion, hypersensitivity reaction, and ureteral obstruction. Study data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capture tools.

Descriptive statistics were performed as appropriate on demographic data and survey answers. Frequencies were estimated for categorical variables and means and standard deviations for continuous variables. Answers from patients and providers regarding likelihood of survival, future treatment, future hospitalization, and future complications were compared using chi-square or Fisher's exact tests as appropriate. Multivariable logistic regression was performed on patient survey answers on covariables including age, race, marital status, religion, FIGO
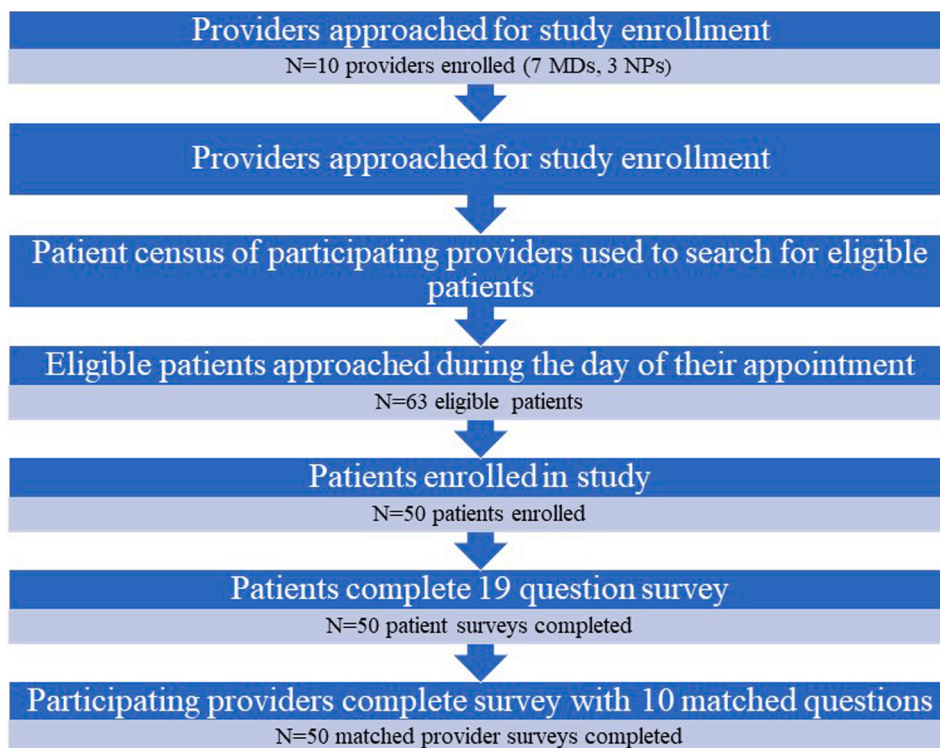

Fig. 1. Flow diagram of study design.

stage, treatment stage (categorized as active treatment for initial diagnosis, surveillance after initial diagnosis, active treatment for recurrence, or surveillance for recurrent cancer) and visit to a medical doctor (MD) compared to a nurse practitioner (NP).

Comparisons were considered statistically significant using a two-sided alpha level < 0.05. All analyses were completed using Stata version 14 (Stata Corp, College Station, TX).

3. Results

Ten providers at the University of Pennsylvania Gynecologic Oncology practices participated in the study (7 MDs and 3 NPs). During the period of enrollment, 63 eligible patients were approached to participate and 50 enrolled (participation rate = 79.4%) and completed the survey; all completed patient surveys had corresponding provider surveys completed (Fig. 1).

Patient demographic and clinical variables are provided in Table 1. On the day of enrollment and survey completion, 26 (52%) patients had an appointment with an MD and 24 (48%) with an NP. The mean length of time patients had established care at the institution's gynecologic oncology practice was 13.4 months (SD = 15.3 mo, range 0–57.3 mo) with a mean of 10.1 prior visits (SD = 10.0, range 1–42 visits). The majority of patients had FIGO stage III disease (50%) with high grade serous histology (66%). Of the 47 (74%) patients in active treatment for their disease at enrollment, 40.5% and 59.5% were being treated for upfront and recurrent cancer, respectively. All patients had previously or were currently receiving chemotherapy, and most patients had also undergone surgery (66%) and received a form of targeted therapy (62%). 48% of patients had had a prior complication and 28% of patients had been hospitalized because of their cancer diagnosis or treatment.

On the initial provider surveys, providers unanimously stated that treating physicians should discuss prognosis with patients (Table 2). Providers most commonly reported discussing prognosis when new treatments were required (30%), when the patient asked (30%), or when new pertinent information arose (20%), and generally preferred one-on-one settings for these conversations (70%). Cancer stage (70%), available treatment options (80%), and patient interest (60%) all influenced the decision to discuss prognosis. Most providers (70%) cited limited appointment time as a barrier to discussions. Providers unanimously agreed that treating physicians should discuss advanced care planning topics with patients, and 90% of providers reported that they directly discussed these aspects of care.

Of the 50 patients who completed surveys, 63%, 37%, and 4% of reported discussing prognosis, living wills/advance directives, and palliative care/hospice services, respectively, with their provider. Most patients cited their gynecologic oncologist (90%) as their main source of information about ovarian cancer prognosis, followed by the Internet (50%), friends/family (30%), medical oncologist (18%), and cancer support group (14%).

The comparison between patient and provider answers regarding prognosis is provided in Table 3. Compared to their provider, patients gave significantly lower estimations of requiring any future therapy (mean score 84.6 vs 74, p <.001) and future chemotherapy (mean score 84.1 vs 69.8, p <.001) and significantly higher estimations of requiring future surgery (mean score 23.3 vs 40, p <.001), achieving remission (mean score 33.5 vs 47.5, p =.009), survival to 1 year (mean score 77.1 vs 86.4, p =.002), and survival to 5 years (mean score 40.5 vs 61.3, p <.001). There was no difference between provider and patient estimations regarding likelihood of future radiation (mean score 11 vs 16.3, p =.13), hospitalization (mean score 56 vs 47.9, p =.14), complications (mean score 57.2 vs 54.2, p =.59), or survival to 6 months (mean score 88.7 vs 89.1, p =.86).

On multivariable analysis of patient survey answers, there was no difference based on evaluated covariables on the likelihood of requiring any future treatment or future radiation. Compared to non-married

Table 1
Patient demographic and clinical characteristics.

Characteristic	
Age (years), mean ± SD	62.6 ± 11.5
Race, n (%)	
White	45 (90)
Non-white	5 (10)
Marital status, n (%)	
Married	34 (68)
Non-married	16 (32)
Religion, n (%)	
Catholic	17 (34)
Non-Catholic religious	19 (38)
No religious affiliation	14 (28)
Past/current history of depression or anxiety (yes), n (%)	4 (8)
Previous primary malignancy, n (%)	
None	45 (90)
Breast	4 (8)
Non-melanoma skin	1 (2)
Advance directive/living will on file, n (%)	
Yes	9 (18)
No	41 (82)
Treating provider on date of survey completion, n (%)	
MD	26 (52)
NP	24 (48)
Type of visit, n (%)	
Chemotherapy/Infusion	42 (84)
Return Patient Visit	8 (16)
Length of therapeutic relationship with provider (months), mean ± SD	13.4 ± 15.3
Length of therapeutic relationship with provider (number of visits), mean ± SD	10.1 ± 10.0
Length of relationship with UPenn Gyn Onc practices (months), mean ± SD	21.1 ± 22.0
Length of relationship with UPenn Gyn Onc practices (number of visits), mean ± SD	24.9 ± 21.4
Primary cancer site, n (%)	
Ovary	36 (72)
Fallopian tube	4 (8)
Primary peritoneal	5 (10)
Likely GYN/Müllerian	5 (10)
FIGO cancer stage, n (%)	
I	5 (10)
II	5 (10)
III	25 (50)
IV	11 (22)
Unknown	4 (8)
Cancer histology, n (%)	
Low grade serous	2 (4)
High grade serous	33 (66)
Clear cell	2 (4)
Carcinosarcoma	1 (2)
Poorly differentiated adenocarcinoma	5 (10)
Other	7 (14)
Stage of treatment, n (%)	
Active treatment for initial diagnosis	15 (30)
Remission/surveillance after initial diagnosis	8 (16)
Recurrent cancer in treatment	22 (44)
Recurrent cancer in surveillance	5 (10)
Previous treatment, n (%)	
Chemotherapy	50 (100)
Surgery	33 (66)
Targeted therapy	31 (62)
Hormone therapy	1 (2)
Radiation therapy	1 (2)
Investigational/clinical trial	19 (38)
Prior complication related to cancer diagnosis/treatment, n (%)	24 (48)
Previous hospitalization at UPenn Hospital System related to cancer diagnosis/treatment, n (%)	14 (28)

women, married patients were significantly less likely to think they would require future surgery (p =.041) or chemotherapy (p =.037). Patients who had a visit with an MD (versus an NP) on the day of the survey were also less likely to think they would require future surgery (p =.032) or hospitalization (p =.006). Older patients were less likely to

Table 2

Provider survey answers regarding prognostic communication.

Survey question	N (%)
How often do you discuss prognosis? (select best answer)	
Once, at initial appt	0 (0)
Once, after therapeutic relationship is established	0 (0)
Each time new pertinent information arises	2 (20)
Each time a new treatment modality is required	3 (30)
Each patient appt	1 (10)
Whenever the patient asks	3 (30)
Other	1 (10)
How do you prefer to communicate with patients with ovarian cancer? (select all that apply)	
One-on-one discussion	10 (100)
Family meeting	5 (50)
Phone call	2 (20)
My Penn Health messaging	0 (0)
Personal email	0 (0)
Distribute information brochures/pamphlets	0 (0)
Refer patients to informational Internet websites	0 (0)
What factors influence your decision to discuss prognosis with patients? (select all that apply)	
Stage of cancer	7 (70)
Treatment options available	8 (80)
Prior or anticipated complications	5 (50)
Length of provider-patient relationship	3 (30)
Quality of provider-patient relationship	2 (20)
Patient interest	6 (60)
Patient family interest	3 (30)
Other	4 (40)
What barriers interfere with discussing prognosis? (select all that apply)	
Patient does not bring it up	4 (40)
Difficulty bringing up topic	2 (20)
Limited time during appointments	7 (70)
Length of provider-patient relationship	2 (20)
Quality of provider-patient relationship	2 (20)
Other	3 (30)

Table 3

Comparison of patient and physician answers regarding future treatment and prognosis.

What is the likelihood that you/ your patient will:	N	Patient estimate, Mean ± SD	Provider estimate, Mean ± SD	Difference between estimates*, Mean ± SD	P-value
Require any future therapy?	50	74 ± 4.2	84.6 ± 3.6	−10.6 ± 3.0	**0.001**
Require future surgery?	50	40 ± 4.7	23.3 ± 2.9	16.7 ± 3.5	**<0.001**
Require future chemotherapy?	50	69.8 ± 4.6	84.1 ± 3.5	−14.3 ± 3.7	**<0.001**
Require future radiation therapy?	50	16.3 ± 3.5	11 ± 1.7	5.32 ± 3.4	0.13
Require future hospitalization related to cancer or cancer treatment?	49	47.9 ± 4.7	56 ± 4.0	−8.2 ± 5.4	0.14
Have a complication related to cancer or cancer treatment?	50	54.2 ± 4.4	57.2 ± 4.3	−3.0 ± 5.5	0.59
Achieve remission?	40	47.5 ± 5.8	33.5 ± 4.9	14.0 ± 5.1	**0.009**
Live for 6 months or more?	50	89.1 ± 2.8	88.7 ± 2.0	0.4 ± 2.5	0.86
Live for 1 year or more?	49	86.4 ± 3.3	77.1 ± 3.1	9.3 ± 2.9	**0.002**
Live for 5 years or more?	49	61.3 ± 4.7	40.5 ± 3.6	20.8 ± 4.5	**<0.001**

SD, standard deviation. Bold text signifies significant p-values.

*Difference = patient estimate – provider estimate.

think they would future require chemotherapy (p =.044). Patients with FIGO Stage IV disease were more likely to think they would achieve remission (p =.024) than stage II or III. Patients who identified as non-Catholic religious were significantly more likely to think they would have a future hospitalization (p =.038) or complication (p =.01) and less likely to think they would survive to 5 years (p =.011) compared to patients who identified as Catholic. There were no differences on any survey questions on multivariable analysis based on patient race or treatment stage.

4. Discussion

In our prospectively administered cross-sectional matched survey study, patients and providers had significantly different expectations regarding ovarian cancer prognosis and treatment. All providers regarded prognostic discussions as important, although there were differences between provider-reported and patient-reported rates of having these conversations.

At our institution, gynecologic oncology providers were unequivocal about the importance of discussing prognosis, but in line with previous studies (Daugherty and Hlubocky, 2008; Robinson et al., 2008; El-Sahwi et al., 2012), they had differing attitudes and approaches regarding how, when, and where to disclose cancer prognosis, ongoing disease progression, and end-of-life issues. Likewise, cancer patients may have differences in the preferred content, timing, and setting of prognostic discussions despite valuing those conversations (Parker et al., 2007; Innes and Payne, 2009). In addition, it is important to point out that these conversations are often ongoing and may need to change as the disease course and treatments change (Frey et al., 2014). Our providers had differences in when they addressed prognosis, but it was commonly when new information arose or a new treatment was required, suggesting the importance of tailoring this conversation to the disease course and treatment response of individual patients.

The majority of cancer patients surveyed desired information regarding prognosis, reinforcing previous studies and highlighting the importance of good communication on this topic (Parker et al., 2007; Frey et al., 2014). There are multiple benefits to discussing end-of-life care early with ovarian cancer patients, including improved quality of life (Radwany and von Gruenigen, 2012) and decreased utilization of healthcare resources (Doll et al., 2013). Most of our patients regarded their gynecologic oncologist as their primary and most-trusted source of information with respect to prognostic information, bolstering literature that demonstrates the primacy of physician communication in treatment and end-of-life decisions (Parker et al., 2007; Innes and Payne, 2009). However, our surveyed providers reported a much higher rate of conversations about prognosis, advanced care planning, and hospice or palliative care than surveyed patients, indicating a disconnect between what information providers believe they are imparting and what patients perceive (Hancock et al., 2007; Mackillop et al., 1988; Gramling et al., ; Robinson et al., 2008). Conversely, providers may need to be more explicit in prognostic conversations to ensure patients understand the topic being addressed.

The value of conversations regarding prognosis between providers and patients is ultimately how it affects patient expectations (Herzog et al., 2014), and patients and providers at our institution had significantly different expectations regarding important aspects of care. While we did not examine why patients and providers held discordant views, other studies suggest that this could be due to a variety of reasons including a lack of communication (Mackillop et al., 1988; Quirt et al., 1997; Frey et al., 2014), patient or provider optimism (Gramling et al., ; Eidinger and Schapira, 1984; Robinson et al., 2008) or providers waiting until a change in patient status (Daugherty and Hlubocky, 2008; El-Sahwi et al., 2012). Interestingly, we found several differences in patient answers based on whether patients had a visit with an MD or NP, which could be due to differences in disease status or to differences in counseling based on the type of provider.

Several demographic characteristics contributed to patient estimates of future treatment and survival including marital status, age, religion, and cancer stage. Interestingly, older patients, Catholic patients, married patients, and patients with more advanced disease appeared to have more optimistic expectations regarding prognosis. Our study was not designed to examine why these factors may have impacted prognostic expectations, although a previous cohort study of patients with advanced cancer demonstrated that individuals with higher levels of religious belief may receive more intensive end-of-life care (Phelps, 2009). We found no differences in survey answers based on race, although our study population was largely comprised of White patients. Previous studies have shown that providers communicate differently with patients based on race (Pollak et al., 2010), but there is a dearth of literature specific to expectations of ovarian cancer prognosis by race or ethnicity. Future studies could use validated surveys to measure facets such as patient coping or self-efficacy skills or perform qualitative studies to better explore the impact of sociodemographic factors on patient expectations regarding prognosis.

Strengths of our study include the high compliance rate of survey completion by enrolled patients and providers, as well as a high rate of participation among eligible patients. Our study enrolled participants who had established long-term therapeutic relationships with providers, which allowed ample time for communication between patients and providers regarding prognosis prior to study initiation. Importantly, providers were blinded to the survey answers of their patients, reducing bias in our comparison of patient and provider estimates regarding prognosis and future treatment. Finally, our multivariable analysis adjusted for multiple factors which could impact the prognosis and treatment course of patients.

Limitations of the study include the survey design, which has inherent selection bias, as well as the small sample size. The study was completed at a single urban academic institution, limiting its generalizability. The patients seen at our practices may not be comparable to the general ovarian cancer population, as our institution sees a large referral and clinical trial population, which may skew the complexity of the population seen as well as potentially their goals of care. In addition, we excluded non-English literate patients, a population that may represent different perspectives on cancer prognosis but in which conversations surrounding prognosis may be more difficult due to language barriers. Demographic data on socioeconomic status, education level, and profession were not compiled, which could influence how patients seek and understand prognostic information.

Innovative interventions that fill in these communication gaps are needed. Several communication guides are available to facilitate prognostic conversations, including a guideline from the American Society of Clinical Oncology (Gilligan et al., 2018) and the ADAPT prognosis tool from VitalTalk (Donesky et al., 2020). At our institution, we have incorporated a Serious Illness Conversation Plan (SICP) and end of life discussions into notes. SICP provides a guide to help providers explore their patients' goals, values, and wishes and has been shown to result in improved patient understanding of disease and documentation of patient end-of-life wishes in multiple care settings (Billie and Letizia, 2020; Massmann et al., 2019; Lally et al., 2020). For maximal usefulness in our patient population, similar tools may need to be tailored based on ovarian cancer disease course and individual patient and physician preferences. Our next institutional steps will include follow-up of our SICP intervention to compare whether our outcomes regarding advanced care planning and end-of-life care have improved over time.

Although discussions regarding prognosis, advanced care planning, and end-of-life care are central to the practice of gynecologic oncology, gaps exist between provider knowledge and patient understanding of disease. Ultimately, open and early communication regarding prognosis should be prioritized and will allow for more informed and patient-centered decision making.

CRediT authorship contribution statement

Sarah P. Huepenbecker: Conceptualization, Methodology, Investigation, Writing – original draft, Funding acquisition. **Xiaochen Zhang:** Formal analysis, Data curation, Writing – review & editing. **Mark A. Morgan:** Conceptualization, Writing – review & editing, Supervision. **Ashley F. Haggerty:** Conceptualization, Methodology, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.gore.2022.101042.

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