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Collusion in Cancer Diagnosis and Prognosis Disclosure a Tertiary Care Centre Analysis

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Abstract

Background: Collusion in cancer care refers to the withholding or selective disclosure of diagnostic and prognostic information from patients, often by family members, with the intention of protecting them from emotional distress. While culturally influenced, this practice may compromise patient autonomy, informed decision-making, and quality of care. Limited data are available regarding its prevalence and determinants in tertiary care settings. ***Objectives:*** To estimate the prevalence of collusion in cancer diagnosis and prognosis disclosure and to identify associated sociodemographic and clinical factors in a tertiary care centre. ***Methods:*** A hospital-based cross-sectional study was conducted among 130 adult cancer patients and their primary caregivers over a six-month period. Participants were recruited using consecutive sampling. Data were collected using a structured, pretested collusion assessment questionnaire administered to caregivers. Sociodemographic and clinical details were obtained from interviews and medical records. Collusion was operationally defined as caregiver unwillingness to allow full disclosure of diagnosis or prognosis to the patient. Data were analyzed using appropriate statistical tests, and associations were assessed using the Chi-square test with a significance level of $p < 0.05$. ***Results:*** The prevalence of collusion was 26.2%. Collusion was significantly associated with lower educational status ($p = 0.03$) and shorter duration since diagnosis ($p < 0.001$). It was most common within one month of diagnosis. Caregivers frequently preferred limiting disclosure, particularly when the disease was perceived as serious or incurable. ***Conclusion:*** Collusion remains prevalent in tertiary cancer care, especially among less-educated patients and in the early post-diagnosis period. Structured communication strategies and culturally sensitive counseling are essential to promote transparent and patient-centered oncology care.

Keywords: Cancer, collusion, caregiver, disclosure, prognosis, tertiary care centre.

INTRODUCTION

Cancer remains one of the leading causes of morbidity and mortality worldwide, with an estimated 19.3 million new cases and nearly 10 million deaths reported globally in 2020[1]. Advances in early detection, multimodal treatment, and palliative care have significantly improved survival outcomes; however, effective communication regarding diagnosis and prognosis continues to be a critical component of comprehensive cancer care. Transparent disclosure enables patients to participate in informed decision-making, plan for the future, adhere to treatment, and exercise autonomy[2].

Truth-telling in oncology has evolved substantially over the past few decades. Historically, non-disclosure of cancer diagnoses was common, particularly in Western countries during the mid-20th century[3]. Over time, ethical principles emphasizing respect for patient autonomy, beneficence, and informed consent have established full disclosure as the standard of care in most healthcare systems[4]. However, in many Asian, Middle Eastern, and Mediterranean cultures, family-centered decision-making models often prevail over individual autonomy. In such contexts, family members may request that physicians withhold or selectively disclose diagnostic and prognostic information to protect patients from emotional distress—a phenomenon referred to as *collusion*[5].

Collusion in cancer care is defined as a situation in which information about diagnosis, prognosis, or disease severity is deliberately withheld or modified, usually at the request of family members, without the patient's explicit consent[6]. While often motivated by compassion, collusion may compromise patient autonomy, hinder informed consent, impair coping mechanisms, and potentially erode trust between patients and healthcare providers[7]. Studies have shown that many patients, even in traditionally family-oriented cultures, prefer honest disclosure about their illness and wish to be involved in treatment decisions[8,9].

The prevalence of collusion varies widely across regions and settings, with reported rates ranging from 16% to over 70%, depending on cultural context and study methodology[10]. In India, disclosure practices are influenced by sociocultural norms, educational status, disease stage, and perceived prognosis[11]. Caregivers often assume a protective role, particularly when the disease is advanced or considered incurable. Early phases following diagnosis may be especially vulnerable periods for non-disclosure due to heightened emotional distress[12].

Despite increasing emphasis on patient-centered care, limited empirical data are available from tertiary care centers in South India regarding the magnitude of collusion and the factors associated with it. Understanding the prevalence and determinants of collusion is essential for designing culturally sensitive communication strategies, structured counseling interventions, and physician-led disclosure protocols that balance respect for family dynamics with ethical obligations toward patient autonomy.

Therefore, the present study was undertaken to assess the prevalence of collusion in cancer diagnosis and prognosis disclosure and to identify associated sociodemographic and clinical factors in a tertiary care setting.

AIM AND OBJECTIVES

Aim

To assess the prevalence and determinants of collusion in cancer diagnosis and prognosis disclosure among patients attending a tertiary care centre.

Objectives

1. To estimate the prevalence of collusion in disclosure of cancer diagnosis and prognosis among adult cancer patients at a tertiary care centre.
2. To identify factors associated with collusion, including sociodemographic variables (age, gender, educational status, socioeconomic status), clinical variables (organ system involved, time since diagnosis, prognosis), and caregiver attitudes toward disclosure.

MATERIALS AND METHODS

Study Design and Setting

This was a hospital-based cross-sectional analytical study conducted at the Department of Oncology of a tertiary care teaching hospital in South India. The study was carried out over a period of six months.

Study Population

The study population comprised adult patients diagnosed with malignancy and receiving treatment (medical, surgical, or palliative) at the tertiary care centre during the study period. Each patient was accompanied by a primary caregiver who was directly involved in treatment decisions and daily care.

Inclusion Criteria

- Patients aged ≥18 years
- Histopathologically confirmed diagnosis of cancer
- Patients aware or potentially aware of their diagnosis
- Presence of a primary caregiver willing to participate
- Patients and caregivers who provided written informed consent

Exclusion Criteria

- Patients with known psychiatric illness
- Patients with cognitive impairment or severe communication difficulties
- Patients who were critically ill and unable to participate
- Caregivers unwilling to provide consent

Sample Size

The sample size was calculated using the formula for estimating a single population proportion:

$$n = Z^2pq/d^2$$

Assuming a prevalence of collusion of 26.4%, 95% confidence level (Z = 1.96), and absolute precision of 8%, the minimum calculated sample size was 117. After adding 10% to account for non-response, the final sample size was rounded to **130 participants**.

Sampling Technique

Eligible participants were recruited using consecutive sampling. All patients fulfilling the inclusion criteria during the study period were approached until the required sample size was achieved.

Study Tool

Data were collected using a structured and pretested collusion assessment questionnaire adapted for the local context. The questionnaire assessed:

- Caregiver knowledge about the illness
- Perception regarding seriousness and curability
- Willingness to disclose diagnosis and prognosis
- Preferences regarding extent of information shared
- Comfort level in discussing the illness with the patient

The tool was reviewed by subject experts in oncology and palliative care to ensure content validity. A pilot test was conducted on 10 patients (excluded from final analysis) to assess clarity and feasibility.

Operational Definition

Collusion was defined as a situation in which the caregiver was aware of the diagnosis or prognosis but expressed unwillingness to allow full disclosure to the patient or preferred withholding essential information regarding the nature, course, or outcome of the illness.

Data Collection Procedure
After obtaining Institutional Ethics Committee approval, eligible patients and caregivers were approached during outpatient visits or hospital admission.

Written informed consent was obtained separately from patients and caregivers.

Initially, the caregiver was interviewed in a private setting to assess knowledge and disclosure preferences. Care was taken to avoid introducing new information regarding the diagnosis during the interview.

If the caregiver reported that the patient was aware of the diagnosis, minimal confirmation was sought from the patient without discussing further clinical details. No additional information regarding disease status, treatment, or prognosis was provided by the investigator during the study interaction.

Sociodemographic details (age, gender, education, socioeconomic status) and clinical variables (organ system involved, stage of disease if available, time since diagnosis, treatment status, and prognosis as documented in medical records) were recorded using a structured data sheet.

Study Variables
Dependent Variable
- Presence or absence of collusion

Independent Variables
- Age
- Gender
- Educational status
- Socioeconomic status
- Type of malignancy
- Time since diagnosis
- Perceived prognosis
- Caregiver's willingness to disclose

Statistical Analysis
Data were entered into Microsoft Excel and analyzed using appropriate statistical software.

Categorical variables were summarized as frequencies and percentages. Continuous variables were expressed as mean ± standard deviation or median with interquartile range depending on normality.

The Chi-square test or Fisher's exact test was used to determine associations between categorical variables and collusion. Independent sample t-test or Mann–Whitney U test was applied for comparison of continuous variables as appropriate.

A p-value <0.05 was considered statistically significant.

Ethical Considerations
The study was conducted after obtaining approval from the Institutional Ethics Committee. Participation was voluntary, and confidentiality of patient information was strictly maintained. Unique identification numbers were assigned to participants to ensure anonymity. No therapeutic decisions were influenced by participation in the study.

RESULTS

Table 1. Socio-demographic Characteristics of Study Participants (n = 130)

Variable	Frequency (n)	Percentage (%)
Age Group (years)		
< 40	12	9.2
40–60	45	34.6
> 60	73	56.2
Gender		
Male	54	41.5
Female	76	58.5
Educational Status		
Primary	30	23.1
Secondary	58	44.6
Graduate/Postgraduate	42	32.3
Socioeconomic Status		
Below Poverty Line	32	24.6
Above Poverty Line	98	75.4

Table 2. Association Between Educational Status and Collusion

Educational Status	Collusion Present n (%)	Collusion Absent n (%)	p-value
Primary (n=30)	12 (40.0)	18 (60.0)	
Secondary (n=58)	16 (27.6)	42 (72.4)	
Graduate/Postgraduate (n=42)	6 (14.3)	36 (85.7)	**0.03***

Chi-square test; p < 0.05 statistically significant

Table 3. Clinical Characteristics of Patients (n = 130)

Variable	Frequency (n)	Percentage (%)
Organ System Involved		
Breast	41	31.5
Head and Neck	18	13.8
Gastrointestinal	14	10.8
Prostate	7	5.4
Lung	9	6.9
GBM	6	4.6
Female reproductive tract	12	9.2
Others	23	17.8
Time Since Diagnosis		
< 1 month	20	15.4
1–6 months	38	29.2
6–12 months	32	24.6
> 1 year	40	30.8
Perceived Prognosis		
Curable	36	27.7
Partly Curable	62	47.7
Incurable	32	24.6

Table 4. Prevalence of Collusion and Disclosure Pattern (n = 130)

Variable	Frequency (n)	Percentage (%)
Presence of Collusion		
Yes	34	26.2
No	96	73.8
Person Informing Diagnosis (n = 96)		
Doctor	30	31.3
Family	18	18.8
Doctor & Family	46	47.9
Self	2	2.0

Table 5. Association Between Time Since Diagnosis and Collusion

Time Since Diagnosis	Collusion Present n (%)	Collusion Absent n (%)	p-value
< 1 month (n=20)	15 (75.0)	5 (25.0)	
1–6 months (n=38)	12 (31.6)	26 (68.4)	
6–12 months (n=32)	4 (12.5)	28 (87.5)	
> 1 year (n=40)	3 (7.5)	37 (92.5)	**<0.001***

Chi-square test; p < 0.05 statistically significant

DISCUSSION

The present study evaluated the prevalence and determinants of collusion in cancer diagnosis and prognosis disclosure in a tertiary care setting. The overall prevalence of collusion was 26.2%, indicating that approximately one in four patients experienced partial or complete withholding of information. This finding is comparable to earlier Indian studies reporting collusion rates ranging between 20% and 40%, though considerably lower than rates exceeding 50% described in certain Asian settings[6,8]. The variability across studies may reflect differences in operational definitions, cultural expectations, healthcare infrastructure, and patient awareness levels.

Prevalence of Collusion

The observed prevalence of 26.2% aligns closely with findings by Chaturvedi et al., who highlighted that collusion remains common in Indian oncology and palliative care settings, particularly in the early stages of diagnosis[6]. However, studies from Japan and other East Asian countries have historically reported substantially higher non-disclosure rates, sometimes exceeding 60%, reflecting stronger family-centered decision-making traditions[10]. In contrast, Western literature demonstrates markedly lower rates of non-disclosure due to long-established ethical norms favoring patient autonomy[3]. This contrast underscores the continuing influence of sociocultural values in shaping disclosure practices in India.

Educational Status and Collusion

A statistically significant association was observed between lower educational status and increased collusion ($p = 0.03$). Patients with primary education had the highest proportion of collusion (40%), while graduates showed the lowest (14.3%). Similar trends have been reported in previous Indian research, where limited literacy was associated with reduced direct communication between physicians and patients and greater reliance on family intermediaries[13]. Lower educational attainment may influence health literacy, awareness of patient rights, and confidence in engaging with medical information.

Ghoshal et al. reported that patients with higher education levels more frequently expressed a desire for full disclosure and active participation in treatment decisions[8]. These findings support the notion that education enhances autonomy-oriented expectations and may reduce family-driven protective nondisclosure. International studies also suggest that higher educational attainment correlates with stronger preferences for transparency and shared decision-making[9].

Time Since Diagnosis

One of the most significant findings of this study was the strong association between collusion and shorter duration since diagnosis ($p < 0.001$). Collusion was most prevalent within the first month of diagnosis (75%) and progressively declined over time. This pattern mirrors findings from Sutar et al., who observed that awareness and open communication increased as patients adapted psychologically to their illness[12]. Early post-diagnosis periods are characterized by heightened emotional distress among caregivers, who may attempt to shield patients from perceived psychological harm.

This temporal trend may also reflect gradual acceptance by family members and improved communication following repeated medical consultations. Similar observations have been documented in palliative care literature, where initial protective attitudes soften as disease trajectory becomes clearer and trust develops between healthcare providers and families[6].

Person Informing the Diagnosis

Among patients without collusion, disclosure most commonly involved both doctor and family members (47.9%), followed by doctors alone (31.3%). This suggests a hybrid model of disclosure, combining professional communication with family involvement. Such collaborative disclosure practices have been described in Asian oncology settings as a culturally adaptive approach balancing autonomy with familial roles[5].

Baile et al., through the SPIKES protocol, emphasized the importance of structured, empathetic communication delivered by physicians[7]. The relatively high proportion of doctor-led disclosure in the present study indicates increasing acceptance of direct communication in tertiary centers. However, the continued involvement of families highlights the persistence of relational decision-making frameworks in Indian society.

Perceived Prognosis and Collusion

Although descriptive analysis showed that collusion was more frequent when disease was perceived as serious or incurable, this association was not statistically examined in the current dataset. Previous studies have consistently demonstrated that families are more likely to request nondisclosure when prognosis is poor. Mystakidou et al. found that caregivers often equated truth-telling with loss of hope, particularly in advanced disease stages[5]. Similarly, Surbone emphasized that fear of causing psychological distress is a dominant driver of collusion globally[11].

Importantly, multiple studies indicate that most patients prefer honest disclosure even in advanced illness, provided communication is compassionate and supportive[9,14]. This disconnect between caregiver perception and patient preference represents a critical ethical and clinical challenge.

Sociocultural Context

The persistence of collusion in the present study reflects the interplay between traditional collectivist values and evolving patient-centered care models. In collectivist societies, families frequently assume protective roles and prioritize emotional safeguarding over individual autonomy[6]. However, growing literacy rates, media exposure, and legal emphasis on informed consent are gradually shifting expectations toward transparency.

Compared to earlier Indian literature reporting higher collusion rates, the relatively lower prevalence observed in this study may indicate improving disclosure practices in tertiary care settings. Structured oncology services, multidisciplinary teams, and increased awareness of ethical standards may contribute to this transition.

Clinical Implications

The findings highlight the need for early communication interventions, particularly within the first month after diagnosis. Educational status should be considered when tailoring communication strategies, with additional support provided to patients and families with limited literacy. Structured counseling sessions involving both patients and caregivers may help reconcile family concerns with ethical obligations toward patient autonomy.

Physicians require training in culturally sensitive communication techniques that respect family involvement while ensuring that patients are not systematically excluded from information about their own illness. Institutional policies and standardized

disclosure protocols may further reduce variability in practice.

Strengths and Limitations

This study contributes to limited regional data on collusion in oncology and provides statistically robust associations with key sociodemographic and temporal factors. However, being a single-center cross-sectional study, causal relationships cannot be established. Caregiver-reported measures may also be subject to social desirability bias. Future multicentric longitudinal studies are warranted to explore evolving disclosure patterns over the disease trajectory.

CONCLUSION

This study demonstrated that collusion in cancer diagnosis and prognosis disclosure remains a significant issue in tertiary care settings, with approximately one-fourth of patients experiencing partial or complete withholding of information. Collusion was more commonly observed among patients with lower educational status and during the early period following diagnosis, suggesting that sociocultural factors and emotional distress immediately after diagnosis influence disclosure practices. Caregivers frequently preferred limiting or avoiding discussion about the nature, course, and outcome of the illness, particularly when the disease was perceived as serious or incurable. These findings highlight the need for structured communication strategies, caregiver counselling, and physician-led disclosure protocols that respect patient autonomy while addressing family concerns. Early psychosocial support and culturally sensitive interventions may help reduce collusion and promote transparent, patient-centered cancer care.

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