

Original Article

Impact of an Early Goals of Care Discussion on Patient Satisfaction and Quality of Life among Seriously Ill Patients Admitted to the Medical Wards – A Quality Improvement Project

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ABSTRACT

Objectives: The objective of this study was to achieve integration of goals of care discussion (GOCD) as a routine part of assessment among seriously ill patients admitted to medical wards and assess its impact on patient satisfaction, caregiver satisfaction and quality of life (QOL).

Materials and Methods: This was non-randomised before and after study – A quality improvement project involving three plan-do-study-act (PDSA) cycles each of 6 weeks duration. The study included a total of 60 patients and their caregivers admitted to the Internal Medicine Unit in a tertiary care hospital in South India. Junior residents from Internal Medicine were trained in conducting a GOCD through a face to face training session and through an online training program using capc.org modules. Through a process of three PDSA cycles, we introduced the documentation of GOCD as a routine part of the assessment of seriously ill patients and assessed its impact on QOL and patient satisfaction.

Results: Following the introduction of GOCD, patient and caregiver satisfaction had a statistically significant improvement across the majority of the assessed domains, and there was an overall improvement in the mean World Health Organization QOL Brief Version QOL scores by 4.8%

Conclusion: Among patients with serious illness, GOCD improved patient and caregiver satisfaction and QOL. Such conversations are essential to align the care delivery with patient preferences and help in providing patient-centred care.

Keywords: Patient satisfaction, Quality improvement, Goals, Quality of life, Patient care planning

INTRODUCTION

Problem

In goals of care discussion (GOCD), the clinician elicits and understands the goals, preferences, and values of the patient and will work to align the treatment plans with the patient's choices and wishes. At present, a structured GOCD is not a part of the standard of care for seriously ill patients admitted to the medical wards. As a result of this, most often, patients' wishes are not known, not documented, and often not respected.

In most hospital settings, the primary care physicians who are involved in end-of-life (EOL) care do not discuss the patient's goals of care until the last 48 hours of life, when very often their capacity to make decisions has been lost, resulting

in the patients being cared for in a way that they would not have chosen to.^[1,2]

In the era of evidence-based medicine, currently, the majority of the focus is being given to cure-driven interventions, with very little importance being given to the quality of care provided. With the focus on improving the quality of care, it is important to understand what outcomes of health would be acceptable for the patient and to clarify the patient's values.

Available knowledge

There is growing evidence stating that GOCD should be conducted early in the course of the disease. GOCD should ideally be a part of every clinical encounter. The initial conversation carried out early during the hospital stay should be aimed at understanding the patient's goals and wishes.

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This should be followed by a more detailed GOCD later on. Notably, healthcare providers infrequently engage patients and families in such conversations.

A qualitative semi-structured interview-based study by Selman *et al.* among patients with chronic heart failure in a tertiary care hospital in the UK showed that none of the patients included in the study had discussed EOL preferences with the treating physicians, and none of them were aware of the alternative future choices available. The patients reported that they were not informed about the implications of their diagnosis. Data indicated a high prevalence of psychological stress among the participants.^[3]

Worldwide, chronic diseases are a major contributor to morbidity. An interdisciplinary team-based approach is the ideal mode of care delivery for these patients with chronic illnesses. An observational study among patients with advanced COPD revealed a high symptom burden adversely affecting the overall quality of life (QOL) of these patients. Early palliative care involvement, by providing comprehensive symptom management and addressing psychological distress, may yield substantial benefits for these patients.^[4]

Evidence suggests that addressing communication skills is directly linked to the quality of patient-centered care. To ensure quality care, it is important for healthcare providers to focus on achieving proficiency in key communication skills. Several studies are highlighting the importance of an effective GOCD. In a multi-institutional cohort study by Mack *et al.*, it was shown that patients with advanced cancer who have discussed their EOL preferences with the physicians had a better understanding of the nature of the illness. Most of these patients chose symptom-directed care over life-prolonging therapies. The care they received was, therefore, consistent with their wishes.^[5]

Numerous data exist to support the effect of EOL discussion on QOL and caregiver burden. A study by Wright *et al.* showed that patients who did not have an EOL conversation received much more aggressive medical treatment in their final week of life, which was associated with worse patient QOL near death. Their bereaved caregivers, in turn, experienced more regret and worse QOL. The association between EOL discussion resulting in less aggressive treatment at the EOL was noteworthy in the study.^[6]

Patient and caregiver satisfaction with the care provided is an important outcome measure in assessing the quality of care. In a cross-sectional study by Stajduhar *et al.*, the 'CANHELP caregiver bereavement questionnaire' was used to assess the bereaved family members' perception of the quality of EOL care. The study emphasised that understanding the family members' perception of quality of care helps to determine specific domains of care that need improvement.^[7]

Rationale

Introducing a standardised approach to sensitive conversations through a structured GOCD will improve the healthcare utilisation and aid in medical decision making. A better-informed patient may be more capable of avoiding unnecessary aggressive interventions at the EOL.

Determining the goals of care for seriously ill patients is a core component of the 'Clinical Practice Guidelines for Quality in Palliative Care'.^[8] Expert communication to establish the goals of care should ideally be provided by the primary treating physicians, in the same way, that hypertension and diabetes mellitus are more often treated by primary care physicians rather than by cardiologists or endocrinologists, thus leaving palliative care specialists to provide expert opinion on the very complex cases only.^[9]

Aim statement

We aimed to study the impact of a structured GOCD on patient satisfaction, caregiver satisfaction and QOL among seriously ill patients admitted to the medical wards.

MATERIALS AND METHODS

Context

A non-randomised before and after study was done as a part of the quality improvement project. Three consecutive cohorts of patients were interviewed through a process of three plan-do-study-act (PDSA) cycles, each of 6 weeks duration, in the department of general medicine in a tertiary care hospital in South India in the year 2018–2019.

Intervention

The study intervention consisted of clinician education and training in conducting GOCD. Internal medicine junior residents (JRs) were trained through a face-to-face training session conducted by a trained palliative care physician and through an online training program using capc.org modules, at the end of which assessment was done, and a certification of credit was provided to the JRs. The core training methodology included case-based discussions, training in communication about serious illness and clarifying goals of care.

A seriously ill patient was defined as:^[10-12]

- Age ≥ 55 years and 1 or more of the following advanced chronic illnesses:
 - Chronic obstructive pulmonary disease (Two of the following: baseline arterial partial pressure of carbon dioxide >45 mm Hg, cor pulmonale, episode of respiratory failure within the preceding year)
 - Congestive heart failure (New York Heart Association Class IV symptoms and left ventricular ejection fraction $<25\%$)
 - Cirrhosis (confirmed by imaging studies or documentation of oesophageal varices) and 1 of the

following: Hepatic coma, child class C liver disease and child class B liver disease with gastrointestinal bleeding

- Cancer (metastatic cancer or stage IV lymphoma).

OR

- Any patient ≥ 80 years of age admitted to hospital from the community due to an acute medical condition.

OR

- You answer 'no' to the following question: 'Would I be surprised if this patient died within the next year?'

All patients who fulfilled the inclusion criteria were enrolled into the study by convenience sampling strategy after obtaining written informed consent.

We excluded patients with no family/caregiver and patients who were expected to die/be discharged within 24 hours.

Outcome variables assessed

To assess and compare patient and caregiver satisfaction and QOL among seriously ill patients admitted to the medical wards before and after the introduction of a GOCD.

Process measure

Through a process of three PDSA cycles, we assessed the impact of GOCD on patient and caregiver satisfaction and QOL of patients with serious illnesses admitted to the medical wards. The CANHELP Lite questionnaire was used to measure patient and caregiver satisfaction of care in the three PDSA cycles, and for assessment of QOL, the World Health Organization QOL Brief Version (WHOQOL-BREF) questionnaire was administered to the patients in all three PDSA cycles, and the difference in scores was compared. The details of the three PDSA cycles are given below:

PDSA 1

We conducted a baseline audit (interview and audit of case sheets) to check whether GOCD is occurring in routine care of seriously ill patients. The eligible patients and their caregivers were interviewed using the CANHELP Lite questionnaire on Day 6 of admission/day of discharge (if discharged within 6 days), whichever is later. Their QOL was assessed using the WHOQOL-BREF questionnaire. This served as baseline data, wherein patient and caregiver satisfaction assessment and QOL assessment were done without the introduction of GOCD.

PDSA 2

JRs were trained in conducting GOCD. Execution of the structured GOCD among patients fitting inclusion criteria over 2 weeks. The discussed GOC was documented in the patient's medical record. Caregiver and patient satisfaction were assessed on day 6 of admission/day of discharge (if discharged within 6 days) using the CANHELP Lite

questionnaire. The patient's perceived QOL was measured using the WHOQOL-BREF questionnaire simultaneously. Analysis of the data was conducted.

PDSA 3

The main aim of the PDSA 3 cycle was to look for the sustainability of the intervention. Patient and caregiver satisfaction and QOL scores were assessed among eligible patients over 2 weeks.

Statistical methods and analysis

To assess patient and caregiver satisfaction among the participants, the CANHELP Lite questionnaire was used. Satisfaction with the care received among patients and caregivers was scored on a Likert scale of 1–5 points.

Before the initiation of the study, Cronbach's alpha score was calculated for internally validating the CANHELP Lite questionnaire. The higher the reliability coefficient, the more accurate (internally consistent) the measure. According to the literature, coefficients of 0.70 or higher are desirable. Our analysis of internal consistency reliability revealed an alpha of 0.708 for the patient satisfaction questionnaire and 0.864 for the caregiver satisfaction questionnaire.

Calculation of QOL scores

Permission was obtained from the World Health Organization to use the WHOQOL-BREF questionnaire as a study tool. During each of the three PDSA cycles, the QOL was assessed using this questionnaire while simultaneously assessing the satisfaction scores among seriously ill patients admitted to the medical wards. This 26-item study tool was used to measure the following four domains of QOL namely, physical health, psychological aspects, social relationships and environment. WHOQOL-BREF study tool consists of four domains. The mean score of individual items within each domain gives the domain score. Mean scores are then multiplied by 4 to make domain scores comparable with the scores used in the World Health Organization QOL-100. Domain scores are scaled in a positive direction with higher scores denoting better QOL.

The collected data were coded and analysed using the Statistical Package for the Social Sciences (version 17.0). Patient satisfaction scores were compared across the three PDSA cycles using an analysis of variance. Descriptive analysis was performed, and the scores were expressed in mean (with standard deviation) and proportion. $P < 0.05$ was considered as a statistically significant difference.

Ethical consideration

The study was registered under the Clinical Trial Registry of India (Reg no: CTRI/2018/11/016307). The study commenced after the study was approved by the Institutional Ethics Committee (IEC KMC MLR 09–18/245).

RESULTS

A total of 60 patients and their caregivers were included in the study through a process of three PDSA cycles. Our study included patients with chronic kidney disease, chronic liver disease, malignancy, heart failure and chronic obstructive pulmonary disease. The study had 20 males (7, 6, 7 in PDSA-1, 2 and 3, respectively) and 40 females (13, 14 and 13 in PDSA 1, 2 and 3, respectively) patients. The maximum number of patients in our study was between the ages of 50 and 59 years across all three PDSA cycles [Table 1].

CANHELP Lite patient and caregiver questionnaire was used to assess the satisfaction at baseline (PDSA 1) and after the introduction of GOCD (PDSA 2 and 3).

Patient satisfaction scores with respect to all the domains assessed had a statistically significant improvement after the introduction of GOCD [Table 2]. Patient satisfaction scores also showed good sustainability from PDSA 2 to PDSA 3.

Caregiver satisfaction scores in the majority of the domains had a statistically significant improvement after the introduction of GOCD [Table 3].

Comparing the measures of QOL across the three PDSA cycles using the WHOQOL-BREF questionnaire as a study tool, there was an overall improvement in the mean QOL scores by 4.8% after the introduction of GOCD [Table 4].

DISCUSSION

In our study setting, the initial prevalence of documented GOCD was zero. Through a process of three PDSA cycles, we aimed to achieve the integration of a GOCD as a routine part of patient assessment among seriously ill patients admitted to medical wards.

In our study, following the introduction of GOCD in PDSA 2 and 3, patient satisfaction had a significant improvement across all the domains that were assessed.

Following GOC discussions, there was a greater perceived patient satisfaction regarding the attending healthcare team, presumably because the patients felt that they were better informed about the nature of the disease.

Several studies have shown that addressing patient preferences is directly linked to higher quality of care.

Our results are in agreement with other studies wherein, following GOCD, the patient satisfaction scores with respect

Table 2: Patient satisfaction scores across the three PDSA cycles.

PDSA cycle	Mean(±SD)	ANOVA P-value	Statistical significance
Quality of care received			
1	4.10 (±0.788)	0.020	Significant
2	4.65 (±0.587)		
3	4.60 (±0.598)		
Relationship with doctors			
1	12.65 (±1.424)	0.000	Highly significant
2	14.40 (±1.188)		
3	14.30 (±1.174)		
Illness management			
1	31.90 (±4.712)	0.000	Highly significant
2	37.25 (±2.936)		
3	38.20 (±2.262)		
Communication of the current illness by the healthcare team			
1	11.65 (±2.084)	0.000	Highly significant
2	14.30 (±1.129)		
3	14.45 (±1.050)		
Decision-making in end-of-life care			
1	12.00 (±2.224)	0.000	Highly significant
2	17.10 (±1.252)		
3	17.50 (±1.573)		

PDSA: Plan-do-study-act, ANOVA: Analysis of variance formula, SD: Standard deviation

Table 3: Caregiver satisfaction scores across the three PDSA cycles.

PDSA cycle	Mean (±SD)	ANOVA P-value	Statistical significance
Quality of care received			
1	4.25 (±0.550)	0.438	Not significant
2	4.40 (±0.754)		
3	4.50 (±0.513)		
Relationship with doctors			
1	13.00 (±1.414)	0.015	Significant
2	14.15 (±1.531)		
3	14.15 (±1.226)		
Characteristics of doctors and nurses			
1	8.55 (±0.887)	0.003	Highly significant
2	9.50 (±0.946)		
3	9.40 (±0.940)		
Illness management			
1	33.90 (±4.633)	0.013	Significant
2	36.40 (±2.703)		
3	37.10 (±2.713)		
Communication and decision-making in end-of-life care			
1	24.40 (±3.926)	0.000	Highly significant
2	30.75 (±3.127)		
3	32.20 (±2.118)		

PDSA: Plan-do-study-act, ANOVA: Analysis of variance formula, SD: Standard deviation

Table 1: Age distribution of patients.

Age group (years)	No. of patients in PDSA 1	No of patients in PDSA 2	No of patients in PDSA 3
20-29	1	2	3
30-39	3	5	4
40-49	6	4	3
50-59	8	7	7
60-69	2	2	2
70-79	0	0	1
	Total 20	Total 20	Total 20

PDSA: Plan-do-study-act

Table 4: QOL scores across the three PDSA cycles.

	Maximum possible score	Mean	SD	Mean (%)	ANOVA test P-value	Statistical significance
PDSA 1	120	82.65	9.366	68.88	0.045	Significant
PDSA 2	120	82.35	9.292	68.63		
PDSA 3	120	88.50	6.848	73.75		

QOL: Quality of life, PDSA: Plan-do-study-act, ANOVA: Analysis of variance formula, SD: Standard deviation

to the quality of care received had a significant improvement in the mean score by 11% from PDSA 1 to PDSA 2.

Consistent with other studies, our study also captured a highly significant association between the occurrence of discussions of GOC and patient satisfaction with respect to the communication of the current illness by the healthcare team, illness management and greater overall satisfaction with respect to their decision-making in EOL care.

Conversations with caregivers, with specific reference to the patient's wishes, values and goals of care help them to make decisions that are congruent with the expressed goals. This association was evident in our study wherein, following a GOCD, the caregiver satisfaction scores regarding their communication and decision-making in EOL care had a highly significant improvement in the mean score by 18% from PDSA 1 to PDSA 2. The domains that concern addressing caregiver satisfaction regarding communication of the current illness by the healthcare team and the support that they received from the healthcare team also showed a highly significant improvement after the introduction of GOCD.

The caregiver's perception of the quality of care received helps us to gain a better understanding of the particular domains of care that need improvement. In the present study, there was a progressive improvement across the three PDSA cycles in the mean caregiver satisfaction scores regarding perceived quality of care, though we could not highlight a statistical significance. Undoubtedly, perceptions of quality of care are influenced by the health system where care is provided, and our study was constrained by limited information from a single healthcare setting. Future multicentric studies are needed in this regard.

Studies have shown that with earlier GOCD, patients experienced a better QOL. On follow-up, their bereaved caregivers also experienced less regret and a better QOL.^[13] In our study, there was an overall improvement in the mean QOL scores by 4.8% after the introduction of GOCD. Among the individual domains assessed, Domain 4 (environmental domain assessing access to healthcare, physical safety and opportunities for acquiring new information) was the only subscale with a statistically significant difference after the introduction of GOCD. To date, only a few studies have been conducted in India regarding communication in palliative care. A similar study done in a Hospice Care Centre in Chennai, India, assessing the impact of palliative care

conversation on QOL using the WHOQOL-BREF study tool also showed that there was an improvement in psychological and environmental domains (Domain 2 and 4, respectively) after the introduction of palliative care.^[14]

Our study was unable to capture a significant association between GOCD and the following three QOL domains, namely, physical health and psychological and social relationships. The possible explanation for this could be that, in the context of terminal illness, the degree of social functioning that is affected by the illness has a significant negative impact on the QOL. Apart from the influence of GOCD, QOL is influenced by several other factors which were not addressed in our study. Furthermore, as clinicians are not exposed to GOCD routinely, there will be several factors which hinder implementing a structured GOCD. These also could have influenced the QOL scores. Furthermore, a longitudinal follow-up study of these patients would give a better understanding of various factors determining QOL.

Interpretation

Addressing goals of care results in overall improvement in the patient and caregiver satisfaction with the care provided. Beyond the estimation of satisfaction scores and QOL assessment, we introduced the concept of GOCD as a routine part of the assessment of seriously ill patients admitted to the medical wards.

Strengths

Internal medicine JRs were trained in conducting GOCD, thus giving our study an added advantage over others, in which investigators have often relied on referrals to palliative care experts for GOCD. We used validated structured clinical interviews for assessing patient and caregiver satisfaction and QOL scores. It is among the very few studies conducted in India on GOCD, and the results in our study match the outcomes from developed nations, thus highlighting the universal nature of the importance of shared decision-making and patient autonomy.

Limitations

Although GOC was discussed explicitly with the patients, we did not audiotape the conversations of GOCD. It was not feasible to follow up on the same patient population beyond one PDSA cycle. Although we assessed the impact of GOCD on QOL, we did not assess its impact on survival, as we did

not have a longitudinal follow-up of our patients. This was a single-centre study thereby limiting generalisation of the results to other healthcare settings.

CONCLUSION

GOCD forms the basis of a constructive clinician-patient relationship. Such conversations are essential to align the care delivery with the patient's preferences. Addressing goals of care results in overall improvement in the patient and caregiver satisfaction with the care provided. Although this was a single-centre study, the results nonetheless offer great promise for integrating GOCD as a routine part of patient assessment among seriously ill patients.

Ethical approval

The research/study approved by the Institutional Review Board at Kasturba Medical College, Mangaluru, number IEC KMC MLR 09-18/245, dated 19th September 2018.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Nil.

Conflicts of interest

There are no conflicts of interest.

Use of Artificial Intelligence (AI)-Assisted Technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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