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ORIGINAL ARTICLE

Parent reported outcomes of quality care and satisfaction in the context of a life-limiting fetal diagnosis

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Abstract

Objective: To identify which quality indicators (QI) predict patient satisfaction.
Methods: A cross-sectional design using a validated tool was administered using a Web-based platform. Parents ($n = 405$) who experienced a life-limiting fetal diagnosis and opted to continue their pregnancy provided feedback on 37 QI and satisfaction with prenatal care. Descriptive analyses and logistic regression identified relationships among variables.
Results: Parental satisfaction with care was 75.6%. Statistically significant differences in mean scores were reported with satisfied patients reporting higher agreement with quality indicators. Parents who were satisfied with their care had 1.9 times the odds of reporting that consistent care was provided (CI: 1.4–2.4, $p < 0.01$), 1.8 times the odds of reporting compassionate care (CI: 1.4–2.5, $p < 0.01$) and 1.8 times the odds that they received help to cope with their emotions (CI: 1.4–2.3, $p < 0.01$). The model correctly predicted parent satisfaction 92% of the time.
Conclusion: Provision of consistent prenatal care is an important quality indicator for this population of parents. The odds of securing satisfied parents increase when families are treated with compassion and given resources to help them cope with the emotionally devastating experiences associated with a life-limiting fetal diagnosis.

Keywords

Parental satisfaction, patient reported outcomes, perinatal palliative care, quality of health care

History

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Introduction

The US infant mortality rate in 2013 was 5.96 deaths per 1000 live births, with congenital anomalies, deformations and chromosomal abnormalities contributing to the leading causes [1,2]. Parents who are given a life-limiting fetal diagnosis may require supportive health services surpassing those of their healthy peers [3,4]. A life-limiting diagnosis is defined as a fetal condition in which there is a shortened life span with no reasonable hope for cure. Such a diagnosis transforms the pregnancy experience and women and their partners are placed into a position where difficult and complex choices must be considered [5]. Recommendations from the American College of Obstetricians and Gynecologists Committee on Ethics and the American Academy of Pediatrics Committee on Bioethics [6] delineate four available options including pregnancy termination, postnatal therapy, palliative care and fetal intervention. Palliative care is an approach to care throughout the pregnancy continuum that aligns with the World Health Organization [7] aims to provide care for patients and their families nearing the end of life, namely early identification of patient and family needs, impeccable assessment, and treatment of problems in the physical, psychosocial and spiritual domains.

Regulatory bodies and national palliative care organizations recently reached consensus on the importance of quality driven, value-based care [8–11]. The patient experience of care is one important quality measure that is being more frequently considered as a mechanism to improve health care services. The literature supports strategies to enhance satisfaction, such as sharing information in a timely, sensitive manner, providing consistent messaging, giving emotional support and partnering with parents to create a plan of care [12]. Data related to patient reported outcomes are critical to address the large gaps in measurement needs increasingly being addressed as a crucial component of patient-centered and fee-for-value care [13]. Quality indicators (QI) can be characterized and quantified, making it possible to secure feedback from parents continuing an affected pregnancy that is both meaningful and useful to providers. Parental satisfaction, one evaluation of health care services, has become integral in today's health care climate. Seminal research on patient satisfaction defines it as an individual's appraisal of health care services received and their assessment of service providers [14]. Satisfaction is the reflection of the patient's expectations, personal preferences and the realities of the care received [14].

The purpose of this study was to identify which QI predict patient satisfaction with care in the prenatal setting when a

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fetus has been diagnosed with a life-limiting condition. The specific aims were to (#1) describe parents' perception of the provision of QI; (#2) compare mean QI scores between patients who were satisfied versus not satisfied with their care; and (#3) identify statistically significant predictors of patient satisfaction.

Methods

A 37-item instrument containing prenatal QI was used to collect data. One global item assessed patient satisfaction with care. The instrument, called *Parental Satisfaction and Quality Indicators of Perinatal Palliative Care* was developed and validated by the first author using Delphi research with 14 international perinatal experts, evidence from the literature and the National Consensus Guidelines (NCP) for Quality Palliative Care [11,15]. There are three distinct timeframes in pregnancy, that is, prenatal, intrapartum, and postnatal. Items in the instrument capture these timeframes and results from the Prenatal Scale are reported here. The Prenatal Scale included three subscales; they are the (1) Compassion Subscale, (2) Support Subscale and (3) Process Subscale. Cronbach's alpha for the 37-item instrument was 0.97 [16].

The Compassion Subscale addressed QI regarding the importance of managing medical needs during the prenatal period and unhurried communication that is clear, sensitive, compassionate and supportive of parental needs. The Support Subscale addressed QI reflective of cultural, spiritual and emotional needs. The Process Subscale was comprised of ten QI items directed at family-centered care delivered in a comfortable environment that incorporated a consistent approach to patient care and seamless transitions. Shared decision making, a designated contact person, and assistance with plans of care were also in the Process Subscale.

Quality indicator items and the parental satisfaction item were placed on a 7-point Likert scale, with 1 indicating ''strongly disagree'', 4 indicating ''neutral or does not apply'' and 7 reflecting ''strongly agree.'' Higher scores indicate greater agreement that the care was provided. The dependent variable, parental satisfaction, was recoded to create a dichotomous variable for the proposed data analyses, specifically logistic regression. Responses of 1–4 (strongly disagree, moderately disagree, disagree, neutral) were coded as ''disagree'' and responses of 5–7 (agree, moderately agree and strongly agree) were coded as ''agree''.

Parents were invited to participate in an online survey, which was distributed via email and posted on websites in February 2015 by webmasters that support families who have experienced a fetal life-limiting diagnosis. The instrument was embedded in the survey along with demographic items and questions requiring narrative feedback. Recruitment efforts intentionally targeted multiple support agencies to capture parents affected by a variety of fetal diagnoses. Inclusion criteria included mothers or fathers over 18-years old who experienced a life-limiting fetal diagnosis and opted to continue the pregnancy living anywhere in the world. Participants needed to be able to communicate in English and access and use a computer. Participants were welcome to contribute to the study regardless of the interval between the birth and survey. Institutional Review Board Project #15SP125 was approved by York College of Pennsylvania and informed consent was acquired at the start of the data collection. The survey was open for four weeks.

We examined items for normality and assumptions were met. Quality indicator items were treated as continuous variables and analyzed using Pearson's *r*. Two items were removed because of high correlations [17] resulting in 35 QI items shown on Table 1. ''The health care team (HCT) cared for my baby with dignity and respect'' was dropped because of high correlation with ''The HCT treated my baby as a person'' ($r = 0.924$). ''I could talk to the HCT about my needs'' was removed because of a high correlation with ''The HCT was compassionate'' ($r = 0.879$).

In Aim #1, we described parents' perception of the provision of QI. In Aim #2, we calculated measures of central tendency and independent samples *t*-tests to examine differences in parent reported QI for those who were satisfied versus those who were not. Assumptions were met for independent samples *t*-tests, except for equality of variance in some subscales. For these cases, we report the appropriate *t*-statistic for unequal variances. In Aim #3, we examined assumptions for logistic regression, which were met. We identified parental predictors of satisfaction as follows: (1) a full logistic regression model was run separately for each subscale, (2) full models for each separate subscale were then examined to determine statistically significant QI predictors of patient satisfaction. We report adequacy of model fit with the Hosmer and Lemeshow test; non-significant results indicate a good model fit. Strength of relationships between QI and parental satisfaction is reported with Nagelkerke R^2. We report odds ratios and confidence intervals for each significant predictor. (3) In the final step, we developed a logistic regression model to predict parental satisfaction using the statistically significant predictors that were revealed from the three subscales. All statistical analyses were performed using SPSS version 20 (Chicago, IL).

Results

The final sample included 405 parents. Parents were primarily Caucasian mothers living in the United States with at least some higher education. The most common fetal diagnosis was Trisomy 18 (52.8%), followed by anencephaly (30%). Sixty-nine percent of the participants learned of the fetal diagnosis prior to 20 weeks gestational age. The majority of women delivered at 37 weeks or beyond, with 61.7% of infants live-born, 32.3% stillborn and 5.9% still living at time of data collection (Table 2). Interval between birth and participation in research varied, with 57% delivering in the past five years, 27% delivering between 2005 and 2009, and the remaining 16% delivering prior to 2005.

In Aim #1, 75.6% of parents reported satisfaction with the care they received. Table 3 provides descriptive data from the Prenatal Scale of the composite subscale scores. Analyses for Aim #2 compared mean prenatal QI scores between patients who were satisfied versus not satisfied with their care, noting statistically significant differences in mean subscale scores with satisfied patients reporting higher agreement with QI: Compassion Subscale ($M = 5.9$ versus 3.3, $t\ (126.6) = 17.78$, $p = <0.01$); Support Subscale ($M = 5.2$ versus 2.9,

Table 1. Quality indicators shown within subscales; odds ratios and confidence intervals.

Quality indicators	
Compassion subscale	
HCT was compassionate	**1.5 (1.03–2.1)**
HCT treated baby as a person	1.1 (0.78–1.6)
Sensitively explained range of possible outcomes about infant's condition	1.2 (0.40–1.8)
Physicians took time to talk to me	1.2 (0.88–1.8)
Sensitively explained infant's condition	1.2 (0.90–1.6)
HCT hoped for the best with me	1.1 (0.82–1.5)
HCT listened to me	1.2 (0.84–1.8)
HCT explained pros and cons of treatment options in a balanced way	.86 (0.61–1.2)
HCT took care of my medical needs	**1.5 (1.03–2.1)**
HCT supported choice to continue pregnancy	.92 (0.70–1.2)
Nurse took time to talk to me	1.1 (0.82–1.6)
HCT used words I could understand	.91 (0.63–1.3)
Explained if wished could not be met	1.3 (0.89–1.9)
Support subscale	
HCT provided grief and bereavement information	1.9 (0.77–1.5)
HCT assessed cultural and family traditions	.92 (0.62–1.3)
HCT provided funeral information	1.2 (0.83–1.6)
HCT assessed spiritual customs	.91 (0.64–1.3)
HCT informed me of sources of support	.97 (0.71–1.3)
Availability of someone to give spiritual support	1.04 (0.73–1.5)
HCT supported cultural and family traditions	1.2 (0.75–2.0)
HCT supported spiritual customs	**1.6 (1.1–2.3)**
While exploring options, given information about PPC	.89 (0.72–1.1)
HCT worked with me to make a treatment plan for my infant	1.2 (0.91–1.6)
HCT helped me cope with emotions	**2.1 (1.5–2.9)**
HCT provided keepsakes	1.1 (0.88–1.4)
Process subscale	
HCT gave planned care to infant	.81 (0.54–1.2)
Designated contact person available	.83 (0.64–1.1)
HCT helped identify my needs	1.1 (0.80–1.5)
Family was included in discussions	.89 (0.64–1.3)
HCT provided care in a consistent manner	**1.9 (1.3–2.7)**
HCT provided comfortable, caring environment	**1.7 (1.3–2.3)**
Transition between providers went well	0.99 (0.72–1.4)
HCT helped to create plan of care	1.0 (0.76–1.4)
HCT helped with decision-making	**1.5 (1.1–1.9)**
HCT welcomed my family	**1.6 (1.2–2.2)**

HCT: Health Care Team; PPC: Perinatal Palliative Care
Data are odds ratio (95% confidence interval)
Bold indicates $p<(0).05$

t (395) $= 16.3$, $p = <0.01$); Process Subscale (M $= 5.9$ versus 3.5, t (134) $= 16.3$, $p = <0.01$). Aim #3 identified statistically significant predictors of patient satisfaction. Table 1 shows results from the full models for each subscale which were initially examined to determine statistically significant predictors of patient satisfaction. These significant predictors were then examined in final logistic regression models. Odds ratios, B and 95% CI for EXP (B) are provided in Table 4.

Prenatal scale: compassion subscale

Two items emerged as statistically significant predictors from the full Compassion Subscale, which were ''The health care team (HCT) took care of my medical needs'' ($p = 0.03$) and ''The HCT was compassionate'' ($p = 0.03$). A reduced binary logistic regression model was then run for these predictors. In the final model, parents who were satisfied with their care had 1.8 times the odds of reporting that their medical needs were met (CI 1.03–2.1) and 2.5 times the odds of reporting that compassionate care was rendered (CI 1.03–2.1). Model fit was adequate (Hosmer and Lemeshow Test: $x^2 = 3.4$, $p = 0.49$), with strong usefulness in prediction (Nagelkerke $R^2 = 0.66$). The model correctly predicted parent satisfaction 89.5% of the time, with greater accuracy for satisfaction (95.9%) compared to non-satisfaction (69.8%).

Prenatal scale: support subscale

Two statistically significant predictors from the full Support Subscale model were ''The HCT supported spiritual customs'' ($p = 0.02$) and ''The HCT helped me cope with emotions'' ($p = <0.01$). A reduced binary logistic regression model was run for these predictors. In the final model, parents who were satisfied with their care had 1.6 times the odds of reporting that spiritual support was provided (CI 1.1–2.3) and 2.3 times the odds of reporting that they had help coping with their emotions (CI 1.5–2.9). Model fit was adequate (Hosmer and Lemeshow Test: $x^2 = 6.7$, $p = 0.46$), with strong usefulness in prediction (Nagelkerke $R^2 = 0.61$). The model correctly predicted parent satisfaction 88% of the time, with greater accuracy for satisfaction (94.3%) compared to non-satisfaction (68.4%).

Prenatal scale: process subscale

Four statistically significant predictors emerged from the full Process Subscale model, which were ''The HCT welcomed

Table 2. Parental demographics and characteristics of infants.

Characteristics*	Categories	n (%)
Parental status	Father	30 (7.5%)
	Mother	372 (92.5%)
Parental country of origin	Australia	8 (2.1%)
	Canada	14 (3.7%)
	United Kingdom	14 (3.7%)
	United States	338 (90.4%)
Parental race	African American	10 (2.5%)
	American Indian or Alaskan Native	0 (0%)
	Asian	8 (2%)
	Hispanic/Latino	24 (6%)
	Native American/Pacific Islander	1 (0.3%)
	White	254 (89.8%)
Parental education	Grade school	2 (0.5%)
	High school or technical school	91 (22.7%)
	Associate’s degree	61 (15.2%)
	Bachelor’s degree	134 (33.4%)
	Graduate degree	103 (25.7%)
	Other	10 (2.5%)
Fetal diagnosis ($n = 394$)	Anencephaly	118 (30%)
	Fetal hydrops	5 (1.3%)
	Hypoplastic Left Heart Syndrome	5 (1.3%)
	Limb body wall complex	7(1.8%)
	Multiple anomalies	11 (2.8%)
	Thanatophoric dysplasia	5 (1.3%)
	Trisomy 13	13 (3.3%)
	Trisomy 18	208 (52.8%)
	Other	22 (5.6%)
Gestational age at diagnosis	0–12 weeks	38 (9.2%)
	13–16 weeks	84 (20.3%)
	17–20 weeks	156 (37.8%)
	Weeks	65 (15.7%)
	> 25 weeks	62 (15.3%)
Gestational age at birth ($n = 401$)	13–20 weeks	7 (1.8%)
	21–24 weeks	10 (2.5%)
	25–32 weeks	65 (16%)
	33–36 weeks	102 (25.4%)
	37–40 weeks	167 (41.7%)
	After 40 weeks	51 (12.7%)
Length of time infant lived ($n = 392$)	Less than 1 h	49 (12.5%)
	1–4 h	62 (15.8%)
	5–24 h	35 (8.9%)
	1–6 days	42 (10.7%)
	1–4 weeks	21 (5.4%)
	1–3 months	22 (5.6%)
	3–13 months	11 (2.8%)
	Still living	23 (5.9%)
	Stillborn	127 (32.3%)
Regret about pregnancy continuation ($n = 402$)	Yes	10 (2.5%)
	No	392 (97.5%)

*$n = 405$ unless otherwise indicated

Table 3. Subscale score descriptives.

	Range	Mean (sd)	Median	Mode
Prenatal subscales				
Compassion subscale	1–7	5.3 (1.5)	5.6	7
Support subscale	1–7	4.6 (1.5)	4.6	7
Process subscale	1–7	5.3 (1.5)	5.6	7

Table 4. Final prenatal scale logistic regression model.

	B (SE)	Adjusted OR EXP(B) (CI 95%)	*p* values
Compassionate care	0.59 (0.15)	1.8 (1.4–2.4)	<0.01
Consistent care	0.63 (0.15)	1.9 (1.4–2.5)	<0.01
Help to cope with emotions	0.57 (0.13)	1.8 (1.4–2.3)	<0.01

my family’’ ($p = 0.01$), ‘‘The HCT provided a comfortable, caring environment’’ ($p = <0.01$), ‘‘The HCT helped with decision-making’’ ($p = 0.01$), and ‘‘The HCT provided care in a consistent manner’’ ($p = <0.01$). In the final model, parents who were satisfied with their care had 1.5 times the odds of reporting that their family members were welcomed (CI 1.2–2.2), 1.6 times the odds of reporting a comfortable, caring environment (CI 1.3–2.3), 1.4 times the odds that they had help with decision-making (CI 1.1–1.9), and 1.7 times the odds of receiving consistent care (CI 1.3–2.7). Model fit was adequate (Hosmer and Lemeshow Test: $x^2 = 6.6$, $p = 0.47$), with strong usefulness in prediction (Nagelkerke $R^2 = 0.66$). The model correctly predicted parent satisfaction 90.3% of the time, with greater accuracy for satisfaction (94.9%) compared to non-satisfaction (76%).

Final prenatal model

Using the eight QI predictors which emerged from the three subscales, a final prenatal model was examined. Statistically significant predictors of parent satisfaction were the provision of consistent care ($p = <0.01$), compassionate care ($p = <0.01$), and help to cope with emotions ($p = <0.01$). In this final prenatal model, parents who were satisfied with their care had 1.9 times the odds of reporting that consistent care was provided, 1.8 times the odds of reporting compassionate care, and 1.8 times the odds that they received help to cope with their emotions (Table 4). Model fit was adequate (Hosmer and Lemeshow Test: $x^2 = 7.1$, $p = 0.31$), with strong usefulness in prediction (Nagelkerke $R^2 = 0.73$). The model correctly predicted parent satisfaction 92% of the time, with greater accuracy for satisfaction (96.3%) compared to non-satisfaction (81.1%). Interestingly, the significant predictors in this model contain one item from each subscale.

Discussion

Being informed of a life-limiting diagnosis during pregnancy is a life altering event for parents, and one which produces psychological consequences for the patient, her partner and family and her health care provider. The literature clearly establishes the emotional devastation parents suffer when receiving a life-limiting fetal diagnosis. The pregnancy experience is transformed, and parents respond with a complex and varied reactions which often can include grief, despair, fear, anxiety, hopelessness, anger and guilt [4,18–20]. How best to cope with this situation requires emotional intelligence on the part of all who are affected, and while everyone wants to ‘‘do their best’’, how to do this has not been easy to accomplish. The current study begins to lay the groundwork for components of quality care highly important to parents and adds strength to the notion that patient centered care can improve the parent-reported outcomes so central in today’s health care environments.

One specific area to note is the importance parents attach to consistency of care. Parents with a life-limiting fetal diagnosis typically see a variety of clinicians during the pregnancy and research indicates parents report fragmented care [21]. Providing consistent care supports the notion that the interdisciplinary team, recommended by palliative care experts, needs to communicate carefully among its members to ensure a seamless approach to care. Such communication will also allow for the setting of appropriate expectations for the parents about how their pregnancy and birth will be managed. The need for a care coordinator has been recognized by the Institute of Medicine [22], and the majority of PPC programs (83%) have responded by hiring individuals, most often nurses, to help manage parental psychosocial needs [23]. Complementary support among providers is essential given the limited amount of time some specialists have for patient interactions [12]. Our findings confirm care coordination emphasizing consistent messaging and an integrated, synchronized approach to care will be essential if we are to accomplish the goals of enhancing patient satisfaction and quality of care.

Clinicians engaged in the care of bereaved parents can support coping mechanisms by assessing patient knowledge, managing their expectations, and assisting with the creation of a tailored plan of care for the pregnancy, birth and death of the infant. These proactive activities will improve the chances of seamless care and consistent messaging and will reduce the emotional risks to all involved in the process. A wide variety of bereavement interventions are routinely offered by nurses and others on the HCT beginning at diagnosis and extending well beyond the birth [23]. In our sample, 67.6% of infants were live-born, and the opportunity to hold a live baby is something evidence has shown is highly desirable and therapeutic for the parents [24–26]. Evidence suggests women find the experiences of parenting, such as dressing and bathing, and talking to the baby, most valuable in creating a bond [27] and often wish to spend time and hold their infant if stillborn [28]. Strategies to help parents cope with their emotions include referring parents to members of the interdisciplinary team familiar with bereavement interventions including sensitive collection of mementos which are overwhelmingly appreciated by parents [26].

Study strengths

Our study has some specific strengths which should be highlighted. First and foremost is that it identifies some key components for predicting parental satisfaction in the prenatal clinical setting, namely consistency of care, compassionate care and emotional assistance. Additionally, our sample’s representativeness to parents continuing a pregnancy with a life-limiting fetal diagnosis is heightened with the robust sample of 405, inclusion of diverse fetal diagnoses, and an international sampling strategy. We realize our findings are not necessarily generalizable given the largely Caucasian and well-educated sample. Nonetheless, our findings are applicable to more diverse populations simply based on the universal nature of parental grief and its need to be managed sensitively and respectfully. Our data also linked the importance of family-centered care and respect for cultural and spiritual customs as distinct parental satisfiers and quality indicators.

Limitations

The current study is not without some limitations. The risk of parental recall bias may have been introduced, although research has shown women have enduring and generally accurate memories of their birth experiences [29] and they recall, in detail, terminology used when communicating with their health care provider [30]. The study design did not allow collection of data to ascertain the competency of providers with respect to their knowledge of perinatal bereavement and mourning. We also do not have data regarding the availability of abortion services and while 97% of our population reported that they did not regret their choice to continue the pregnancy, there is the possibility that this choice of continuation was the only option available for 31% of the participants. We were not able to collect long-term follow-up data, the influence of other siblings or the efficacy of this model of care in cases of unexplained stillbirth at term, where prenatal preparation for an adverse outcome would not be possible. Nonetheless, the data presented here demonstrate that there are some factors that accurately predict overall satisfaction with care under the circumstances described, and that focus on improving performance in these areas may represent a worthwhile strategy for improving the quality of care for parents who opt to continue their pregnancy affected by a life-limiting condition.

Our data confirm that specific quality indicators can successfully predict patient satisfaction in the setting of an anticipated fetal or neonatal loss. Focusing on the inclusion of the specific indicators identified as being statistically significant into the care plans of patients who are expecting a child with a life-limiting condition may be an important means for increasing not only patient satisfaction but also the overall quality of care. We feel that despite some limitations, our data are compelling and that prospective evaluation of this methodology is warranted.

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Declaration of interest

The authors report no declarations of interest

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