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ORIGINAL ARTICLE

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Neighborhood deprivation is not associated with abortion consideration or completion in patients with fetal myelomeningocele

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Abstract

Objective: The objective of this study was to evaluate whether patient-level neighborhood deprivation index (NDI) was associated with termination of pregnancy consideration and completion in patients presenting with fetal myelomeningocele.

Methods: This was a retrospective cohort analysis of patients with fetal myelomeningocele presenting to a fetal treatment center (FTC) in Illinois between 2018 and 2024. The exposure was NDI calculated from patient zip codes. The NDI was analyzed as both a dichotomous and ordinal exposure. The co-primary outcomes were abortion consideration prior to FTC consultation, ascertained by nurse intake, and abortion completion after consultation. Bivariate and log-binomial regression analyses were performed. Covariates were selected based on $p < 0.10$ on bivariate analyses. Otherwise, $p < 0.05$ indicated statistical significance.

Results: A total of 157 participants were included. Evaluation of neighborhood deprivation as a dichotomous exposure revealed no association with abortion consideration or completion. AdditionallLy, no association was found on log binomial modeling after controlling for gestational age at presentation to the FTC and maternal race or ethnicity for abortion consideration (aRR 0.87, 95% CI 0.59–1.28) or completion (aRR 0.86, 95% CI 0.59–1.28). These results were similar when treating the NDI as an ordinal exposure.

Conclusions: Contrary to our hypothesis, NDI is not associated with abortion consideration or completion in patients with fetal myelomeningocele.

Key points

What is already known about this topic?

- Neighborhood deprivation is an established risk factor for poor outcomes in obstetric and perinatal care, and fetal myelomeningocele is more prevalent in patients from areas of higher deprivation.

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- Many clinical factors impact pregnancy decision-making for fetal myelomeningocele; however, the sociodemographic factors that may also impact decision-making are incompletely understood.

What does this study add?

- This study demonstrates that neighborhood deprivation is not associated with abortion consideration prior to fetal treatment center consultation or completion among patients with a fetus with myelomeningocele.
- Patients from similar neighborhood deprivation areas make a range of choices regarding the pregnancy management of fetal myelomeningocele. This study reinforces the need to provide balanced counseling to all patients.

1 | INTRODUCTION

Prospective parents of children with severe congenital anomalies face difficult decisions regarding pregnancy continuation or termination. These decisions are based on various factors including disease severity and prognosis for the child, personal beliefs, and sociodemographic environment.[1–6] For a select group of severe fetal anomalies, in utero treatment may allow for successful continuation of pregnancy and mitigate certain long-term effects of the disease. Such is the case for fetal myelomeningocele (fMMC), the most common congenital central nervous system anomaly, where maternal-fetal surgery (MFS) offers potentially improved neurologic outcomes and decreased need for ventricular shunting.[7,8] However, many patients who meet criteria for MFS do not elect to undergo it, choosing instead to continue the pregnancy with planned postnatal repair or undergo termination of pregnancy (TOP).[7–10] In one study, 26% of patients who were offered prenatal repair of fMMC elected to undergo postnatal repair instead, with maternal risks of prenatal surgery, risk of preterm labor, and their partner's opinion identified as influential factors for decision-making.[11] The sociodemographic factors that likely also impact parental decision-making for fMMC are incompletely understood, but may include access to care, financial encumbrance, ability to complete the required postoperative care and follow-up, and future caregiver responsibilities, as patients have lifelong sequalae of the condition regardless of whether or not they undergo prenatal repair.[2–6,12–15]

To better understand the factors that impact parental decision-making for fMMC, we investigated neighborhood deprivation index (NDI), a validated measure of the degree of social disinvestment in a geographical area. NDI is a composite metric describing a patient's environmental context rather than individual socioeconomic status, taking into account the average income, education, housing quality and employment of people residing in a given geographical area.[16,17] Patients from the highest NDI areas are more frequently impacted by fMMC, and NDI is an established risk factor for morbidity and mortality for a variety of obstetric and fetal conditions.[12,18–23] Our objective was to determine whether patient-level NDI is associated with TOP consideration prior to consultation and TOP completion after consultation for fMMC at a large tertiary FTC in Illinois, a state with legally protected access to TOP.[24] Given the significant barriers to accessing and completing MFS care as well as the relationship of sociodemographic disadvantage to adverse obstetric and fetal outcomes, we hypothesized that higher NDI would be associated with increased consideration and completion of TOP for patients with fMMC.[12,13,25]

2 | MATERIALS AND METHODS

2.1 | Data

This was an analysis of a retrospective cohort of patients with singleton pregnancies with fMMC who presented to a regional FTC affiliated with a large tertiary care children's hospital (Chicago Institute for Fetal Health [CIFH] at Ann and Robert H. Lurie Children's Hospital of Chicago). Patients who presented between 2018 and 2024 were included in the study. Patients who completed TOP prior to presentation to the FTC as well as those with twin pregnancy with fMMC were excluded from the study. Institutional Review Board approval was obtained from Ann & Robert H. Lurie Children's Hospital of Chicago (IRB # 2020–3250).

All patients referred to the FTC had a presumed diagnosis of fMMC that served as the reason for referral. Prior to presentation at the FTC or any prenatal counseling by FTC providers, patients were asked whether they were considering TOP by an intake nurse coordinator. Answers of "yes" or "no" were then selected by the nurse coordinator on an intake form. Forms with both answers selected, neither selected, or other answers written in were not included in the analysis of abortion consideration due to an inability to clearly determine if a patient was considering TOP. Patients then presented for comprehensive fetal evaluation, whereby fetal ultrasound, magnetic resonance imaging (MRI), and genetic evaluation through amniocentesis were obtained at our FTC, or outside MRI/laboratory tests were reviewed by our fetal radiologists. Thereafter, patients received coordinated multidisciplinary counseling and elected to proceed with either prenatal surgical repair, expectant pregnancy continuation with plan for postnatal surgical repair, or TOP. Surgical intervention was completed at our FTC and pregnancy terminations were performed at external facilities. Pregnancy decisions were collected either from a formal report by the patient or

ascertainment of medical records by clinical research nurses or licensed social workers.

The primary exposure of the study was NDI, which was obtained based on the patient's reported zip code of residence. NDI is generated as a composite score for a given Census Block Group and converted to a 1–100 score based on that neighborhood's rank compared to the national percentile.[16] This composite score is based on 13 metrics that reflect income, education, housing quality and employment within a given area.[26] Patient NDI was divided into quintiles within the cohort and subsequently analyzed as both a dichotomous (i.e., above average to greatest vs. average to least deprivation) and ordinal exposures. The primary outcomes of this study were patient-reported TOP consideration and TOP completion after consultation at our FTC.

Demographic and clinical information were obtained from the patient medical records. MMC severity was evaluated via multiple ultrasound and MRI parameters, including size of the lesion, upper level of the lesion, Chiari malformation grade, presence of talipes, presence of severe ventriculomegaly, and other structural anomalies.[27–29] Apart from the present study's exclusion of patients with a body mass index greater than 40 kg/m^2 (rather than 35 kg/m^2), surgical repair candidacy was consistent with criteria established in the Management of Myelomeningocele (MOMS) trial.[7] From 2018 to 2020, patients were primarily offered open surgical repair of fMMC. After changing surgical practice at the institution, from 2020 to 2024 patients were primarily offered fetoscopic surgical repair.

2.2 | Statistical analysis

Analyses were completed using Stata (StataCorp, College Park). Bivariate analysis was performed via Chi-square test and Fisher's exact test for categorical variables and Wilcoxon rank-sum test for continuous variables. Log-binomial regression analyses were performed to assess for covariates independently associated with TOP consideration or completion. Covariates were selected based on $p < 0.10$ on bivariate analyses and were retained in the model after stepwise backwards selection if $p < 0.10$. Otherwise, $p < 0.05$ indicated statistical significance. Tests of normality were performed for all continuous data. Post-hoc, given the overlap in results for gestational age (GA) with respect to median (interquartile range [IQR]), we chose to report mean ± standard deviation as well for demonstration of the difference in the distribution of GA between groups.

3 | RESULTS

3.1 | Patient cohort characteristics

A total of 157 patients presenting to CIFH with fMMC were included in the analysis. Biomedical and sociodemographic data of the entire cohort are presented in Table 1. Median (IQR) age of patients at presentation was 31 (27–35) years, and GA at presentation was 22 (21–23) weeks. 110 (70.5%) of cases were determined to be candidates for prenatal repair, with 32 (29.1%) offered open and 78 (70.9%) offered fetoscopic repair. 100 (63.7%) patients resided in Illinois and 115 (73.2%) presented after passage of the 2019 Reproductive Health Act. 95 (60.5%) patients were from areas with above average to highest NDI, whereas 62 (39.5%) patients were from areas of lowest to average deprivation. There were significant differences in the cohort between patients from each NDI group (Table 2). On dichotomous analysis, patients from above average deprivation areas were younger (30[24–34] vs. 32[28–35] years, $p = 0.004$) and more likely to be of Latinx ethnicity (43.5% vs. 7.4%, $p < 0.001$). A trend was observed of patients from higher NDI areas to be more likely to reside in Illinois (72.6% vs. 57.9%, $p = 0.06$) and be of higher GA at initial consultation (median [IQR] 22[21–23] vs. 22[21–23];

TABLE 1 Biomedical and sociodemographic data of pregnant people with fetuses with myelomeningocele ($n = 157$).

Age, in years	31 (27–35)
Self-reported race	
White	120 (76.4)
Black	14 (8.9)
Other	23 (14.7)
Latinx ethnicity	34 (21.7)
Residing in Illinois	100 (63.7)
Nulliparous	56 (35.7)
Presentation to CIFH after passage of RHA	115 (73.3)
Presence of genetic and/or structural abnormality	15 (9.6)
Presence of talipes equinovarus[a]	41 (26.6)
Presence of severe ventriculomegaly	78 (49.7)
Grade III Chiari malformation[b]	102 (68.0)
Highest level of lesion[c]	
L3 and above	69 (46.6)
L4-S1	79 (53.4)
Size of lesion, in centimeters[d]	1.5 (1.1–1.9)
GA at initial consultation	22 (21–23)
Candidate for prenatal repair[e]	110 (70.5)
Fetoscopic repair offered[g]	78 (70.9)
Considering abortion prior to consultation[f]	52 (39.1)
Underwent abortion after consultation	42 (26.8)

Abbreviations: GA, gestational age; RHA, 2019 Illinois Reproductive Health Act (i.e., removal of gestational age limit for abortions).
[a]Available for 154 participants.
[b]Available for 150 participants.
[c]Available for 148 participants.
[d]Available for 143 participants.
[e]Available for 156 participants.
[f]Available for 133 participants.
[g]Percent of total candidates for prenatal repair.

TABLE 2 Biomedical and sociodemographic data of pregnant people with fetuses with myelomeningocele by NDI.

	Above average to most deprivation (n = 62)	Average to least deprivation (n = 95)	p-value[a]
Age, in years	30 (24–34)	32 (28–35)	**0.004**
Self-reported race			
White	44 (71.0)	76 (80.0)	0.14
Black	9 (14.5)	5 (5.3)	
Other	9 (14.5)	14 (14.7)	
Latinx ethnicity	27 (43.5)	7 (7.4)	**<0.001**
Residing in Illinois	45 (72.6)	55 (57.9)	0.06
Nulliparous	23 (37.1)	33 (34.7)	0.76
Presentation to CIFH after passage of RHA	45 (72.6)	70 (73.7)	0.88
Presence of genetic and/or structural abnormality	4 (6.5)	11 (11.6)	0.41
Presence of talipes equinovarus[b]	12 (20.3)	29 (30.5)	0.16
Presence of severe ventriculomegaly	33 (53.2)	45 (47.4)	0.47
Grade III Chiari malformation[c]	37 (63.8)	65 (70.6)	0.38
Highest level of lesion[d]			
L3 and above	30 (51.7)	39 (43.3)	0.32
L4-S1	28 (48.3)	51 (56.7)	
Size of lesion, in centimeters[e]	1.4 (1.1–1.8)	1.6 (1.2–2.1)	0.08
GA at initial consultation	22 (21–23)	22 (21–23)	0.06
Candidate for prenatal repair[f]	41 (67.2)	69 (72.6)	0.46
Fetoscopic repair offered[g]	30 (73.2)	48 (69.6)	0.69
Outcomes			
Abortion intent	23 (43.4)	29 (36.3)	0.40
Abortion completion	15 (24.2)	27 (28.4)	0.55

Note: Data are median (IQR) or n (%) unless otherwise specified. Bold indicates statistical significance <0.05.

Abbreviations: CIFH, Chicago Institute for Fetal Health; GA, gestational age; NDI, Neighborhood Deprivation Index; RHA, Reproductive Health Act.

[a]Chi-squared or Fisher's exact test for categorical variables, Wilcoxon rank-sum test for continuous variables.

[b]Available for 154 participants.

[c]Available for 150 participants.

[d]Available for 148 participants.

[e]Available for 143 participants.

[f]Available for 156 participants.

[g]Percent of total candidates for prenatal repair.

mean ± standard deviation 22.6 ± 2.5 vs. 21.9 ± 2.0, p = 0.06). Boxplot distributions of maternal age and GA are presented in Appendix 1 and 2, respectively.

3.2 | TOP consideration and completion

Of the total cohort, 133 (84.7%) patients had available data on TOP consideration from pre-consultation telephone intake (Figure 1). Before consultation, 52 (39.1%) patients considered TOP, and 81 (60.9%) did not. Of the patients who considered TOP, 28 (53.8%) underwent termination and 24 (46.2%) did not undergo termination. Of the patients who were not considering TOP on pre-consultation evaluation, 8 (9.9%) underwent TOP and 73 (90.1%) continued their pregnancies. 24 patients did not have available data on TOP consideration, and 6 of these (25%) underwent TOP and 18 (75%) continued their pregnancies.

3.3 | Neighborhood deprivation and TOP consideration/completion

In comparing neighborhood deprivation as a dichotomous variable ("above average to greatest deprivation" vs. "average to least

deprivation"), there was no significant difference in the primary outcomes of TOP consideration and completion. Additionally, there was no significant relationship of TOP consideration or completion with NDI when treated as an ordinal exposure. 23 (43.4%) patients from areas of above average to greatest deprivation areas considered TOP compared to 29 (36.3%) from areas of average to least deprivation ($p = 0.40$). 15 (24.2%) patients from areas of above average to greatest deprivation completed TOP compared to 27 (28.4%) from areas of average to least deprivation ($p = 0.55$).

On log binomial modeling, stepwise backwards selection of potential confounding covariates with $p < 0.10$ on bivariate analyses demonstrated retention of only state of residence and GA at the time of consultation as confounding covariates. On multivariate regression modeling, NDI was not significantly associated with abortion consideration (aRR 0.87, 95% CI 0.59–1.28) or completion (aRR 0.86, 95% CI 0.59–1.28). Figures 2 and 3 demonstrate the geographical distribution of patients across the Chicago area (Cook County) and the state of Illinois based on pre-consultation TOP consideration and TOP completion, respectively.

4 | DISCUSSION

In this study, we hypothesized that higher neighborhood deprivation would be positively associated with TOP consideration and/or completion in patients with prenatally diagnosed MMC. Contrary to

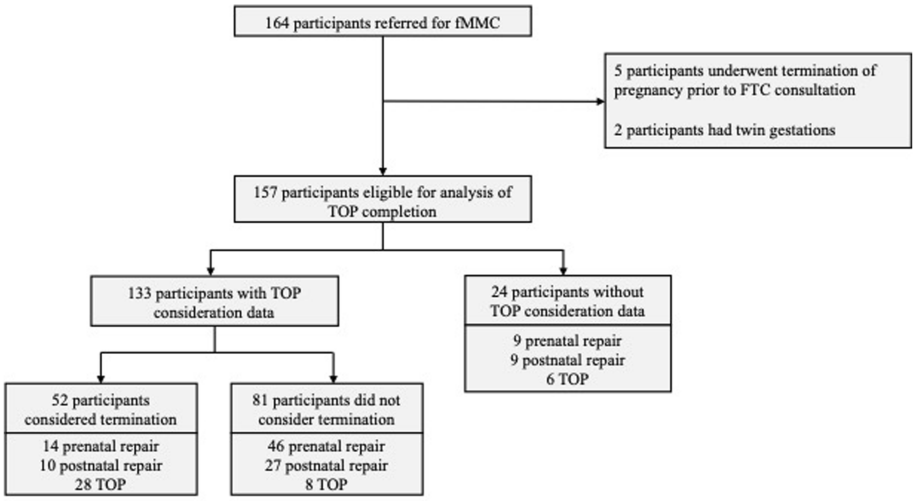

FIGURE 1 Assembly of the study cohort, consideration of termination of pregnancy, and pregnancy outcome decision.

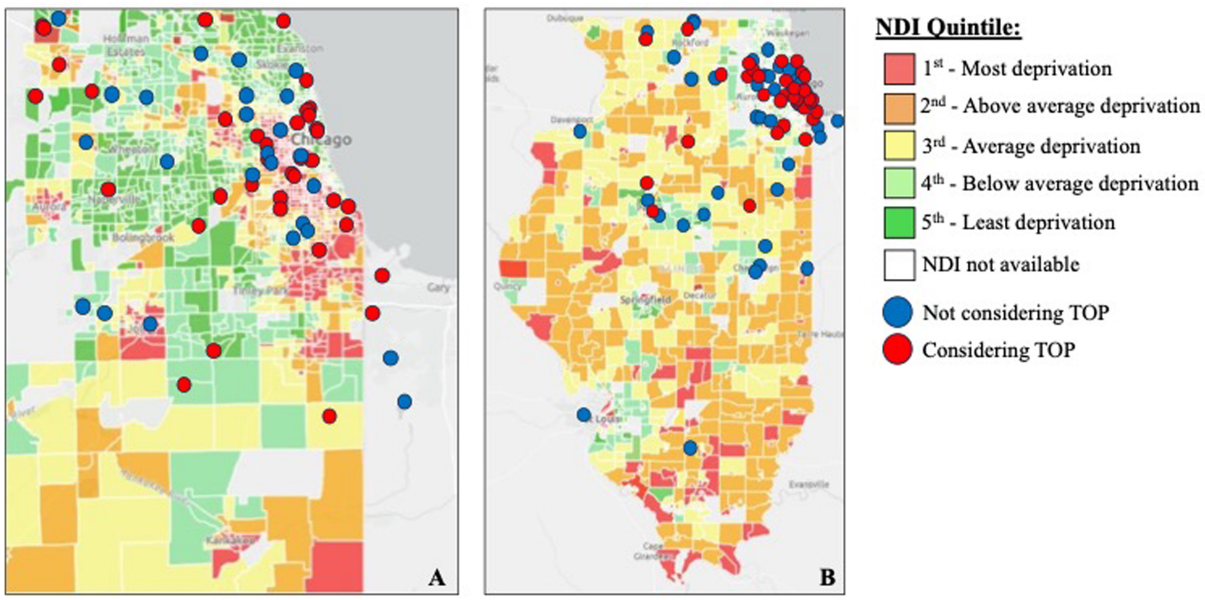

FIGURE 2 Distribution of patients considering or not considering TOP prior to consultation according to NDI within (A) the Chicago area (Cook County) and (B) the state of Illinois. TOP, termination of pregnancy.

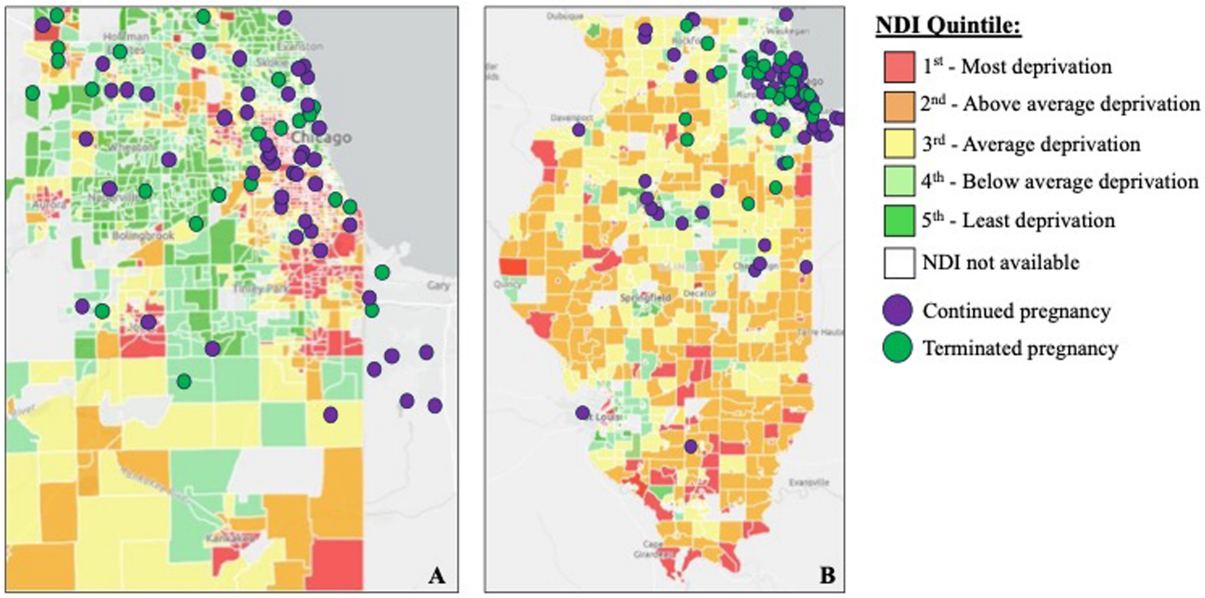

FIGURE 3 Distribution of patients continuing pregnancy versus completing TOP according to NDI within (A) the Chicago area (Cook County) and (B) the state of Illinois. TOP, termination of pregnancy.

our hypothesis, our analysis demonstrates that NDI is not associated with TOP consideration or completion among people with fetal myelomeningocele presenting to an FTC. Though a negative result, this still represents an important addition to the literature on prenatal counseling for severe congenital anomalies, as it reflects our limited understanding of factors that contribute to TOP consideration and completion.[30] Furthermore, this study indicates that patients from areas with similar deprivation indices make a wide range of decisions regarding the management of fMMC. To our knowledge, only one other study has investigated the relationship of NDI to pregnancy decision-making for fetal anomalies. In that study, a large cohort of patients in Scotland with a broad array of prenatally diagnosed chromosomal anomalies was evaluated and, like our study, did not find neighborhood deprivation to be associated with TOP.[31]

Many other factors may impact a patient's consideration or completion of TOP, including perceptions of raising a child with one or more disabilities, need to care for one or more other dependents in the household, or prior interactions with people living with repaired congenital anomalies.[32,33] Pregnancy decision-making in the context of antenatally diagnosed severe congenital anomalies is highly individualized, and influenced by multiple factors including religious beliefs, legality of the spectrum of pregnancy decision-making options, and community or family stigma regarding TOP and disability.[34–36] For some patients, TOP is not considered a possible option even in the presence of a severe congenital anomaly due to stigma regarding abortion from community and family members.[37] Alternatively, patients from other cultures may consider the stigma of raising a child with severe anomalies a reason for considering TOP.[37] These highly disparate cultural beliefs highlight the importance of environment on decision-making for severe congenital anomalies, which served as the impetus to evaluate the impact of NDI on pregnancy decision-making. This study reinforces the utmost importance of performing a thorough exploration of patients' preferences and needs, providing nonjudgmental counseling for all patients, and subsequently supporting patient decision-making regardless of the chosen outcome.[38] Two findings in this study, that 28 (52.8%) of 52 patients initially considering TOP ultimately completed it, and that 8 (9.9%) of 81 patients not considering TOP still completed it, demonstrate that while patients may have a pre-existing partiality toward either pregnancy continuation or termination, this decision will often change after the counseling received at FTCs.

This study also found that important clinical differences exist between patients from higher and lower areas of deprivation. Importantly, patients from above average to most deprived areas were younger and more frequently of Latinx ethnicity. A trend existed for patients from higher NDI areas to be of higher GA at presentation and to be from Illinois. It is interesting to observe that a lower proportion of out-of-state patients were from high NDI areas, potentially indicating the presence of disparities in access to specialty care for patients from higher NDI areas outside of the FTC catchment area. Furthermore, even small differences in time of presentation are potentially relevant for families faced with urgent decisions on whether or not to proceed with MFS, given the broadly accepted GA limit of 25 weeks 6 days for fMMC.[39] The timing of presentation may impact provider conversations about the urgency of decision-making and change the overall directiveness of counseling, which is of particular importance given that conversations requiring more urgent decision-making may be happening more frequently with young patients and persons from marginalized groups.[40] These populations would be interesting to explore in the future as we attempt to understand barriers to complex reproductive health care and differences in the content of prenatal counseling. Furthermore, this information reinforces the need for policy changes

aimed at improving access to complex prenatal care for families, particularly in areas of higher deprivation, as differences in GA at presentation may significantly alter the treatment options available for patients. Additional investigation on the relationship between sociodemographic factors and abortion decision-making for other congenital anomalies that may have different monitoring requirements, treatment options, and prognosis is of significant interest.

Strengths of this study include its relatively large scale for a rare congenital anomaly such as fMMC, and the prospective decision to evaluate abortion decision-making prior to formal consultation is unique as it allows us to understand preferences of patients as they present and before counseling at an FTC. An additional strength of the study is the location of this FTC in an abortion-expanded state such as Illinois, where the spectrum of treatment options was available to patients. Previously published rates of TOP for MMC for patients in the Midwest region of the United States are highly variable, ranging from 34% to 78% depending on lesion severity, but are generally concordant with this study.[3,41] The ability to access both MFS and abortion services in Illinois and the lack of relationship of NDI with TOP consideration and completion indicates the possibility that patients may be less influenced by sociodemographic factors in their decision-making in an abortion-expanded state. It is not known whether such a relationship exists in other states with different policies on abortion; however, this information may be useful in informing policy changes outside Illinois that aim to foster equal access to the spectrum of options for prospective parents.

This study also has several limitations worthy of consideration. First, data on TOP consideration was not available for all patients, primarily due to inconsistencies in data collection on intake and less often patient preference not to disclose over telephone intake. Those patients who prefer not to disclose may have important differences for which this study was not able to account. However, it is important to note that patients with available data on consideration underwent TOP in a similar proportion to those without available data on consideration (27% vs. 25%). Patients presenting to our FTC may have already received extensive, in some cases non-directive, counseling from referring physicians. It is conceivable that the content of pre-consultation counseling could vary by geographical region and training of the referring provider (i.e., general obstetrics and gynecology, family and community medicine, or maternal-fetal medicine), especially in abortion-restricted states where regulations may restrict discussion of all options, but this was not investigated in this study.[42] Further research on factors that impact patient decision-making, including counseling provided prior to FTC consultation, language used by providers at the FTC, and individual barriers to caregiving in the context of a severe fetal anomaly diagnosis, is needed. Additionally, this study evaluated patients presenting to a single center in Illinois, a state with expanded coverage for TOP. The relationship of NDI to TOP consideration and/or completion may be different in other states or regions of the world where the option of termination is not readily accessible and where personal, ethical or religious beliefs regarding prenatal intervention are different.[43–45] Additionally, NDI is one of several validated metrics by which the extent of deprivation in a community can be assessed. These indices have multiple overlapping features, and one prior study identified moderate levels of correlation between NDI, social disability index, and social vulnerability index (SVI), but less correlation with area deprivation index.[46] NDI was chosen in this study as its intended use is to quantify levels of disadvantage in a community, as compared to a metric such as SVI developed with the intention of identifying low-resource communities for support after natural and anthropogenic hazardous events.[46,47] Though NDI has been previously utilized in multiple studies related to maternal-fetal health, utilization of alternate indices in future studies may be warranted.[20,21,23] Furthermore, it is important to note that patients are considered adequately "exposed" to neighborhood deprivation when residing in a given area over a one to 3-year time period. As patient zip codes were only collected upon presentation, the duration of residence within the reported zip code could not be obtained in this study.[48] Finally, while NDI is composed of various metrics that impact socioeconomic status, it should not be used as a proxy for socioeconomic status as it is a population-level score that may be different from an individual patient's circumstance. In this sense, it is an extrinsic rather than intrinsic assessment of factors that may impact decision-making, and future studies may specifically address individual factors such as socioeconomic status and level of education that may impact TOP consideration and completion.

Based on the current findings, we conclude that NDI is not associated with abortion consideration or completion in patients with fMMC. Though higher NDI is an important risk factor for spina bifida occurrence and other adverse pregnancy outcomes, the lack of relationship with pregnancy termination for severe fetal anomalies highlights the highly individualized nature of these complex decisions.

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None.

CONFLICT OF INTEREST STATEMENT

Dr. Premkumar is a consultant for GenBioPro.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

The authors of this study have complied with APA ethical standards in the treatment of their samples. Data for this study were collected with approval from the local Institutional Review Board (IRB# 2020–3250).

PATIENT CONSENT STATEMENT

Written consent was obtained from each patient in this study for participation in this research.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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