



Assessment of Value-Based Healthcare Delivery in Cardiac Care for Children of Amish Families

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ABSTRACT

Background: Value-based healthcare is a model proposed by Porter that aims to provide high quality care which is patient-centric and cost-effective. It recognizes unique needs of different populations and promotes healthcare provisions that are customized to their specific needs.

This study describes the family experiences and health seeking behaviors of insured and uninsured children who underwent cardiac surgery. Since the majority of the uninsured were Amish, the results can be extrapolated to them.

Methods: Pediatric Integrated Care Survey (PICS) was sent to parents/guardians of 160 children who had undergone at least one cardiac surgery and were followed at Cardiology Care for Children. In this study, most of the self-pay consisted of the Amish. The survey consisted 5 components: Access, communication, family impact, goal creation and team functioning. Composite score calculation was done to gauge favorable responses. An independent sample t-test was conducted to assess the differences in patient-centered care, with a 95% confidence interval ($p < 0.05$), between the insured and self-pay.

Results: The self-pay reported fewer medical comorbidities and had lower utilization of healthcare than those who were insured; of which vision care, access to primary care and medical surgical specialty were significantly lower. The self-pay felt that they had better communication with the healthcare team and the family impact was discussed, whereas the insured felt that the short and long term goals were better defined. Stress was discussed more with the insured whereas difficulty in receiving care was discussed more with the self-pay. The self-pay did not have help with school issues or were offered services with the in-school team. Participation in health events and educational services were not offered to the self-pay.

Conclusion: The study reflects that the different populations have different needs that are important to them and this may be based on their cultural roots. One would expect that the self-pay Amish community would have greater comorbidities due to founder gene effect but those reported by patients were fewer. The cost of care for the self-pay Amish community may also have also influenced the utilization of services. This study indicates patient-centered outcomes vary among patient populations. This is influenced by their socio-cultural beliefs and resources. Care must be customized to meet the needs of the patients and the community.

Keywords: Value-based healthcare; Amish; Pediatric integrated care survey; Patient-centeredness

Received:	29-March-2023	Manuscript No:	IPQPC-23-16368
Editor assigned:	31-March-2023	PreQC No:	IPQPC-23-16368 (PQ)
Reviewed:	14-April-2023	QC No:	IPQPC-23-16368
Revised:	19-April-2023	Manuscript No:	IPQPC-23-16368 (R)
Published:	26-April-2023	DOI:	10.36648/1479-1064.23.31.14

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Citation Chowdhury D, Ather M, Snyder C, Kodavatiganti M, Eenennaam FV, et al. (2023) Assessment of Value-based Healthcare Delivery in Cardiac Care for Children of Amish Families. Qual Prim Care. 31.14.

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LIST OF ABBREVIATIONS

(VBH) Value-based Health Care; (PICS) Pediatric Integrated Care Survey; (FFS) Fee For Service; (RACHS) Risk Adjustment for Congenital Heart Surgery; (CAHPS) Consumer Assessment of Healthcare Providers and Systems

INTRODUCTION

Value-Based Healthcare (VBHC) is an emerging concept that takes into account the perspectives of individuals receiving care. This model has its foundations and is defined by Michael Porter as the value of the care by means of the resources used and the anticipated outcome. The way the value of care can be determined is through a ratio between the outcomes in health for patients and the cost incurred by the health system [1]. Therefore, it is a health system that is patient and outcome driven. Comparatively, traditional paradigms of healthcare are not focused on the value of care such as the Fee for Service (FFS) reimbursement model. In FFS, patients are required to pay for every use of healthcare facilities typically with high out-of-pocket expenses. In FFS models, services are paid for by the patient through an insurer, commission, or administrator. An FFS system pays for the health services for the patient without acknowledging the results of outcomes, patient satisfaction, and is expensive.

As a result, adding value to healthcare becomes very important. This can be achieved by assessing outcomes through registries, establishing benchmarks and implementing quality initiatives that lead to efficient, cost effective and coordinated care [2]. This is advantageous to both the patients and the healthcare providers. To patients, VBHC allows them to experience quality healthcare, drive their care based on their preferences, and allow them to receive integrated care. To healthcare providers, it serves to contain costs and help ease financial burdens. With an increase in healthcare requirements and the advancement of technology, healthcare costs are at a rise. VBHC will allow healthcare providers to focus on health aspects directed by patients needs and help them direct investments towards those goals.

VBHC requires critical assessments of health outcomes, which helps shape and improve healthcare systems. These are described in three tiers by Porter, which become the basis of VBHC. Tier 1 accounts for health status, such as mortality and functionality, tier 2 accounts for the type of care and recovery and tier 3 accounts for sustainability of health [3]. All these outcomes should be considered by healthcare providers to cater to patients in a sustainable and integrated way, in which integrated care encompasses team-based care, connection to life, community health, and future planning [4].

The Amish community puts great emphasis on family, including extended family. Due to their strict adherence to cultural values, Amish children attend Amish operated schools and get formal education until the eighth grade. The children have a basic curriculum that involves writing and arithmetics. They are involved in Amish-owned family businesses and farms and do not use technology at homes, schools, or workplaces [5]. The Amish believe in shared responsibility of the community to help fellow members. They consider insurance to be detrimental to

this belief. Therefore, they do not take aid from the government or insurance companies and are also exempted from the Affordable Act of 2010 [6]. As a result, the Amish are uninsured for different reasons than non-Amish patients are uninsured. In the Amish, the primary reason for being uninsured is strictly due to religion and culture. This implies that the Amish will pay for all of their health services out-of-pocket. However, if the expenses are not affordable, they will seek the community's help which would be provided through alms or community collections.

METHODS

The study uses the Pediatric Integrated Care Survey (PICS), a validated survey developed by Ziniel et al. [7] which was designed to evaluate integration of children's healthcare through assessing the child's families' experiences. This survey included 19 experience items that assess five aspects of healthcare: Access, communication, family impact, goal creation and team functioning. The survey was mailed to 160 participants with a self-stamped return envelope. The patients' families were contacted thrice by phone; first was to inform them that they will be receiving a survey in the mail, second was a week later to confirm if they have received the survey, and a third phone call a week later to confirm that the survey had been mailed back to the clinic.

The participants of this study were the parents/guardians of children who had undergone at least one cardiac surgery, irrespective of the complexity and place of surgery. The children were being followed at Cardiology Care for Children; an outpatient clinic located in Lancaster, Pennsylvania. The study population had a significant interaction with the healthcare system as their child had undergone cardiac surgery. The clinic caters to patients that come from various ethnic backgrounds of which 15% belong to the Amish; and present with a wide range of cardiac pathologies which may or may not be associated with genetic syndromes. It is in close association with academic hospitals in Pennsylvania and Delaware where patients are referred for cardiac surgeries that range from Risk adjustment for congenital heart surgery (RACHS) 1-6, in complexities. IRB approval was obtained for the study. Through a series of questions, 19 items adapted from the PICS survey assessed communication, family impact, goal creation and team functioning, demonstrated. The options given to gauge the favorability of their responses for the 19 items were as follows; never, rarely, sometimes, usually, almost always, and always. The bottom two boxes suggest 'never' and 'rarely' and the top two boxes suggest 'almost always' and 'always.' However, short-term goals and access to medical records were answered in a yes or no manner, with yes being a favorable response. The favorability of responses and the composite scores were further compared between insured and uninsured. The questionnaire assessed patient characteristics, healthcare needs of the child, utilization of medical services, medications, equipment, and healthcare perceptions. These were done using frequencies and percentages. This was compared between insured and self-pay. To maintain patient confidentiality and anonymity, the details and the location of cardiac surgery were not inquired in the questionnaire. The responses to the survey were taken as consent from the patient/family. The IRB felt strongly that a signature not be obtained as

it could reveal the identity of the patient.

Composite score calculation was done, adapted from Consumer Assessment of Healthcare providers and Systems (CAHPS) Surveys, which indicates the percentage of participants who gave a favorable response to the questions asked. The results of the calculations were compared between the insured and self-pay. An independent sample t-test was conducted to assess if differences exist in between the care received by insured and self-pay, with a 95% confidence interval ($p < 0.05$). In addition to cumulative scores, the 5 components of the survey were compared between insured and self-pay.

RESULTS

160 parents and guardians of children who had undergone car-

diac surgery were identified and the survey was mailed to them. Of those sent, 57 surveys were filled and returned back, making the response rate 36%. There are a multitude of factors that impact survey response rate and are not exclusive to one reason. The response rate is likely due to lack of incentive, lack of desire; the survey was forgotten, poor survey timing, etc.

Table 1 describes the patients' baseline characteristics. Of the respondents 46% of the patients were male, 23% were between ages 1 to 3 years, and 53% were between 4 to 12 years of age. 37 (67%) were insured and 17 (30%) were self-pay; 11 of whom were Amish (58%). The demographics of the two groups were similar. Overall, 85% of the participants had 2-5 healthcare providers. Majority of the patients (70%) had no ER visits, and 70% had no additional hospital admissions.

Table 1: Patient characteristics.

	N (total)	N	%
Child Characteristics			
Age	57		
<1 years		3	5.3
1 to 3		13	22.8
4 to 12		30	52.6
13 to 17		7	12.3
18 and above		4	7
Sex (Male)	57	26	45.6
Ethnicity	57		
Amish		13	22.8
Non Amish		44	77.2
Health insurance	55		
Govt		15	27.3
Pvt		22	40
None		17	30.1
Dont know		1	1.8
Healthcare needs of the Child			
#healthcare providers	54		
02-May		46	85.2
06-Oct		5	9.3
Nov-15		1	1.9
16-20		2	3.7
>20		0	0
Types of healthcare providers			
PCP/Pediatrician		49	86
Med-Surg		33	57.9
Home Health Care		2	3.5
Nurse		5	8.8
School		7	12.3
Behavioral Health		5	8.8

PT/OT		15	26.3
Social Worker		7	12.3
CAM		2	3.5
Therapist		2	3.5
Other		8	14
ER visits	56		
Never		39	69.6
01-Feb		13	23.2
03-May		4	7.1
>6		0	0
Hospital stay	57		
never		40	70.1
01-Feb		10	17.5
>3		7	12.3
Use of prescribed medicine	55	40	72.7
Use of special therapy	57	16	28.1
Emotional/developmental/behavioral problems	57	10	17.5
Use of medical equipment at home	57	15	26.3
Use of special education services	50	14	28
Use of following services			
Mental Health		3	5.2
Substance Abuse		0	0
Home Health Care		3	5.2
Vision Care		15	26.3
Hearing Care		1	1.8
Mobility Aids		0	0
Communication Aids		1	1.8
None		38	66.6
Medical Comorbidities			
Behavioral		10	17.5
Developmental		10	17.5
Breathing		11	19.2
Neurological		4	7
None		1	1.7

Table 2 describes the differences in perception of health and healthcare utilization between insured and self-pay. The self-pay reported less medical comorbidity than those who were insured, with none reporting developmental and behavioral problems. Healthcare utilization was lower in the self-pay. 27% of the self-pay had an education plan, compared to 47% of the

insured. None of the self-pay utilized the school aid, possibly because they were unaware of it or were not part of the traditional public school system. None of the self-pay had hearing care. 5% of the self-pay had mental health services compared to 26% of insured. 5% of the self-pay utilized vision care compared to 37% in the insured.

Table 2: Comparison of health perception and healthcare utility between insured and uninsured.

Demographics	Insured		Self pay		Fisher's Exact
	n	%	n	%	
Amish	2	5%	11	58%	<0.0001
Other children with special medical needs	14	37%	6	32%	ns

Stopped working to provide care	10	26%	6	32%	ns
Financial difficulties attributed to care	8	21%	4	21%	ns
Medical comorbidities					
Developmental/Behavioral problems	10	26%	0	0%	0.0221
Respiratory distress	9	24%	2	11%	ns
Neurological impairment	3	8%	1	5%	ns
None	18	47%	14	74%	0.0305
Service Utilization					
Routine preventive care	35	92%	16	84%	ns
Individualized education plan	18	47%	4	21%	ns
Vision care	14	37%	1	5%	0.0114
Special therapy	13	34%	4	21%	ns
Mental health	10	26%	1	5%	ns
Home Health care	3	8%	0	0%	ns
Hearing care	1	3%	0	0%	ns
Provider team					
Pediatrician or family doctor	36	95%	13	68%	0.0127
Medical surgical specialty	27	71%	6	32%	0.0094
Physical or occupational therapist	12	32%	3	16%	ns
School Aid health	7	18%	0	0%	ns
Social worker	7	18%	0	0%	ns
Behavioural health	5	13%	0	0%	ns
Home nursing	4	11%	1	5%	ns
Complementary/alternative medicine	1	3%	1	5%	ns
Therapies employed					
Prescription medications	30	79%	12	63%	ns
Home medical equipment	11	29%	5	26%	ns
Communication aid	1	3%	0	0%	ns
Mobility aids	0	0%	0	0%	ns
Explicit goals of care					
Short-term	27	71%	7	37%	0.0214
Long-term	27	71%	8	42%	0.046

There was significant discrepancy in having a primary care doctor and medical surgical specialty as providers for the families. 95% of the insured had a pediatrician or a family doctor, compared to 68% of the self-pay. 71% of the insured medical surgical specialties, compared to 31% of the self-pay. None of the uninsured had school aid, a social worker, or behavioral health services. No significant differences were noted in the therapies employed. A significant number of the self-pay felt that short

and long-term goals were not communicated to them. In comparison, 71% of the insured group felt that both types of goals were explicitly described.

PICS Results

The responses of participants in the PICS questionnaires in each of the categories are shown in [Table 3](#) and the most favorable responses by insured and self-pay are analyzed in [Table 4](#).

Table 3: PICS results (Overall).

	N	Response category number	% responses in the bottom boxa	% responses in the bottom 2 boxesb	25% percentile	Mean	SD	Median	75% percentile	% responses in top 2 boxesc	% responses in top boxd
Factor 1: Access to care											
Delays: Lack of sufficient services	57	6	77.1	92.9	1	1.3	0.6	1	1	0	0
Delays: Lack of information	57	6	86	98.2	1	1.2	0.41	1	1	0	0

Factor 2: Comm with CTM*												
CTM explained things in understandable manner	57	6	0	0	5	5.5	0.71	6	6	91.2	59.6	
Family comfortable voicing concerns with CTMs	45	6	0	0	4	4.5	2.43	6	6	91.1	82.2	
CTMs listened carefully to what family has to say	57	6	0	0	5	5.4	0.89	6	6	87.7	61.4	
CTMs treated family as a full partnere	57	6	0	0	5	5.6	0.78	6	6	89.4	71.9	
Factor 3: Family impact												
Took whole family into account	56	6	21.4	44.6	2	3.4	1.95	3	6	33.9	25	
Discussed stress	55	6	23.6	45.4	2	3.1	1.77	3	4	23.6	16.4	
Discussed difficulties	53	6	30.1	49	1	2.9	1.8	3	4	20.7	17	
Offered different communication	57	6	15.8	28.1	2	3.8	1.84	4	6	43.9	26.3	
Offered peer connections	57	6	40.3	52.6	1	2.7	1.8	2	4	21.1	14	
Asked about need for other services	28	6	46.4	57.1	2	2.3	1.6	2	3	14.3	35.7	
Factor 4 : Care goal creation												
Short-term goals	55	2	40	-	0	1.3	0.97	2	2	-	60	
Long-term goals	54	2	36	-	0	1.2	0.97	2	2	-	64	
Factor 5: Team functioning and quality												
Access to same medical record	31	2	100	-	2	1.7	0.75	2	2	0	0	
Knew other advice	53	6	0	15	3	4.2	1.41	4	5	47.1	24.5	
Assigned and explained responsibility	54	6	14.8	22.2	3	4.1	1.85	4.5	6	50	35.1	
Aware of tests/evaluations	51	6	3.9	5.8	4.4	5	1.26	5	6	72.5	43.1	
Followed through on responsibilities	55	6	0	0	5	5.6	0.81	6	6	87.3	70.9	
Considered "big picture"	57	6	0	1.8	5	5.4	0.82	6	6	91.2	57.9	
Helped with school issues	18	6	72.2	72.2	0	1.1	1.77	1	1	16.7	16.7	
Aware of health events/school care/educational services	29	6	44.8	44.8	1	2.7	2.25	1	4	27.6	27.6	
Offered communication with in-school team	13	6	46.1	61.5	0	0.9	1.65	0	1	23	15.4	

*CTM: Care team member

- Never Least favourable response option
- Rarely Least favourable response options
- Almost Always Most favourable response options
- Always Most favourable response option

Table 4: Comparison of the respondents in the most favourable responses between Insured and Self pay.

	Insured			SelfPay			Fisher
	Total	N	%	Total	N	%	
Factor 1: Access to care							
Delays: Lack of sufficient services	40	0	0	17	0	0	ns
Delays: Lack of information	40	0	0	17	0	0	ns
Factor 2: Comm with CTM							
CTM explained things in understandable manner	40	35	87.5	17	17	100	0.1338
Family comfortable voicing concerns with CTMs	33	30	91	12	11	91.6	0.9506
CTMs listened carefully to what family has to say	40	33	82.5	17	17	100	0.0694
CTMs treated family as a full partnere	40	35	87.5	17	16	94.1	0.4617
Factor 3: Family impact							
Took whole family into account	39	12	30.8	17	7	41.2	0.4539
Discussed stress	39	10	25.6	16	3	18.8	0.0546
Discussed difficulties	37	7	18.9	16	4	25	0.6184
Offered different communication	40	18	45	17	7	41.2	0.7932
Offered peer connections	40	8	20	17	4	23.5	0.7688
Asked about need for other services	25	4	16	3	0	0	0.4624
Factor 4 : Care goal creation							
Short-term goals	39	27	69.2	16	7	43.7	0.1967
Long-term goals	39	27	69.2	15	7	46.7	0.2532
Factor 5: Team functioning and quality							
Access to same medical record		0			0		ns
Knew other advice	38	16	42.1	15	9	60	0.2441
Assigned and explained responsibility	39	18	46.2	15	9	60	0.3681
Aware of tests/evaluations	36	25	69.4	15	12	80	0.4443
Followed through on responsibilities	40	32	80	16	15	93.8	0.2079
Considered "big picture"	40	35	87.5	17	17	100	0.1303
Helped with school issues	15	3	20	3	0	0	0.4096
Aware of health events/school care/educational services	23	8	34.8	6	0	0	0.0952
Offered communication with in-school team	11	3	27.2	2	0	0	0.4193

Access: Majority of the patients said that they had adequate access to healthcare with no delays, with 92.9% agreeing for no lack of sufficient services and 98.2% agreeing for no lack of information. The results were similar when the insured and the self-pay were analyzed separately.

Communication: Communication was perceived to be better by the self-pay. 100% of the self-pay reported that they received explanations in an understandable manner and that they were listened to carefully, while in the insured this was seen 87.5% and 82.5% respectively. Both the groups were equally comfortable voicing their concerns. 87.5% of the insured and 94.1% of the self-pay were treated as full partners in care.

Family impact: 30.8% of the insured and 41.2% of the self-pay reported that their entire family was taken into account. Stress was discussed more with the insured whereas difficulty was discussed more with the self-pay, although both reported them to be ranging approximately between 18% and 25%. Different communications and peer connections were offered to both groups equally. Only 16% of the insured participants and none of the self-pay were asked about the need for other services, which may account for the underutilization of services by self-

pay.

Creation of short and long-term care goals: Short-term goals for patients and their families include those that affect patients' health and day-to-day assessments. Examples of short-term goals are follow-up care, medications, dietary, and exercise changes. Long-term goals pertain to quality of life and career. Overall, the short and the long-term goals were reported by 60% and 69% of the participants. Significant differences were seen when the insured were compared with the self-pay. Short-term goals were reported by 69.2% of insured and 43.7% self-pay. Long-term goals were reported by 69.2% of insured and 46.7% of self-pay.

Team functioning: Of the responses, the favorable aspects that were covered by the healthcare providers were the consideration of the 'big picture' (91.2%), follow-up through responsibilities (87.3%), and awareness of tests and evaluations (72.5%). While these differences were not significant between the insured and self-pay, there were differences seen in other components. None of the self-pay had help with school issues, were offered communication with the in-school team, or were aware of health events or educational services. Composite score com-

parisons of favorable responses in **Table 5** showed a significant difference in communication and team functioning with more favorable responses by the self-pay. Care goal creation was seen

more in the insured group. No significant differences were seen in access to care or family impact.

Table 5: Composite score, indicating the favorability of responses comparison between insured and uninsured.

	Insured		Uninsured		P value
	Mean (%)	SD	Mean (%)	SD	
Access to care	0	0	0	0	1
Communication	87.4	30.76	97.1	8.3	0.025
Team functioning	48.3	24.87	57.4	22.56	0.043
Care goal	66.25	45.84	58.4	50.72	0.093
Family impact	25.8	33.48	30	32.02	0.495

DISCUSSION

Patient centeredness is a core principle for VBHC, which makes understanding of the perceptions of patients, their families, and communities very important. This requires patient engagement at individual, organizational, and system levels. At individual levels, the patients and their families should be given the liberty to effectively communicate and be involved in shared-decision making. At organizational levels, patients and families should be provided with platforms where they can, as members of patient/parent led organizations or forums, participate in policy level changes and guide towards improvement of the health-care system [8].

Patient and family-centered care is a concept that strives to engage patients and their families to determine the type of care they receive, so as to improve patient directed outcomes and satisfaction [4,8]. This is being adopted widely by hospitals along with the development of tools to assess the needs of the patients and tailor healthcare facilities accordingly [7,9,10]. Various communities such as the Amish have a distinct cultural and religious background that profoundly influence their way of living, perception of health, and utility of healthcare services [11]. These unique beliefs and practices make it important for healthcare providers to understand the values certain groups have towards health and tailor their care accordingly.

Evaluation for access to healthcare may be a limitation of the study because the participants are from one clinic and are a small patient population which does not represent all patients. The unique cultural practices of the Amish leads to their altered perceptions of health and wellbeing, which is reflected in the differences seen in the survey. The differences may be due to healthcare disparities or presumptions made by clinicians. Enrichment of certain alleles by virtue of a small founding population leads to an increased number of genetic diseases [12]. These diseases confer children belonging to the Amish community to have a myriad of neurological, developmental and behavioral problems. Despite this, the self-pay, majority of which consisted of the Amish, reported these medical comorbidities far less than the insured participants.

While the self-pay reported that all received clear explanations and had all of the questions answered, this may be due to receiving different explanations than the insured group. Despite having better perceived communication with the health care providers, they reported a lower utilization of healthcare fa-

cilities, including health care providers, school health workers, social workers, or those offering behavioral assistance. An integrated continued care is essential for better health outcomes and improved quality of life.

Therefore, it is imperative for clinicians to identify factors that prevent these patients from availing these services. This also points to biases within the health care system that may prevent the uninsured from taking advantage of these services.

One method for high value care and higher service utilization is to clearly define short and long-term goals with the patients and their families. Another factor that plays a crucial role is cost. Because health service utilization is associated with high costs, it becomes unaffordable for those without insurance to avail these services. Clinicians must try to find community partners that can deliver similar care at an affordable cost.

Communication is an integral part in the doctor-patient relationship. Studies have shown that adequate communication is associated with better hospital functionality, leads to increased patient satisfaction, and improved patient outcomes [13,14]. It allows patients to fully understand the care they were given and adhere to the instructions provided to them [15]. Effective communication also leads to decreased readmissions [16]. In our study, the majority of the patients had a favorable response regarding communication. The results showed that 70% of the patients never had an ER visit as seen in **Table 1**. This could be due to the adequate instructions given during hospital visits which allowed them to appropriately manage their children. Another factor for low ER visits could be they had access to medical personnel after hospital hours who could direct their care. While communication between healthcare professionals and the patients were effective in this aspect, this is not the case in other areas.

Family centeredness works on various principles and aims to build a strong partnership between the medical providers and families working towards the best interest of the patient [17]. This allows the healthcare personnel to recognize that family is a constant in the patient's care, gauge the cultural norms of the families, and engage families to make their own decisions while providing support [18,19]. The family impact of health-care was assessed in this study and was found to be unsatisfactory in both groups, in self-pay more than insured. These results suggest further efforts to ensure that families are held equal stakeholders in the decision-making of the patient's care. The

impact of a child with medical needs on the family should be included as an important part of care delivery. It is important to reflect on why none of the self-pay were asked of the need for other facilities. Was it due to the patient's preferences or perhaps were neglected owing to the assumption that the Amish would prefer it that way.

The discussions regarding school work, school events, and communication with the school team was minimal for the self-pay. The Amish schools are unique and consist of Amish teachers who are careful not to allow external influences to affect the cultural practices of the community [17]. It is evident that the self-pay answered unfavorably for questions related to school. They were least helped with school issues, were not aware of the school events, and were offered least communication with the school team.

CONCLUSION

The study reflects that different populations have different needs that are important to them and this may be based on their cultural roots or perspectives. One would expect that the self-pay Amish community would have greater comorbidities due to founder gene effect but those reported by patients were fewer. The cost of care for the self-pay Amish community may also have also influenced the utilization of services. This study indicates patient-centered outcomes vary among patient populations. This is influenced by their socio-cultural beliefs and resources. Care must be customized to meet the needs of the patients and the community. The focus should be put on the specific needs of the unique community, with the patient's families participating as equal stakeholders in decision making.

DECLARATIONS

Ethics approval

Lancaster General Hospital IRB. Filling out the survey was taken as consent. No separate consent was obtained as data was de-identified and surveys could not be traced to individual patients/families.

ACKNOWLEDGEMENT

None.

CONSENT FOR PUBLICATION

Not applicable.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

SOURCE OF FUNDING

The authors declare that they have no funding for the research.

AUTHORS CONTRIBUTION

- **Concept and design:** DC, KS, KB, FVE

- **Data collection:** MK
- **Data analysis:** MA, KS
- **Manuscript writing and revision:** DC, CS, MK, MA, KS, KB
- All authors have approved the submitted version and are accountable for their contributions

REFERENCES

1. Salvatore FP, Fanelli S, Donelli CC, Milone M (2021) Value-based health-care principles in health-care organizations. *Int J of Org Anal* 29(6): 1443-1454.
2. Zipfel N, van der Nat PB, Rensing BJWM, Daeter EJ, Westert GP, et al. (2019) The implementation of change model adds value to value-based healthcare: A qualitative study. *BMC Health Serv Res* 19(1): 643.
3. Porter ME, Lee TH (2013) The strategy that will fix health care. *Harvard Business Rev*.
4. Singer SJ, Burgers J, Friedberg M, Rosenthal MB, Leape L, et al. (2011) Defining and measuring integrated patient care: Promoting the next frontier in health care delivery. *Med Care Res Rev* 68(1): 112-127.
5. Kraybill DB, Nolt SM, Wesner EJ (2010) Amish enterprise: The collective power of ethnic entrepreneurship. *Glob Bus Econ Rev* 12(1).
6. Rohrer K, Dundes L (2016) Sharing the load: Amish health-care financing. *Healthcare (Basel)* 4(4): 92.
7. Ziniel SI, Rosenberg HN, Bach AM, Singer SJ, Antonelli RC (2016) Validation of a parent-reported experience measure of integrated care. *Pediatrics* 138(6): e20160676-e20160676.
8. Smith M, Saunders R, Stuckhardt L, Michael McGinnis J (2013) Committee on the learning health care system, institute of medicine. *engaging patients, families, and communities*. Nat Acad Press.
9. Wells N, Bronheim S, Zyzanski S, Hoover C (2015) Psychometric evaluation of a consumer-developed family-Centered Care Assessment tool. *Matern Child Health J* 19(9): 1899-909.
10. Byles J, Byrne C, Boyle MH, Offord DR (1988) Ontario child health study: Reliability and validity of the general functioning subscale of the McMaster family assessment device. *Fam Process* 27(1): 97-104.
11. Nolt SM (2016) *A history of the Amish: Third edition*. Melksham England: Good Books.
12. Anand G (2008) Opting out; 'Old Order' Mennonites and Amish who shun insurance face rising bills; Should hospitals cut them a break? *Wall Street Journal*.
13. Disch J (2012) *Quality and safety in nursing: A competency approach to improving outcomes*. Ames, Iowa: John Wiley & Sons, Inc.

14. PSQH (2017) Communication: A critical healthcare competency.
15. King A, Hoppe RB (2013) "Best practice" for patient-centered communication: A narrative review. *J Grad Med Educ* 5(3): 385-393.
16. Senot C, Chandrasekaran A, Ward PT, Tucker AL, Moffatt-Bruce SD (2016) The impact of combining conformance and experiential quality on hospitals' readmissions and cost performance. *Manage Sci* 62(3): 829-848.
17. Bethesda MD (1989) National Center for Family-Centered Care. Family-centered care for children with special health care needs. *Assoc Care Child Health*.
18. Bishop KK, Others A (1993) Family/professional collaboration for children with special health needs and their families.
19. Bishop K, Woll J, Arango P (2002) Family-centered care projects 1 and 2. NM: Algodones Associates.