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Assessing the Empowerment of Minors through Relational Autonomy in Paediatric Healthcare in Benin City, Nigeria*

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Abstract

This study explores relational autonomy in paediatric healthcare, with a focus on Benin City. It aims to empower minors by involving them in shared decision-making processes. Relational autonomy emphasizes social relationships and interdependence in decision-making, essential in the paediatric healthcare setting where minors rely on caregivers. There is limited knowledge about relational autonomy in Nigeria due to the lack of legal framework and research studies. This study using an empirical methodology examines minors', doctors', and parents' attitudes and identifies factors influencing minors' autonomy in healthcare decisions. It aims to contribute to developing child-centred and more autonomous approaches for minors in healthcare and well-being.

Keywords: Empowerment, Minors, Autonomy, Paediatric, Healthcare

1.1 Introduction

From a Feminist viewpoint on rights, they contend that we are relational beings as our relationships with others shape who we are and what interests us.⁸⁷⁶ In other words, through our relations to our human or natural environment, we develop our sense of identity and capacity for self-determination.⁸⁷⁷ Alanen describes this ideology in terms of generational order. Accordingly, a generational order is a structured network of relations between generational categories positioned in and acting within necessary interrelations.⁸⁷⁸ This position believes that in terms of children's rights, their lives, however, are not individualistic, but rather relationship-based. The child is in an inseparable interdependent relationship with their guardians and the relational nature of children's lives cannot be ignored. Regarding rights, children should not be primarily viewed as individualistic rights for the state to protect or liberty rights to be free from state interference or parental protection, but as rights to have the state support the relationships children need to grow and develop into adults.⁸⁷⁹ Spikes argued that respecting children's autonomy includes evaluating developmental

⁸⁷⁶ *ibid.*

⁸⁷⁷ *ibid.*

⁸⁷⁸ Leena Alanen, 'Generational Order' in Jens Qvortrup, William A. Corsaro and Michael-Sebastian Honig (eds) *Palgrave Handbook of Childhood Studies* (Palgrave Macmillan 2009) 161 at 170; Jens Qvortrup 'Childhood as a Structural Form' in Jens Qvortrup, (ed) *The Palgrave Handbook of Childhood Studies* (Macmillan 2009) 25.

⁸⁷⁹ Pamela Laufer-Ukeles, 'The Relational Rights of Children' *Connecticut Law Review* (2016) 48 (3) 741- 816 at 749.

capacity for assent.⁸⁸⁰ This process builds on the relationship between the child, parents, and caregivers, which will support the child in making decisions on complex medical procedures until they reach the required age of capacity which can be referred to as a process of shared decision-making (SDM).⁸⁸¹

In the 1980s and early 1990s, which brought about a rise in shared decision-making, the American Academy of Pediatrics Committee on Bioethics (1995) recognised the limitation with proxy consent. It notes that no one was well suited to give consent for the child's patient.⁸⁸²

Relational autonomy through SDM enhances a child's decision-making involvement by incorporating patients' preferences about treatment options to foster better health outcomes.⁸⁸³ Since it enhances treatment adherence, reduces decisional conflict and increases patient satisfaction for adults.⁸⁸⁴ It also shows similar results for minors.⁸⁸⁵

An important distinguishing characteristic is the involvement of parents whose legal authority to decide for the child needs to be balanced against a child's growing decisional capacities. This implies a triadic shared decision-making process in the child's best interest that involves the child, parent(s) and physician.

From a human rights perspective, the concept of relational autonomy can be inferred from the core principles of the CRC.⁸⁸⁶ Of relevance are articles 5 and 12. When examined side by side, these articles balance parental guidance and the evolving competence of the child. The implication of parental interference dwindles as the child ages and can make decisions. Once a child can express his opinion based on available information, the CRC urges state parties to respect these views. Due weight be given

⁸⁸⁰ JP Spikes, Two Ethical Foundations for Pediatrics: The United Nations Convention on the Rights of the Child and Bioethical Principles in Nico Nortje and Johan C. Bester, *Pediatric Ethics: Theory and Practice* (Springer, 2022) 117.

⁸⁸¹ Ricardo Wijngaarde et al, 'Shared decision-making between paediatrics haematologists, children with sickle cell disease and their parents: an exploratory study' *European Journal of Pediatrics* (2024) 183 398-402.

⁸⁸² Aviva L Katz et al. 'Informed Consent in Decision-Making in Pediatric Practice' *Pediatric* (2016) 138 (2).

⁸⁸³ F. Legare et al, 'Interventions for Increasing the Use of Shared Decision Making by Healthcare Professionals. Cochrane Database' *Syst Rev.* (2018) 7:CD006732; G Elwyn et al, 'Shared decision making: developing the OPTION scale for measuring patient involvement.' *Qual Saf Health Care* (2003) 12(2)93–99.

⁸⁸⁴ KD Wyatt et al, 'Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis. *Acad Pediatric* (2015) 15(6)573–583.

⁸⁸⁵ B. Feenstra (2014) Interventions to Support Children's Engagement in Health-Related Decisions: A Systematic Review. *BMC Pediatric* (2014) 14:109.

⁸⁸⁶ The core principles under the CRC are, non-discrimination, the best interest of the child, the right to survival and development and the views of the child.

to the child to determine the outcome or assisted through a supported decision to determine such outcome. This form of autonomy is relational.

In Nigeria, from a societal perspective, children share relationships with their community and family members, which makes such a relationship not individualistic but family-oriented.⁸⁸⁷ In most cases, this decision-making model is described as paternalistic which is evident in the provision of the National Health Act 2014.⁸⁸⁸ The law's definition of the child as any person below the age of 18 years, is sacrosanct to making certain legal decisions in Nigeria, particularly healthcare decisions.⁸⁸⁹ In that context, the minor is responsible for obeying every decision taken on their behalf without consultation on the child's views.⁸⁹⁰ The above reasons are not farfetched, as most research findings noted that, generational relationships and cultural views have an impact on whether or not mid-adolescents are allowed to participate in decision-making.⁸⁹¹ The research revealed that most children surveyed think their parents always have their best interests at heart.⁸⁹² Nevertheless, these research findings suggest that minors are often excluded from decision-making and denied access to participate in matters that affect their well-being until they have attained the age of majority.⁸⁹³

In addition, opposition and contentions against children's participation are usually enshrined in social norms, tradition and religious beliefs regarding the relationship between children and adults, and how this acts as a trajectory for defining their rights to participation generally.⁸⁹⁴ Hence, children are usually socialised to conduct

⁸⁸⁷ Peter I. Osuji, *African Traditional Medicine: Autonomy and Informed Consent* (Springer, 2014) 93.

⁸⁸⁸ S. 64 of the National Health Act 2014.

⁸⁸⁹ S. 64 of the National Health Act 2014. Which defines a user as any person who is 18 years of age. However, persons under the age of 18, need parental support to access healthcare services. See further the case of *MDPDT v Okonkwo* [2001] 6 NWLR (Pt. 710) where the Supreme Court held that a person could exercise autonomy for informed consent when he or she is an adult.

⁸⁹⁰ *Ibid.*

⁸⁹¹ E.O. Okewumi & O. Akanle, 'Children's Participation in Decision Making within the Family Context of Yoruba Culture,' *Child Ind Res* [2022] 15 235–247 <<https://doi.org/10.1007/s12187-021-09866-5>> accessed 8 July 2023; Olayinka Akanle, 'Childhood Construction, Child Rights and Development in Nigeria: Trajectories from the Yoruba of South-Western Nigeria,' *Journal of Social Issues* [2012]15(2). 359-379.

⁸⁹² *ibid.*

⁸⁹³ *ibid.*

⁸⁹⁴ AjaNwachuku, M.A, the Nigerian Child and the Right to Participation: A Peep through the Window of "The Best Interest" Clause of the Child's Rights Act. *Beijing Law Review*, (2017) 8 159-170. <https://doi.org/10.4236/blr.2017.82009>; K. C Ozoemenam, 'Child Participation in Development Programming: Lessons from Southern Nigeria,' *Texila International Journal of Academic Research* [2017] 4 (2) 2.

themselves only to be seen and not heard, particularly when they are in the presence of adults.

Furthermore, few or no studies exist to examine the case of minors and their participatory capacity in healthcare decisions in Nigeria.⁸⁹⁵ Moreover, the absence of empirical research in Benin City, Nigeria creates a gap in literature and empirical data, which hampers a robust discourse on the subject matter in the academic, medical, and legal communities. The rationale for this paper is to fill the existing gap in literature and empirical data. Against this backdrop, the paper aims to investigate the attitudes and perceptions of minors, parents and doctors on the application of the relational autonomy approach in healthcare as a basis for mature minors' involvement to promote better health outcomes and satisfaction.

This study answers the following questions; what is the normative framework for healthcare decision-making in Nigeria? how do stakeholders perceive the participation right of the mature minor in healthcare decision-making in light of the normative framework which is rooted in legal and socio-cultural limitations? Lastly, how feasible is the application of relational autonomy for mature minors bearing in mind the paternalistic approach of healthcare decision-making in Nigeria and existing barriers?

The above research questions, without doubt, raise socio-legal issues which necessitate the adoption of a socio-legal approach to examine the intersection between law and sociocultural factors in the application of the mature minor doctrine in Nigeria. The rationale of this paper is to fill the existing gap in both literature and empirical data to test the feasibility of the relational autonomy model using Benin City as a case study. This will inform the development of laws and policies to fully address the needs of mature minors based on the evolving capacities to promote their participation in healthcare decision-making

⁸⁹⁵Iniabasi N. Isonguyo and Anthonia Adindu, 'Adolescents and Utilization of Family Planning Services in Rural Community in Nigeria', *Research on Humanities and Social Science* [2013] 3 (1); Federal Ministry of Health, 'Guidelines for Young Persons' Participation in Research and Access to Sexual and Reproductive Health Service in Nigeria' (2014); Enebeli, Emmanuel Chukwunwike, 'Interrogating the Fundamentality and Issues Relating Consent to Medical Examination and Treatment Procedures in Nigeria' <[https://d1wqtxts1xzle7.cloudfront.net/57592219/consent.docx?1539931652=andresponse-content-disposition=attachment%3B+filename%3DINTEROGATING THE FUNDAMENTALITY AND ISSU.docx&Expires=1674547791&Signature=KdwydmLV0XGMgaD0EnYCxfaavIO4NJPPg4PYDtoXtanJGZ2uljy0CL1MGlrSuaoWV4FruVe3b0yK0Yr1YeGJ91zS9lCtP0~5nQu](https://d1wqtxts1xzle7.cloudfront.net/57592219/consent.docx?1539931652=andresponse-content-disposition=attachment%3B+filename%3DINTEROGATING%20THE%20FUNDAMENTALITY%20AND%20ISSU.docx&Expires=1674547791&Signature=KdwydmLV0XGMgaD0EnYCxfaavIO4NJPPg4PYDtoXtanJGZ2uljy0CL1MGlrSuaoWV4FruVe3b0yK0Yr1YeGJ91zS9lCtP0~5nQu)> accessed 23 January 2023; Emmanuel R Ezeome and Patricia A. Marshall, 'Informed Consent Practices in Nigeria', *Developing World Bioethics* [2009] 9 (3) 148-148; Hadiza O. Okunrobo, 'Expanding the Frontiers for the Adolescents Participation Right in Health care Decision-Making in Nigeria' *Nigerian Current Law Review*, [2019] 183-210.

1.2 Method

The following method was adopted to assess stakeholders' perception of the participation of mature minors in healthcare decision-making.

1.2.1 Study design and participants

The cross-sectional survey method was used in this study. The choice of this method is informed by the fact the population of study though large, can easily be sampled through this method. This involved a one-time contact with the prospective research participants who were contacted once, administered the questionnaire, and thereafter retrieved for analysis. The sample size for the research was 460. The participants consisted of 372 minors, 38 Parents, and 50 medical practitioners. The sampling method used in this study is the multistage random sampling technique. The Participants particularly the minors (within the ages of 13-17 years) in senior secondary schools and paediatric doctors in the various elected fields were selected using the purposive sampling techniques. The Local Government Areas were selected using stratified random sampling, while parents were selected using the simple method.

The questionnaire was administered to the students in the public schools using a systematic random sampling method. The students were contacted during school hours, i.e., 9 am-2 pm (WAT) when lessons were ongoing after due consultation and permissions had been obtained from the relevant authorities. From the register of the classes, the prospective participants were selected systematically using the names on the class register. In this regard, students on numbers 1, 10, 20, 30 ... N were selected and administered the questionnaire on the spot for completion the same day. Peradventure, the student on a selected number like number 20 in the register was absent or indisposed, and the next number 21, was administered the questionnaire without prejudice to sex or other variables. To effectively administer the questionnaires to parents through simple random sampling, doctors through purposive sampling were selected. The parents were contacted at the school premises during pickups and drop off of their children to administer the questionnaire. In contrast, doctors were contacted at the clinics. The researchers waited to collect the questionnaire and also ensured that the questionnaires were returned.

1.2.2 Ethical consideration

The study received ethical approval from the Research Ethics Committee of the College of Medical Sciences, University of Benin (CMS/REC/01/VOL.2/182), the Ethics and Research Committee of the University of Benin Teaching Hospital

(ADM/E 22/A/VOL.VII/148214) and approvals were obtained from the parents. The Head of Schools visited for the study on the minors. Written informed consent/assent was obtained from both the minors and parents before the questionnaires were administered. Before the audio recording was done, written consent was obtained from the participants.

1.2.3 Statistical analysis

The data collected using the questionnaire were screened for errors, non-compliance, and other omissions or commissions. The incomplete, mutilated, or wrongly completed questionnaires were discarded. The properly completed questionnaires were analysed using simple descriptive statistics and the Statistical Package for Social Sciences (SPSS version 21). The results of the analysis are presented in tables, percentages, columns, and bar graphs, and cross-tabulation of variables was carried out to reveal hidden and salient information that enriches the findings of this study.

1.3 Results

The results are presented using thematic areas such as the concept of healthcare decision-making in the study area, relational autonomy through shared decision-making, benefits of shared decision-making, challenges and the viable ways of addressing these barriers.

1.3.1 Participants characteristics

The socio-demographic characteristics of the participants presented in Tables 1 A -C explained the following characteristics gender, age, parent's occupation, doctors' department, and years of experience.

3.1.1 Section A. Socio-demographic characteristics of participants

Table 1 below, presents the socio-demographic characteristics of the participants for the quantitative study. These comprised minors (372), parents (38) and doctors (50). In terms of gender, there were more females at 134 (36%) than males for the minors. Most of the participants were aged 15 years at 137 (36.8%) with 13 years as the least with 16 (4.3%).

Parents characteristics based on gender comprised of 20 (52.6%) of females while male at 18 (47.4%). Still, in Table A, the majority of the parents were between the ages of 41-50 at 26 (68.45). The parents' educational qualification ranges from First degree at 20 (52.6%), while postgraduate degree and SSCE were at 16 (42.1%) and 2 (5.3%) respectively. Most of the parents worked as civil servants 18 (47.4%), while the least were artisans and Nurses/Doctors at 2 (5.3%) respectively.

Table 1A: Socio-demographic characteristics of participants for the quantitative survey.

Minor (n=372)	Response	Frequency	Percentage
	Gender		
	Male	134	36
	Female	238	64
	Age range		
	13 years	16	4.3
	14 years	85	22.8
	15 years	137	36.8
	16 years	93	25.0
	17 years	41	11.0
Parents (n=38)	Gender		
	Male	18	47.4
	Female	20	52.6
	Age Range		
	30-40 years	02	5.3
	41-50 years	26	68.4
	51-60 years	10	26.3
	Educational Qualification		
	SSCE	02	05.3
	First degree	20	52.6
	Postgraduate degree	16	42.1
	Occupation		
	Teacher	12	31.6
	Civil servant/Public servant	18	47.4
	Artisans	02	05.3
	Farmers	04	10.5
	Nurses/Doctors	02	05.3
Doctors (n=50)	Gender		
	Male	30	60
	Female	20	40
	Department		
	Mental Health	08	16
	Obstetrics/gynaecology	19	38
	Dentistry	05	10
	Paediatrics	05	10
	Family medicine	05	10
	Surgery	06	12
	Ophthalmology	02	04
	How long have you worked as a doctor?		
	1-5 years	17	34
	6-10 years	21	42
	11-15 years	05	10

	16-20 years	07	14
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(Fieldwork 2022)

Doctors, on the other hand, comprised more males at 30 (60%) to female participants at 20 (40%). With regards to the area of specialisation, most of the participants 19 (38%) specialised in Obstetrics and Gynaecology, 8 (16%) in Mental Health, 6 (12%) in Surgery, 5 (10%) worked in dentistry, paediatrics, and family medicine, lastly, 2 (4%) in ophthalmology. On the years of service as doctors in their institutions, 21 (42%) of the participants affirmed that they have put in 6-10 service years, 17 (34%) have put in 1-5 years, 7(14%) had put in 16-20 service years, and 10% had put in 11-15 years of service.

1.3.2 Section B: Concept of Healthcare Decision-making

This section presents the results of participants' attitudes on healthcare decision-making and shared decision-making as garnered from the three questionnaires in the contingency tables 2.

On who makes the medical decisions for minors, 258 (69.4%) of minors, 33 (86.8%) of parents and 50 (100%) of doctors which consist of a majority of the participants affirmed that parents decide for their minors. The responses indicated a paternalistic model of healthcare decision-making as it showed that parents were the primary decision-makers. The reason is that, in Nigeria, parents exercise rights over their children, who are their responsibility. So, they make healthcare decisions for their children, especially without a social welfare system to support treatments without parental support.

Out of the total participants, around 45.2% of minors, 63.2% of parents, and 84.0% of doctors are aware of the age at which a child can start making healthcare decisions under the law, while 54.8% of minors, 36.8% of parents, and 16% of doctors lack knowledge of the age of legal capacity. Overall, 70.2% of minors, 65.8% of parents, and 58.0% of doctors agreed that minors should have a say in their healthcare treatments only when they reach legal capacity. However, 29.3% of minors, 34.2% of parents, and 42.0% of doctors disagreed, while 0.5% of minors were uncertain. Most parents and doctors believe minors should be of legal age before participating in healthcare decisions due to their inability to make wise decisions. However, the majority of minors, parents, and doctors agree that explaining the nature of the ailment to the minor before any treatment is necessary. (See Table 2 below)

In the survey, most minors (56.2%), parents (86.2%), and doctors (100%) believed minors should be informed about the nature of their sickness. A smaller percentage believed minors should be informed about treatment procedures (32.2% of minors, 89.7% of parents, and 100% of doctors) and risks involved (35.2% of minors, 55.2% of parents, and 100% of doctors). Additionally, 39.5% of minors, 37.9% of parents, and 100% of doctors believed minors should be informed of treatment options

Table 2: Distribution of participants according to their opinions on healthcare decision-making.

Response	Minors n=372	Parents n=42	Doctors n=50
Frequency (%)			
Who decided on the minor's treatment?			
Parent	258 (69.4)	33 (86.8)	50 (100)
Guardian	49 (13.2)	02 (05.3)	
Doctors	53 (14.2)	03 (07.9)	
Myself	10 (02.7)		
Do you know the age under the law at which a child is free to make healthcare decisions?			
Yes	168 (45.2)	24 (63.2)	42 (84.0)
No	204 (54.8)	14 (36.8)	08 (16.0)
Do you believe minors only have a say in healthcare decisions when they have attained the age prescribed?			
Yes	261 (70.2)	25 (65.8)	29 (58.0)
No	109 (29.3)	13 (34.2)	21 (42.0)
Undecided	02 (0.5)		
If yes, why?			
Inability to understand and make a wise decision		18 (72)	11 (37.9)
Parental duty and guidance are important		4 (16)	07 (24.1)
It is the law		3 (12)	11 (37.9)
Total		25 (100)	29 (100)
Should the doctor explain to the minor the nature of the ailment before any treatment is given?			

Yes	347 (93.3%)	29 (76.3%)	46 (92.0%)
No	25 (6.7%)	9 (23.7%)	4 (8.0%)
If yes, please tick the information that minors should receive before healthcare personnel gives any treatment			
	Minors (n=347)	Parents (n=29)	Doctors (n=46)
Nature of the sickness	195 (56.2%)	25 (86.2%)	50 (100%)
Nature of the risk	122 (35.2%)	16 (55.2%)	50 (100%)
Treatment choice	137 (39.5%)	11(37.9%) _	50 (100%)
Treatment procedure	112 (32.2%)	26 (89.7%)	50 (100%)

1.3.3 Section C: Relational autonomy through shared decision-making

In the Table below, the participants were asked if it is necessary to seek both parents' and minors' opinions regarding treatment for the minor, about 350(94.1%) minors, 32 (89.4%) parents and 44 (88.05) doctors which constitute a majority of the participants believe that certain healthcare treatments require parents and minors opinion.

The participants were presented with questions requiring multiple responses. Hence, the participants who agreed that shared decision-making was necessary were presented with 22 treatments/examinations, ranging from minor to complicated or invasive to non-invasive treatments. Most of the responses were recorded in fourteen (14) treatment options. These options are presented from the highest to the lowest as follows: blood transfusion minors at 109 (31.1%), parents at 30 (93.8%) and doctors at 32 (72.7%,); blood donation (Minors at 126 (36%), parents at 17 (53.1%) and doctors at 18 (40.9%); suicidal tendencies (minors at 64 (18.3%), parents at 11 (34.4%) and doctors at 25 (56.8%); rape (Minors at 86 (24.6%), parents at 11 (34.4%) and doctors at 23 (52.3%); contraceptive advice (minors at 50 (14.3%), parents at 17 (53.1%) and doctors at 19 (43.1%); drug addictions (minors at 76 (21.7%), parents at 6 (18.8%) and doctors at 19 (43.1%). While others are sickle cell, depression, appendicitis, eye examination, sexually transmitted diseases, and HIV testing. Similarly, 148 (42.3%) of minors and 9 (28.1%) of parents for the treatment of malaria believe there is a need for shared decision-making as opposed to doctors who do not consider the need for shared decision-making in these treatments. (See Table 3 below).

The majority of participants believed that shared decision-making is necessary because of parental care and support, the benefit to the minor, the child's opinion, treatment cost, ailment severity, and the child's inability to understand treatment.

Table 3: Distribution of participants on their opinion about relational autonomy through shared decision-making for minors.

Responses	Minors	Parents	Doctors
	Frequency (%)		
Do you believe that certain health treatments/ examinations require parents' and minors' opinions?			
Yes	350 (94.1)	32 (89.4)	44 (88.0)
No	22 (05.9)	06 (10.6)	06 (12.0)
If yes, please tick from the treatment			
Malaria	148 (42.3%)	9 (28.1%)	
Contraceptive Advice	50 (14.3%)	17 (53.1%)	19 (43.2%)
Depression	63 (18%)	10 (31.3%)	12 (27.3%)
Blood donation	126 (36%)	17 (53.1%)	18 (40.9%)
Drug addiction	76 (21.7%)	6 (18.8%)	19 (43.2%)
Asthma	75 (21.4%)	6 (18.8%)	9 (20.5%)
Appendicitis	80 (22.9%)	13 (40.6%)	16 (36.4%)
Sexually transmitted diseases (STDs)	132 (37.7%)	14 (43.8%)	4 (9.1%)
Rape	86 (24.6%)	11 (34.4%)	23 (52.3%)
Suicidal tendencies	64 (18.3%)	11 (34.4%)	25 (56.8%)
Eye examination	73 (20.9%)	8 (25%)	11 (25%)
Blood transfusion	109 (31.1%)	30 (93.8%)	32 (72.7%)
Sickle cell disease	85 (24.3%)	5 (13.5%)	25 (56.8%)
HIV testing	81 (23.1%)	12 (37.5%)	
Mark from the options reason (s) why the(se) treatment (s) require a shared decision.			
Parents must pay for the treatments	135 (38.6%)	9 (23.7%)	15 (34.1%)
It is serious	76 (21.7%)	14 (36.8%)	14 (31.8%)
Such involvement will benefit the minor	33 (9.4%)	16 (42.1%)	24 (54.5%)
The need for parental support	186 (53.1%)	24 (63.2%)	35 (79.5%)
Lack of an understanding of the procedures	69 (19.7%)	5 (13.2%)	15 (34.1%)
The minor's opinion is essential.	40 (11.4%)	20 (52.6%)	18 (40.9%)

Source: Fieldwork 2021

3.4 Section D: The benefits, barriers and viable solution to Minors' participation in shared healthcare decisions.

This section presents the results of the study as it relates to participants' opinions on the benefits of relational autonomy through shared decision-making in Benin City, the barriers to its implementation and the viable solutions to empower minors participation using the model. See Figures 1-3 below.

Figure 1. Distribution table of participants' opinions on the benefits of minors' participation

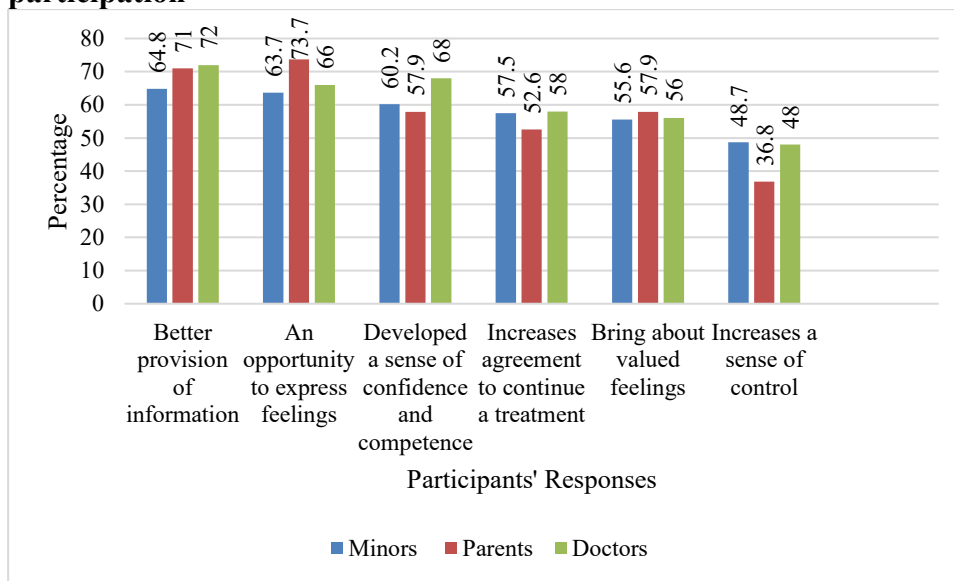
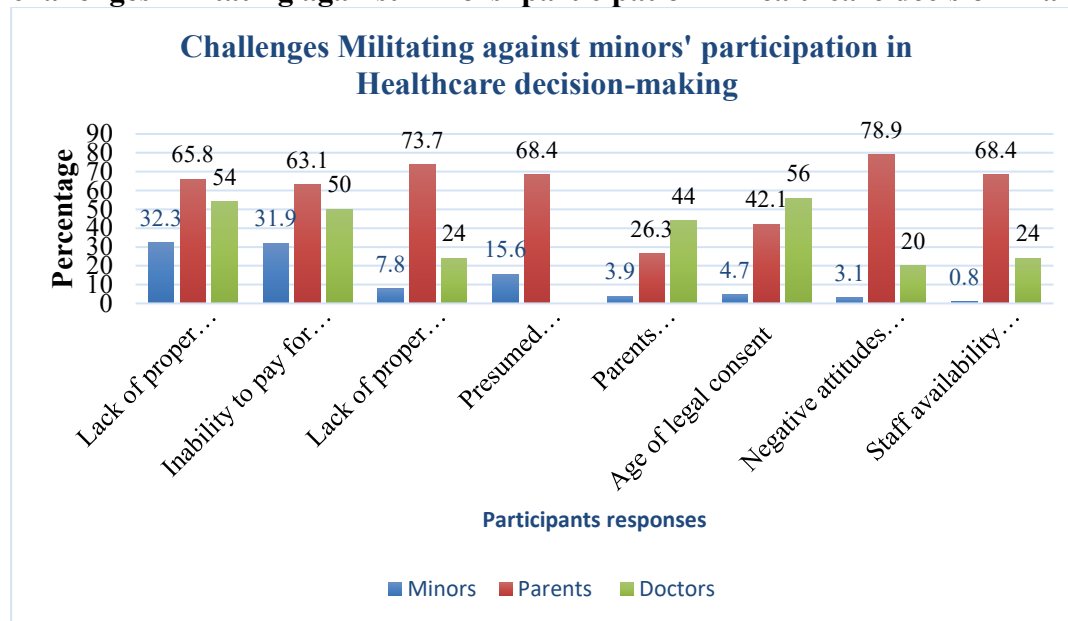


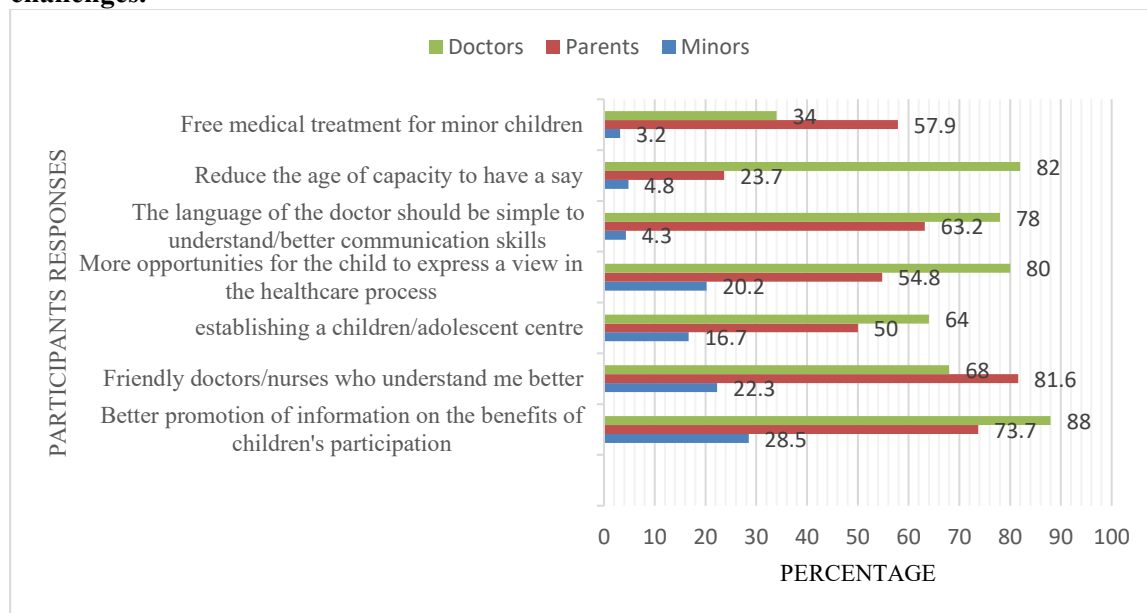
Figure 1 above, reveals that most of the participants believed that better provision of information and an opportunity to express feelings stand out as the highest benefits minors may derive when involved in healthcare decision-making

Figure 2: Distribution of Participants according to their opinion on the major challenges militating against minors' participation in healthcare decision-making.



According to Figure 2, lack of proper information about treatment was a significant barrier for 32.3% of minors, 65.8% of parents, and 54% of doctors. The inability to pay for medical treatment was a challenge for 31.9% of minors, 63.15% of parents, and 50% of doctors. About 15.6% of minors and 68.4% of parents believed minors' inability to make wise decisions was a major barrier. Other challenges included language barriers, lack of proper communication, parents' overprotectiveness, age of consent, and negative attitudes toward healthcare personnel. (see Figure 2).

Figure 3: Distribution of participants' opinions on the possible solutions in mitigating the challenges.



According to Figure 3, minors, parents, and doctors provided multiple responses on how to mitigate barriers to minors' healthcare participation. Promoting information on minors' healthcare participation was seen as the most effective solution by 28.5% of minors, 73.7% of parents, and 88% of doctors. Other solutions suggested by participants include friendly doctors understanding the minor's health concerns, establishing an adolescent centre, and creating more opportunities for minors to express themselves.

The results show that parents significantly believed that friendlier doctors and nurses would better mitigate these challenges (81.6%), while on the contrary, doctors believed in better promotion of information (88%).

1.4 Discussion of findings

The findings discussed hereunder are based on participants' opinions on the four thematic areas earlier presented in the results. Hence the findings of the study showed that despite having a paternalistic model for healthcare decision-making in the study area, (see Table 2), which reflects the social construction of childhood as a fragile and precarious state and the construction of maturity and agency from the perspectives of Locke and other scholars to justify paternalism. It further explains the legal limitations conferred on

minors under the National Health Act 2014 and the posture of the Child Rights Act 2003, which corroborates the views of Mills, who argued that children must get to the age of legal capacity to be able to make decisions and in the absence of such, parental and institutional guidance are necessary for the protection of the child's wellbeing. This belief explains why children, despite not knowing the age of legal capacity to make healthcare decisions, still insist on parents making the medical decisions on their behalf. Another reason is the economic dependence of the minors on their parents to pay the medical bills when they visit the hospital. This reason further reinforces the argument canvassed by Montgomery⁸⁹⁶ and Archard⁸⁹⁷ justifying paternalism on children.

A major strength of the study lies in examining the relevance of shared decision-making between minors and parents to enhance decision-making capacities for minors. Based on the existing paternalistic decision-making model, the study showed from participants' responses that shared decision-making will benefit the child if the parents support the child's opinion in invasive or complex medical procedures or treatments. Supporting the child in making healthcare decisions is at the heart of the relational model for medical decisions, which this study believes will enhance the paternalist model. The relational model combines the paternalistic protective model and autonomy model through a supportive environment as the child's capacities keep evolving in cases of complex medical procedures, which makes the model an adequate fit for Nigerian society.

The findings showed the relevance of parental support, which is typical in most African societies. Also, the participants identified the need to respect the child's opinion, showing a gradual shift from paternalism in specific healthcare treatments. Interestingly, parents and doctors recognised the need to consider the child's belief in certain healthcare decisions because such involvement will benefit the child. This signifies a gradual shift from paternalism to a guided support process for the child. In this process, minors are nurtured to make decisions based on their evolving capacities, and most of the vulnerabilities that minors may encounter will receive adequate support from their parents either in care or due to financial support. The opinion of the minors is expressed not in terms of 'consent' but 'assent'.

Moreover, the findings of this study reinforced the views of the CRC and the new sociology of childhood, which focuses on children as active social agents in their present lives and disagrees with the view of childhood as a phase in reaching

⁸⁹⁶ Jonathan Montgomery, 'Children as Property' *Modern Law Review* [1988] 51 323; Marc Stauch and Kay White, *Text, Cases and Materials on Medical Law and Ethics* (6th ed, Routledge, 2018) 26- 27.

⁸⁹⁷ David Archard, *Children, Rights and Childhood* (3rd edn, Routledge, 2015) 31.

adulthood.⁸⁹⁸ These constructions are also structured under the CRC, which recognises the need for parental guidance based on the child's evolving capacities and the need to have a say in matters that affect the child.⁸⁹⁹ The findings from the study are in tandem with the views of scholars such as Alanen and others who placed reliance on the need for relational autonomy in healthcare decisions. This approach is needed to support the child's evolving capacities.⁹⁰⁰ Based on the peculiarities of the Nigerian communalistic system, this approach will be apt to enhance the decision-making abilities of minors in cases of this nature.

Another strength of this study is examining the attitude of minors, parents, and healthcare professionals on whether mature children have a participation right in healthcare decision-making and, if so, to what extent. Findings from the study established that most participants affirmed that minors from ages 13-17 years (mature minors) have a right to express themselves in the healthcare decision process. (For further illustration, see Figure 12).

From the discussion of findings above, there is a strong indication that information is fundamental to a minor's participation in the healthcare decision process. Consequently, the majority of the participants were in agreement that a child should receive information before the commencement of treatment. (See Table 2).

Concerning the content of the information, every participant agreed that minors should be aware of the types of treatments available, along with their associated risks, choices, and procedures. Interestingly, parents questioned whether the minor should be told about treatment options and whether they should be made aware of the risks. In addition, parents might not feel comfortable with the minor knowing the risk. The

⁸⁹⁸ *ibid.*

⁸⁹⁹ See arts. 5, 18 and 12 of the CRC.

⁹⁰⁰ Leena Alanen, 'Generational Order' in Jens Qvortrup, William A. Corsaro and Michael-Sebastian Honig (eds) *Palgrave Handbook of Childhood Studies* (Palgrave Macmillan 2009) 161 at 170; Jens Qvortrup 'Childhood as a Structural Form' in Jens Qvortrup, (ed.) *The Palgrave Handbook of Childhood Studies* (Macmillan 2009) 25; Pamela Laufer-Ukeles, 'The Relational Rights of Children' *Connecticut Law Review* [2016] 48 (3) 741; Wayne Vaught, 'Autonomy and the Rights of Minors, in David Weisstub and Guillermo Diaz. Pintos (eds), *Autonomy and Human Rights in Healthcare: An International Perspective* (Springer, 2008) 11; Roy Gilbar, and Charles Foster, 'It's Arrived! Relational Autonomy Comes to Court: ABC v. St George's Healthcare NHS Trust [2017] EWCA 336' *Medical Law Review* [2017] 26 (1) 25-133; R., Gillon, 'Ethics Needs Principles- Four Can Encompass the Rest-and Respect for Autonomy Should Be 'First Among Equals'', *Journal of Medical Ethics* [2003] 29 310-312; John Tobin, *The Right to Health in International Law*, (New York: Oxford University Press, 2012) 136; Pamela Laufer-Ukeles, 'The Relational Rights of Children' *Connecticut Law Review* [2016] 43 (3) 741.

paternalistic model, which primarily positions parents as decision-makers for their children based on parental obligations, is the foundation for parents' reluctance to allow minors to make these choices.

The findings from this study reinforce the relevance of information as fundamental to a minor's participation in health care decisions. The relevance of information supports the findings from previous research, which have highlighted the need for information as a right to give informed consent in healthcare decisions.⁹⁰¹ Furthermore, the CRC has reiterated the need for information as a fulcrum to minor participation.⁹⁰² The findings from this study now provide data that will advance a legal framework for minors' participation in the study area.

On the benefits of participation, all the participants unanimously agreed that benefits will accrue to the minor, such as the participation will bring better provision of information, an opportunity to express feelings and aid the minor in developing confidence and competence. (See figure 1). The findings indicate that doctors and minors strongly believed that all the benefits would impact the minor if the right atmosphere is created. Previous medical research has also supported these benefits as accruing to the child.⁹⁰³

Lastly, on the barriers and ways to mitigate these barriers, responses of participants established that they entirely agree that the inability to pay for treatments, inability to make wise decisions and lack of proper information and communication are mostly the barriers that affect minors' participation. On the contrary, they tend to share divergent opinions on the other barriers (see Figure 2). While parents perceived that a lack of

⁹⁰¹ Michael Freeman, *A Mana Carter for Children* (Cambridge, 2020) 68-69; Aviva L. Katz, Sally A. Webb and Committee on Bioethics, 'Informed Consent in Decision-Making in Pediatric Practice', *America Academy of Pediatrics Technical Report* (2016).

⁹⁰² See art.13 which supports art. 12 of the CRC.

⁹⁰³ I. Runeson, I. Hallstrom, G. Elander and G. Hermeren, 'Children's Participation in the Decision-Making Process during Hospitalization: An Observational Study' *Nursing Ethics*, [2002] 9 583–598; P. Boylan, 'Children's Voices Project: Feedback from Children and Young People about Their Experience and Expectations of Healthcare'. *Commission for Health Improvement* [2004]1–37; J Coad, et al. 'Evaluating the Impact of Involving Young People in Children's Services in an Acute Hospital Trust' *Journal of Clinical Nursing* [2008] 173115–3122. 'Evaluating the Impact of Involving Young People in Children's Services in an Acute Hospital Trust' *Journal of Clinical Nursing* [2008] 173115–3122; Priscilla Alderson and Mary Goodwin, 'Contradictions within Concepts of Children's Competence' *International Journal of Children's Rights* [1993]1 303- 313; Priscilla Alderson, Katy Sutcliffe and Katherine Curtis, 'Children's competence to consent to medical treatment', *Hastings Centre Report* [2006] 36 (6) 25-34.

institutional support determines the barriers to minors' participation in healthcare, doctors viewed it from a legal, social, and cultural perspective.

In addressing the barriers, findings from the study showed that all the participants believed that better promotion of information on the benefits of minors' participation in healthcare decisions, friendly doctors and nurses, more opportunities for a minor to express a view, respect for the dignity and privacy of the minors, and child appropriate language use were the perceived solutions to mitigating these barriers. If implemented in the study area, these solutions promote a minor's participation in healthcare decision-making, invariably creating a child-centred environment. Interestingly, the study shows that minors' and parents' responses were negative for a reduced age of capacity and respect for the child's privacy. Hence, there is a need for proper sensitisation and enlightenment of parents and minors because of the paternalistic decision-making model, which has created deep-rooted barriers for minors.

1.5 Conclusion

The findings from this study based on participants' perceptions and attitudes established that in clinical practice, minors could be empowered to participate in healthcare decision-making through shared decision-making based on the Nigerian society which is largely paternalistic. Based on the perception of minors, parents, and doctors, the study further accentuates the evolving capacities of minors based on age as a model for participation in healthcare decision-making. Responses from the consultants established that participation in healthcare for minors has benefits, promoting better health outcomes and access to healthcare services for these minors. Since this exception is not provided for under the law, there is a need for legislative amendment of the Child Rights Act 2003 and National Health Act 2014, public sensitisation and awareness on the rights of minors to participate in healthcare decisions, child-centred policies that prioritise minors' healthcare should be established, with special emphasis on providing age-appropriate information and opportunities for minors to express themselves.