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Original Article

Exploring Parental Decision-Making in Paediatric Clinical Trials: Evidence from Malaysia

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Abstract The study investigates factors influencing parental decision-making in paediatric clinical trials through in-depth interviews with parents at two hospitals in Northern Malaysia. Key findings reveal that parents' previous experiences with clinical care significantly impact their willingness to participate, with trust in healthcare providers and effective communication being essential. Parents are more inclined to enroll when they perceive their child's condition as serious and believe the trial offers better treatment options. Economic considerations also play a crucial role, as many parents are drawn to the cost-effective care provided during trials, alleviating financial burdens. The study emphasizes the importance of enhancing communication skills among healthcare professionals and building trust to increase parental participation in clinical research. Ultimately, a collaborative approach between healthcare providers and families is crucial to strengthen paediatric clinical trials, ensuring children benefit from advancements in medical treatments and receive safe, effective care tailored to their needs.

Key words Malaysia; Paediatric clinical trials; Parental decision-making; Qualitative research

Introduction

Conduction of the clinical trial in children is crucial to ensure the safety and efficacy of the medicine available for the children.[1] The conduction of the clinical trials in children are crucial as they focus their attention to the unique physiological and developmental characteristic of the children, ensuring that new medications are safe and effective for this population. Previously, some medicines developed based on the adult's data, which may lead to inappropriate dosing subsequently increase the risks to the children. Therefore, by conducting these clinical trials, it is necessary to improve the treatments options and healthcare decisions, then enhance the well-being of the children.[1,2] The parents play an important role as a surrogate decision-maker, by provide both emotional support and guidance to the children in making decision to participate in the clinical trial.[3] Moreover, both parents and children would collaborate in decision-making to participate in the clinical trial which they shared the information regarding the clinical trial and asking their child's opinion in decision-making process.[3]

Previous studies found that trust in the clinician and the medical care system has influenced the parental decision-making process to participate in the clinical trial.[4,5] Furthermore, the parents also weigh the risk and additional procedure that could harm their children in participating in the clinical trial. Moreover, parents also willing to participate in the clinical trial because they are motivated by the potential benefit to the children and sense of

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altruism, which they could contribute the benefit of the clinical trials result to other children in future. Additionally, the appropriate timing being approach by the clinical trial team and the access and clarity of the information provided to the parents could enhance the participation of the parents in the clinical trial.[5,6]

In Malaysia, it was reported that the level of paediatric clinical trials across various therapeutic area, was moderate per clinical trial site. This report highlights almost 64% of the contacted clinical sites in the country expressed interest in paediatric clinical trials conduction, which almost 71% of these sites had prior experience in conducting similar clinical trials. In conducting paediatric clinical trials in the country faces several challenges, including the complexity of obtaining consent and assent, the involvement of additional procedures especially the invasive procedure and the involvement of placebo-controlled study design. Furthermore, issues related to patient follow-up and high withdrawal rate can hinder trial integrity. Despite the challenges facing, the notable interest and capability in conducting paediatric clinical trials in this county appears to be promising.[7]

This study aims to explore the factors that influencing the decision-making process among the participated parents in the paediatric clinical trials, based on their perspectives. To the best of our knowledge, this issues seldom been addressed in this country and information available are limited. Further exploration is needed to effectively tackle this issue hence could improve children's participation in future clinical trials.

Material and Methods

Study Design

The study employed qualitative methods, utilising face-to-face semi-structured interviews for data collection. This approach was chosen to gain an in-depth understanding of parents' comprehension, experiences, and perspectives regarding clinical trials involving their children. The research was conducted at two hospitals: Hospital Sultanah Bahiyah in Alor Setar, Kedah, and Hospital Tuanku Fauziah in Kangar, Perlis. These locations were selected due to their involvement in clinical trials and their status as government-funded specialty hospitals.

Participants

The participants included parents of children enrolled in clinical trials. The selection criteria focused on parents who had been involved in the decision-making process for more than three months. A purposive sampling method was used to select participants based on specific inclusion and exclusion criteria; including able to communicate in Malay/English language and non-citizen will be excluded in this study. The total sample size was 12, which the recruitment was until saturation of data was reached.[8] The demographic characteristics of the participants were summarised in Table 1. The study initially included a pilot study with two participants, who were not included in the final analysis. The pilot study was conducted to evaluate and refine the semi-structured interview guide by testing its clarity and relevance through interviews with two participants. It also provided preliminary insights into parents' perspectives on clinical trials, helping to ensure the effectiveness and ethical integrity of the main study's data collection process.

All participants are engaged in a trial on Diabetes Mellitus medication, which includes a control group receiving a placebo. This clinical trial is Phase III research. The potential side effects included mild ketonemia that might be detected especially with fasting and hypoglycaemic event.

Data Collection and Analysis

Data was collected through semi-structured interviews, which were recorded using a digital voice recorder. The interviews were conducted in Malay to ensure comfort and ease of communication for both the researcher and the participants. Thematic analysis was employed to analyse the data. This involved several steps: organising and preparing data, transcribing interviews, familiarising with the data, coding, and developing themes. The analysis aimed to identify key themes and sub-themes related to parental decision-making in clinical trials.

Result

The factor that influenced the parental decision-making to participate in the clinical trials. The themes were summarised in Figure 1.

Theme 1: Trust and Initial Engagement

The presence of a trust relationship between a doctor and their patient enhances the possibility of parents responding positively when approached to participate in clinical research. Most parents shared the belief by saying that:

Table 1 Summary of socio-demographic characteristics of the participants

Parent code	Age (years)	Gender	Level of education	Occupation	Family income (RM)	Marital status	Age of Child (years)	Child's gender	Clinical trial
#P1	39	Female	Secondary	Hawker	1000	Married	13	Girl	Diabetes Mellitus
#P2	60	Male	Primary	Self-employed	2000	Widower	15	Girl	Diabetes Mellitus
#P3	61	Male	Secondary	Self-employed	1500	Married	17	Girl	Diabetes Mellitus
#P4	56	Female	Secondary	Housewife	1500	Married	14	Girl	Diabetes Mellitus
#P5	39	Female	Secondary	Housewife	1000	Married	15	Boy	Diabetes Mellitus
#P6	48	Female	Secondary	Housewife	1000	Married	13	Girl	Diabetes Mellitus
#P7	45	Female	Secondary	Medical Assistant	4500	Married	12	Boy	Diabetes Mellitus
#P8	55	Female	Secondary	Teacher	3000	Married	11	Girl	Diabetes Mellitus
#P9	63	Male	Secondary	Hawker	1000	Widower	15	Girl	Diabetes Mellitus
#P10	55	Female	Secondary	Housewife	1500	Married	10	Girl	Diabetes Mellitus
#P11	59	Female	Tertiary	Retired teacher	4500	Married	17	Boy	Diabetes Mellitus
#P12	51	Female	Tertiary	Clerk	4000	Married	11	Boy	Diabetes Mellitus

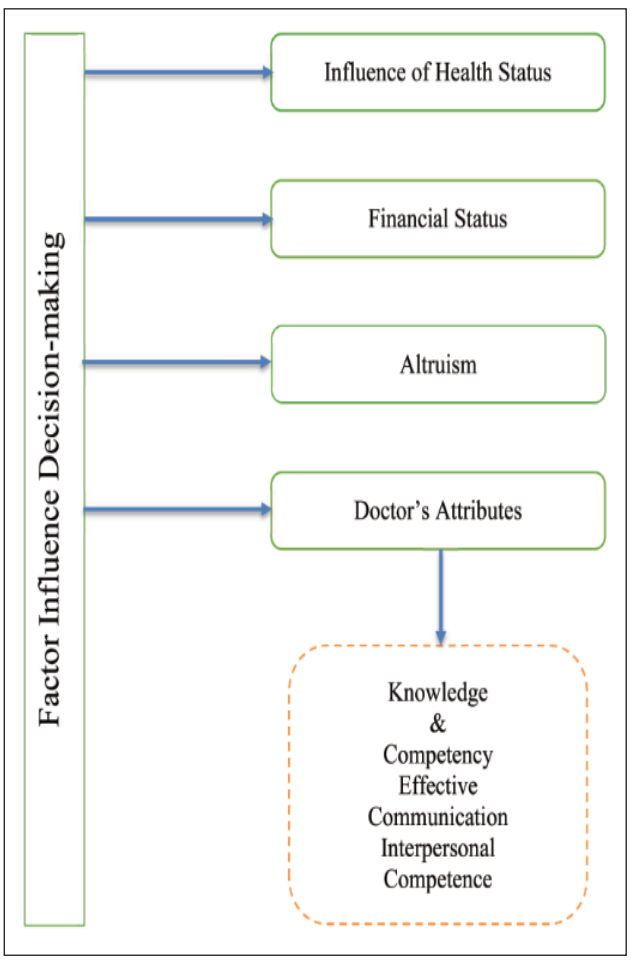

Figure 1 Parentals' Decision-making Process for Children Participation in the Clinical Trial.

"[…] so I've been engaging with the doctor for years… I trusted the doctor and I've no issue in trusting the information (regards the clinical trial) that I got from the doctor at the health clinic where my daughter routinely went [...]" (P1)

"I trusted the doctor who treating my daughter... I have known this doctor for a long time… so I am more open to the suggestion (to participate) [...]" (P3)

"[…] my son has been follow-up under this doctor for a year… I knew her and I trusted that she would suggest the best option […]" (P12)

Theme 2: Influence of Health Status

Majority of the parents stated that they would not typically be willing their children to participate in clinical research studies if they were not confronted with the actuality and difficulties of dealing with poor health of the children, as the children were in the state of poorly control diabetes despite of medication that has been started. The parents claimed that:

"My daughter's Diabetic was quite bad, and this scared me. So, taking part in this study is my way in finding new treatment alternative for her […]" (P4)

"[…] when my daughter first been diagnosed with Diabetes, I felt so worried as she was too young… her blood sugar is not well control after taking the medication, so I did agree to the doctor suggestion to let my daughter participate in the trial as I wanted the best treatment for her […]" (P6)

"My son has poorly Diabetes control, yes…he already on medication…if they have other options to help reduce his blood sugar…certainly I'll agree to that […]" (P12)

Theme 3: Altruism

Most parents reported that a considerable to enroll in research with the altruistic goal of benefiting others who are unable to participate for some reason, whether in the immediate future or future generations. As mentioned by the parents,

"[…] the doctor told me that, if this study success, in future, everyone can get the same medicine. For me this is good as you can help others, because not everyone got the opportunity to involve in this study." (P4)

"[…] for me if I can help him by allow him to be enrolled in this clinical trial, concurrently I also can help other children with the same condition in having good health and cure from the disease." (P10)

"[…] this (clinical trial) is good, you can help future generations in getting new medicine […]" (P11)

Theme 4: Financial Status

The parents seize this opportunity to take full advantage of the offer, as they are provided with free medical treatment, which in this current economy burden, this opportunity would much be appreciated. As parents stated that,

"With current bad economy status, it is worth to grab this opportunity. They give us medication, check-up, and consultation free of charge. If similar medication sells at the outside pharmacy, it would be expensive, we can't afford to buy them [...]" (P1)

"They gave some incentive (money) for every study visit…for me that was very good…this can also motivate the child to adhere to the study procedure as they felt appreciated to continue in this study […]" (P2)

"If we wanted to see a specialist, usually we need to pay extra... but if we follow this study, we can be seen by the specialist for free [...]" (P5)

Theme 5: Doctor's Attributes

The professional characteristics of the doctors in conducting the consent consultation constitute the following sub-themes that emerged as having an impact on the decision-making for participate in clinical research and impact the retention of clinical research participants till the end of the trial.

Sub-theme 1: Knowledge and Competency

The medical professionals involved in the clinical trial team have extensive experience in conducting research, as acknowledged by most parents. Parents also confident that the clinical trial doctor is an expert in the field. As stated by the parents,

"She (clinical trial doctor) is a specialist, we can know a lot (knowledge of disease), so, she is competent in conducting the clinical trial […]" (P5)

"[…] the doctor is a specialist, an expert in this field (clinical trial), so I'm confident the clinical trial conducted by her team." (P9)

"[…] the confident and trust because the doctors is a specialist in the area and must be competent in running the clinical trial […]" (P11)

Sub-theme 2: Effective Communication

The parents expressed satisfaction when addressed by the doctors in a clear. They appreciated the use of national language and the avoidance of technical jargon. They mention that,

"[…] I'm understand the doctor's explanation, used simple language (Malay language), that is very good […]" (P6)

"[…] the information given by the doctor's was easy to understand, in Malay language, it was good enough to give me confidence […]" (P7)

"I understand... they explained in Malay, and it was easy to understand, this medicine is still in trial […]" (P8)

Sub-theme 3: Interpersonal Competence

The presence of interpersonal competence was crucial in enhance the parents' comfort and ease. Parents demonstrated a higher likelihood to interact with research team when they saw they are amiable and easy to be approached. As the parents mention that,

"[…] doctor and study coordinator are very nice and helpful […]" (P4)

"[…] I can see that the study team are very professional, and they are very detail when treating my child… I am very satisfied with their great services." (P6)

"The study team is very good and so tolerable; we can anytime call the doctor for any inquiries, and they are willing to help us at any time […]" (P9)

Discussion

The trust in the medical practitioner and the presence of prior relationships have been found to considerably impact the decision-making process. This study found that, a clinical trial recommended by reputable medical professionals increases the likelihood of the parents to give consent. Being invited to participate in a clinical trial by a trusted doctors was seen as a great opportunity for the parents, as not everyone who is regularly seen at the clinic would receive such an invitation. Parents willingly accepted the invitation to participate, as they saw it as a recommendation from their doctors as they would provide the most effective treatment choice for their patients and would not choose an alternative that could harm the patients. Moreover, this finding was consistent with the previous research found that the trust is of utmost importance, all parents polled expressed a strong preference to get information about a clinical trial from their child's doctors, rather than from an unfamiliar doctor.[9]

Additionally, in the past, the doctor-patient relationship encompasses the concepts of paternalism and autonomy. Paternalism has been a dominant model for more than 25 centuries, which doctors utilise their experience and knowledge to prioritise the patient's best interests as a moral obligation. The paternalistic approach assumes that patients and doctors have the same goals, that doctors are capable of accurately evaluating patient choices, and with the necessary expertise of the doctors, they are able to select the most suitable course of action.[10] On the other hand, the notion of autonomy upholds the dignity of individuals and advocates for the patient's right to have their will respected. It can be defined as the process of "self-determination" where one considers the opinions of an expert and their own personal circumstances. However, in modern times, the interaction between doctors and patients has shifted towards a more participatory approach, with a focus on the patient's needs and preferences. This means that patients are now expected to be well-informed about their health condition and involved in all aspects of their healthcare journey. The patient is taking a more proactive role in making decisions regarding their own health.[11] However, this study found that the parents tend to rely on the opinion of the healthcare professionals, rather than exercising their autonomy, because they showed a fair expectation of physicians possess greater knowledge. Moreover, the parents seem to participate in the clinical trial mostly due to their trust in the clinician-patient engagement, that has present initially, rather than making a thoughtful decision based on their own perspective. As a result, this study shows that paternalism is dominant in making decision-making among the parents. This finding consistent with previous study that the vulnerability of the participants was exacerbated by the presence of a trusted doctor rather than a carefully considered and well-informed choice, which the invitations to participate in clinical trial were presented to potential participants by a trustworthy medical professional.[12]

The health status of the children greatly influenced the parental decision-making process. Furthermore, the participation of the potential patients in the clinical trial was motivated by hope to cure from a serious condition of the illness.[13,14] This study found that the parents experiencing concern and challenges in managing the children's poorly controlled diabetes. Therefore, this condition has influenced the decision to participate in the clinical trial after receiving the invitation from the doctor. Moreover, previous study showed that, parents are more likely to participate in the clinical trial if the children's medical condition was serious.[6] Furthermore, parents believe that the participation in the clinical trial is an alternative way or an option to access the better treatment for their children. In addition, previous study has found that parents would consider to an alternative treatment for their children's serious health condition, and parents also considered to participating in the clinical trial due to their optimism for a potential treatment.[15]

Participating in clinical research was regarded to contribute to scientific advancement and benefit others, known as altruism. Patient preferences refer to the decisions made by individuals regarding their health and medical care, based on their personal beliefs, values, and experiences.[16] One of the ideal individual preferences to involve in the clinical trial is altruism, they should be motivated to engage in participation primarily to make an altruistic contribution towards advancing knowledge, which could potentially benefit future patients.[13] In this study, the parents expressed their appreciation to the research team for being given the opportunity to participate in this clinical trial, because they saw this as a valuable chance to assist other children who, for various reasons, were unable to be enrolled in the clinical trial. Moreover, they believe that the outcome of the clinical trial would benefit others by providing a cure for the illness. This altruistic behaviour has also been shown in prior research conducted among cancer patients participating in clinical trials. The participants with early-stage cancer in the study expressed their main motivations as the hope for a cure and

the desire to assist future patients. On the other hand, individuals with advanced-stage or unresectable malignancies were more inclined to provide altruistic reasons, such as their desire to help others, including the research doctors.[13] Thus, altruism is one of the factors influence parents' decision to participate in clinical trials as it has been demonstrated that altruism is an ideal personal preference for participating in these trials, indicating that parents not only desire their children to be cured but also have the intention to help other children facing similar conditions.

The economic status of the parents would influence the decision to participate in the clinical trial. This is due to the escalating cost of routine medical care that the parents already cover including the routine care cost, investigational cost and non-medical cost (transportation, meals, accommodation, etc.).[17,18] However, in clinical trial, all the medical treatment and procedure were offered for free during the children enrolment. This study found that the parents were attracted to the free medication including other medical care offered to their children during the enrolment period in the clinical trial, regardless of their economy status. Additionally, previous study has shown that the access of free medication is important in children's clinical trial participation, especially in lower family income,[19] while another study also reported that one of the reason parents participate in the clinical trial because the provided free medical supplies and equipment during the clinical trial.[20] Therefore, by addressing and eliminating the financial issues, not only enhance the enrolment in clinical trial but generally improve the research findings by the greater involvement in clinical trials.

The parents' overall encounters with clinical care have influenced their willingness to embrace additional healthcare services, such as clinical research. This study found that the parents decided to participate in clinical trial was influenced by their belief in the clinical team that had provided excellent care for their children, with extensive knowledge and competency. Moreover, it showed that a favourable encounter with clinical care previously would foster confidence and sway potential parents to embrace research opportunities, while unfavourable conduct of clinical care from clinical staff before, would discourage parents from further engagement in healthcare services, including clinical trial.[21] This study indicates that the knowledge and competency of the research team, particularly the doctors, can influence the likelihood of parents giving consent for their children to participate in the clinical trial. This finding corresponds to the results of an earlier study, which indicate that improving the competency of research professionals is necessary to increase the likelihood of participation in clinical trials.[21]

Effective communication skills are crucial in the process of obtaining informed consent for involvement in clinical trial.[22] Aligned with the principle of informed consent, consultation refers to the doctors capacity to communicate with patients using a language that is comprehensible and easily absorbed by the patients.[23] This study found that the parents value the good communication skills showed by the doctors during the informed consent process, that they understand the information delivered to them using the national language, which is Malay language. Thus, the effective and transparent communication of the doctors during the consultation phase of informed consent improves their overall comprehension of the clinical trial involving their children. This finding aligns with prior research that discovered, most patients demonstrate respect and appreciation for the clinician's superior expertise, they tend to respond positively to any invitation or offer as a demonstration of kindness and respect.[24] Additionally, other study suggests providing communication training, developing more interactive informational materials, utilising digital alternatives, enhancing overall understanding of research participation, and promoting patient and public involvement to enhance the participation in the clinical trial.[25] Hence, it is imperative to ensure that the doctors have a comprehensive comprehension of the trial information and can proficiently engage with potential participants, thereby increasing the probability of their participation.

Moreover, the parents highly appreciated the interpersonal competence of the clinical trial team, such as their kind attitude and thoughtful approach towards the parents. This could potentially impact the parents' willingness to grant consent for the participation of their children in the clinical trial. The presence of readily accessible doctors who can address participants' inquiries offers additional advantages for increasing participation. Additionally, previous studies have shown that having empathetic and supportive research personnel can alleviate the burden on patients and enhance their willingness to participate.[26] Therefore, the research team's willingness and ongoing support to the parents is a valuable opportunity to increase their participation in the completion of the clinical trial.

Conclusion

In conclusion, the factors that influence parental decision-making are trust in medical professionals, effective communication, and prior relationships with healthcare providers, which significantly influence parents' willingness to consent to their children's participation in clinical trials. Additionally, parents are motivated by the potential benefits for their children and the desire to contribute to future advancements in treatment. The study emphasized the importance of addressing parents' concerns about risks and ensuring they have adequate information to make informed decisions. Overall, promoting a collaborative relationship between parents and healthcare providers is essential for enhancing parental engagement in clinical trials.

Ethical Considerations

This study was approved by the Medical and Ethics Committee, Ministry of Health Malaysia, NMRR ID-22-02970-KA2.

Recommendations

Future studies should focus on identifying specific barriers that prevent parents from enrolling their children in clinical trials, as well as conducting comparative research between trial participants and those receiving standard care to assess differences in satisfaction and outcomes. Additionally, including diverse populations in research will enhance understanding of how demographic and cultural factors influence parental decisions regarding clinical trial participation.

Conflict of Interest

All authors declare no conflict of interest.

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