

ORIGINAL RESEARCH

Perceptions of caregivers and healthcare providers regarding vaccinations for children with immune mediated inflammatory disorders (IMIDs) in Nairobi, Kenya

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Abstract

Background: Children with immune mediated inflammatory disorders (IMIDs) are at an increased risk of various types of vaccine preventable diseases. Appropriate immunization practices are therefore key for survival, and for improving the treatment outcomes in these children. This study explored the perceptions of caregivers and healthcare workers regarding vaccination for children with IMIDs at Kenyatta national hospital and Getrude's children hospital, in Nairobi Kenya.

Methods: This was a mixed-methods study involving interviewer administered questionnaires for caregivers, self-administered questionnaires for health workers, and focus group discussions for caregivers of children suffering from IMIDs and attending the rheumatology clinics at the Kenyatta National Hospital and Gertrude's Children's Hospital. The study included 103 primary caregivers of children aged 0-18 years with IMIDs and 76 healthcare workers.

Results: Most of the caregivers (80%) were female; and two thirds (66%) had attained secondary education or higher. Most (90.6%) caregivers believed that vaccines are safe, 88.2% that vaccines are effective, 97.1% had full trust in vaccines and would readily accept their children to be vaccinated. Further, the caregivers (92.5%) knew that their children could benefit from additional vaccines (other than the routine childhood EPI listed vaccines) and would support additional vaccines for their children if recommended by a doctor. However, only 10.6% (10/103) of caregivers reported that their children had already received at least one of the additional vaccines. Some caregivers (9.4%) expressed fears and misgivings about the additional vaccines for their children. These misgivings include the risk of adverse events following immunization that the children were too young for additional vaccines, or that the child was unwell at the time. The health workers supported the need for additional vaccines for children with IMIDs and vaccine education for caregivers and health workers.

Conclusion: Most caregivers and healthcare workers of children with IMIDs accepted and supported additional vaccines, over and above those administered in the routine EPI programme, for children with IMIDs. The biggest promoter of vaccine acceptance and uptake was recommendation of vaccination by health workers while potential barriers included vaccine safety concerns, inadequate vaccine knowledge and concerns of vaccine cost and accessibility.

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Introduction

Patients with immune mediated inflammatory disorders (IMIDs) are at an increased risk of infections, partly due to altered cytokine signatures, dysregulated immunity and frequent use of immunosuppressive therapies (1). Available evidence suggests that patients with IMIDs are at a higher risk of herpes zoster, human

papilloma virus and respiratory tract infections (2-5). These patients are hypothetically more likely to visit health facilities more frequently than the general population, further increasing their risk of exposure to infectious pathogens. Adequate measures aimed at reducing the risk of infections such as adequate immunization are therefore desirable.

Available evidence supports immunization of patients with IMIDs using the same schedule as that used for other children with precautions on the use of live vaccines (4, 6). Prior concerns over failure to develop sufficient protective antibody concentrations and increased risk of developing persistent autoimmune disorders related with administration of certain vaccines have not been proven (4, 6, 7). As a result, vaccination against common vaccine preventable infections is recommended for patients with IMIDs.

In Kenya, the vaccines offered in the routine national immunization programme include polio, BCG, DPThepatitis B-Hib, pneumococcal conjugate, rotavirus, measles, rubella and HPV (10-year-old girls only). Herpes-zoster and influenza vaccines are not routinely offered. Despite availability of these vaccines, the fully immunized child (FIC) rate is 55 % for children aged 12–23 months and 38% for those aged 24–35 months (6). This means that many children with IMIDs are likely to have missed out on immunization with these vaccines. The current best practice recommends booster immunization against diphtheria and pertussis at about 5-7 years and 11-12 years of age for better protection due to concerns of waning immunity(8). The World Health Organization (WHO) and the Advisory Committee on Immunization Practices (ACIP) also recommend additional pneumococcal vaccine doses for children living with HIV, premature children, children with immune suppressive conditions, and post-transplantation (8). Vaccination against *Neisseria meningitidis* and *Haemophilus influenzae* type b bacteria has now been included under this recommendation(8). Because patients with IMIDs are particularly at risk for severe respiratory infections, they are likely to benefit greatly from provision of these vaccines.

The current Kenya national vaccine strategy aligns with the immunization agenda 2030 (IA 2030) which envisions a world where everyone, everywhere, at every age, fully benefits from vaccines to improve health and well-being (9). The national immunization programme thus seeks to expand the category of people accessing vaccination services in addition to those accessing routine childhood vaccines (21). This in essence includes focus on the benefits of vaccines for special at-risk populations such as patients with IMIDs. The policy guidelines recommend that children with immunosuppressive conditions including IMIDs complete the routine immunization schedule and in addition, receive 23-valent pneumococcal polysaccharide vaccine (PPSV-23); a polyvalent meningococcal vaccine and seasonal influenza vaccine (21). However, the current health systems are not aligned towards provision of increased access to vaccines in line with the IA 2030(9). Even though these additional vaccines are recommended for at risk groups, they are not offered as part of the national immunization program but are available commercially (at an additional cost to the patients) upon recommendation by the healthcare providers (21).

This study sought to assess the perceptions of caregivers and healthcare workers on recommended vaccines for patients with IMIDs, and determinants of uptake of these vaccines. The overall goal was to contribute to the improvement of access and uptake of the expanded range of vaccines and boosters for patients with IMIDs and to increase awareness among patients, caregivers and healthcare workers of the importance of life course immunizations for patients with IMIDs.

Methods

Study design, site, setting and population

This was a mixed methods study, with a repeat cross-sectional approach, and included both qualitative and quantitative aspects. The study was conducted at the rheumatology clinics of Kenyatta National Hospital (KNH) and Gertrude's Children's Hospital (GCH) from 10 February 2022 to 20 October 2022. The KNH paediatric rheumatology service runs a weekly clinic to which children with suspected or confirmed rheumatic disorders are referred for evaluation and management. The clinic is headed by a paediatric

rheumatologist with support from paediatric residents as well as four adult rheumatologists. The GCH paediatric rheumatology service similarly runs a weekly clinic for children with suspected or confirmed rheumatic disorders. On average 6-8 and 4-6 patients respectively are seen in each clinic every week. Both clinics receive patients from across the country as they are 2 of 3 facilities in the entire country that have dedicated specialist paediatric rheumatology services. The GCH clinic serves the higher end of society that can afford private health care, while KNH clinic serves the public sector, mainly located in the lower socio-economic stratum.

The target population included caregivers of all children attending rheumatology clinics. They were screened and all children with a confirmed diagnosis of IMID were identified and offered the opportunity to be included in the study. The study participants were consecutively enrolled over the nine-month enrollment period. A total of 103 caregiver-child pairs were included. Only those caregivers (and their children) who failed to give consent for study participation were excluded from the study. The survey for healthcare workers was conducted using a self-administered questionnaire that was distributed to paediatricians attending the annual Kenya Paediatric Association scientific conference in 2022. The conference brings together paediatricians from across the country and attracts over 75% of all registered paediatricians in the country annually. These clinicians manage children with different conditions including IMIDs and refer patients as necessary to rheumatology clinics, but none were involved in management of the study participants. We distributed 250 questionnaires and received a response from 76 (30.4%) healthcare workers who provided their consent.

Study Procedures

Interviewer administered questionnaires was used to collect data from caregivers of children with IMIDs attending the two rheumatology clinics. After the interviews, caregivers were taken through a health education session by the study nurse at the clinics as a benefit from the study and to address concerns raised by the caregivers. During these sessions, caregivers were educated on the importance of ensuring their children with IMIDs are up to date with vaccination and receive all recommended vaccines for which they are eligible. Knowledge gaps and participant questions were also addressed. Cards and flyers with current information and recommendations on vaccination were then given to the caregivers to take home. The health education sessions were repeated at subsequent clinic review sessions to reinforce the correct messages, aimed at improving the knowledge, attitude and practices (uptake of recommended vaccines following recruitment) of the caregivers about vaccinations.

Additionally, focus group discussions (FGDs) were held with the caregivers to explore themes that were not exhaustively addressed in the interviews. All study participants were invited for a meeting with the study investigators at the KNH research Central. Twenty-five consented to participate in the FGDs. These participants formed the groups that completed five FGDs.

The knowledge attained on life-course vaccinations was assessed using separate questions in the questionnaire while attitude was assessed on the willingness to take up available vaccines. Practices were assessed by determining the number of index children with IMIDS who were eligible for and received at least one vaccine at the follow up visit, as well as those who took up the vaccines offered to them as part of the study incentive at the study closure (3 month) visit. A Likert scale was used to assess their level of agreement or disagreement with various aspects of uptake of vaccines for the children with IMIDs.

For the health care workers, data were collected using a self-administered tool which was distributed to all the participants during the 2022 annual scientific conference at the Kenya Paediatric Association.

Data analysis

The data were summarized in tables and percentages; and qualitative results were classified into themes. The research investigators ensured data were stored in password protected folders and devices; and that no

name or identifiers were used on the questionnaires. Data collection and entry was done electronically by the research assistants to a secure server. The data were checked for completeness and accuracy and cleaned by a separate research assistant and data analyst daily. The monitoring and evaluation (M&E) officer tracked the progress of the study and project activities as per the project work plan and timeliness and advised the study principal investigators on any needed corrective measures. The study principal investigators met with study teams weekly to receive monitoring reports and evaluate study progress.

Results

Cohort characteristics

A total of 106 caregivers were approached to participate in this study. Three caregivers were excluded, due to lack of consent from their spouses or from the child's parent (where the caregiver was not the child's parent), thus leaving 103 participants for the study. Of the 103 caregiver participants, the majority (80%) were female, 65% were between 35 and 50 years of age, 66% had attained secondary education or higher, and 70% were of the Christian religious faith.

Caregiver opinions

As shown in Table 1, 90 % of the participants at baseline were willing to accept additional vaccines (other than those administered in the routine EPI program) for their children. The remaining 10% said that their children had either already been vaccinated or they had fears regarding the risk of adverse events following immunization (AEFI). Other reasons for vaccine hesitancy included that some caregivers considered their children too young for additional vaccines, received inadequate information to help them make informed choices regarding the vaccines, or the child was unwell and currently under medication.

Variable (N = 103)	Percent (Yes)	Percent (No)	Percent (I don't know)
I believe Vaccines are safe	90.57	3.61	5.82
I believe Vaccines are effective	88.24	9.35	2.41
I have full trust in vaccines and would readily accept my child to be vaccinated	97.11	1.06	1.83
I know that my child could benefit from additional vaccines	92.5	2.5	5.0
I support additional vaccines for my child if the doctor recommends them	90.2	7.0	2.8
My child has received some of the special/additional vaccines for IMIDS	10.6	89.4	
I have some fears and misgivings about additional vaccines for my child with an IMID	9.4	90.6	

Table 1. Caregiver views on vaccines for children with IMIDs

The views and opinions of caregivers regarding the need for additional vaccines for children and adolescents with IMIDs is summarized in Table 2. Among the reasons that would prevent caregivers from taking their children for immunization were cost considerations, long distance to an immunization centre, competing priorities such as work and fear of AEFI. All but one of the respondents thought that vaccines are safe for children with IMIDs though there were still concerns about possible AEFI and the need for greater education of caregivers on the various vaccines before they can be administered to the children.

No.	Interview Questions for caregivers	Summary of the responses
1	Reasons that may prevent the respondent from taking their children for vaccination	 Lack of transport/lack of transport money Lack of consultation fee Fear of the unknown Distance from respondent home/location to the health facility Mistreatment by health workers Increased cost of services Being denied permission at place of work (to leave and take the child for vaccination)/being at work Lack of consultation and investigation fee Unforeseen occurrences/emergencies Afraid the child may develop side effects The risk involved Lack of enough time The child being on other medication Vaccine cost Lack of knowledge about the vaccine Sickness of the mother Increased cost of services Don't have any reason Competing activities – that immunization is not a priority
2	Whether the caregiver considers vaccines safe	The sole respondent who said vaccines are not safe was probed further or why s/he thinks they are not safe and said, " <i>It depends on the type of</i> <i>vaccine</i> "
3	Any safety concerns for additional vaccines in children with IMIDs	 Fear of the unknown Afraid that the child may react to the vaccine/develop side effects/fear that the child may become more sick The wish to have knowledge about the vaccine before it is administered
4	Any reasons for incomplete vaccination	 Vaccines were not there at that time / vaccines were not available at the health facility when the child was due for immunization. Lack of knowledge on the last vaccine that the child had received Child is still young Child is still undergoing vaccination/on track Still learning about vaccination

Table 2. Caregiver expressed opinions on the need for additional vaccines for children with IMIDs

Health worker opinions

The respondents were familiar with diseases included in the IMIDS, and though 90.7% of the respondents knew there that additional vaccine antigens should be given to children with IMIDs, only 10.4% had ever recommended these vaccines to their patients. All the respondents knew of a situation when a child should not receive a vaccine. Among the situations highlighted were severe immunosuppressive states, known previous anaphylactic reaction to a vaccine, extreme preterm birth, active infections, prior serious AEFI

such as paralysis and severe primary immunodeficiency states. Further, 88.4% knew that certain vaccines should not be given to a patient with IMID and would not recommend these vaccines for a severely immunosuppressed child with IMID. Vaccines mentioned by the respondents were MMRV, yellow fever, BCG and OPV. In response to the question about the vaccines that would specifically be recommended for children with IMIDs in addition to those in the EPI schedule, the respondents mentioned all the available vaccines except OPV and BCG. Table 3 below gives a summary of some of the responses by health workers during the survey.

Table 3. Health care worker (paediatrician) views	s on vaccines for children with IMIDs
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Variable ($N = 76$)	Percent (Yes)	Percent (No)	Percent (I don't know)
Are you familiar with conditions included under IMIDS?	98.2	1.8	
Are there special vaccines you think children with IMIDs should receive? (If yes specify)	90.7		9.3
Have you ever recommended any additional vaccines to patients with IMIDS?	10.4	89.6	
Do you know of any situation when a child should not be vaccinated? (If yes, specify) *	100		
Is there any vaccine that you would NOT give or recommend to a child with IMIDs? (If yes specify) **	88.4	7.3	4.1
I support additional vaccines for children with IMIDs over those under routine immunization ***	84.6		15.4

Findings from Focus Group Discussions for Caregivers

Theme 1: General knowledge of immunization

The study found that most of the caregivers were knowledgeable about the importance of immunization in general and for their children in particular. This included a satisfactory understanding that recommended additional vaccines could be beneficial to their children. There was differing understanding on how additional vaccination would protect a child with an IMID. Some caregivers believed that immunization could offer 100% protection, while some said immunization makes the child stronger and resilient towards infections.

"... vaccines are important in prevention of illnesses and diseases like measles and pneumonia which can kill the child." (quote from a caregiver to a child suffering from an IMID)

"...... If a child receives this immunization, he has a lot of strength to withstand any infection when compared to one who is not immunized..." (quote from a caregiver to a child suffering from an IMID)

"... immunization through these vaccines is very important, since the vaccinated children will not suffer from any related infections again" (quote from a caregiver to a child suffering from an IMID)

"... Since the other vaccines have been very helpful to my child, I think any added immunization and vaccines would be important, because vaccinated children may get no infection from that disease." (a mother with a child with IMIDs)

Theme 2: Availability and quality of immunization services

The respondents raised a major concern around their fears that even if vaccines were recommended, availability and access barriers remain a major problem and concern.

"We always bring our children to hospital when requested to. Now that some added vaccines are advised, my worry is some of us may not afford them, they are expensive. Besides, the supply is usually unstable and unreliable even when the government promises to buy them. How sure are we that the vaccines will be there when we bring the children for immunization?" (a male caregiver whose child attends the clinic regularly.

"The problem is the availability of the vaccines and also some of us did not know about them. Some vaccines are very expensive and not under NHIF. So, a mother can't afford. I wish there was a way these vaccines can be availed just like the other childhood vaccines. (quote from a caregiver to a child suffering from an IMID)

"Some of us do not have even enough transport money to come to the clinic appointments, so buying vaccines is a problem. We even fail to raise money to buy prescribed drugs. The child condition is permanent, and the drugs are expensive. When you add the price of the vaccines, it becomes very hard to afford." (quote from a caregiver to a child suffering from an IMID)

Theme 3: Health worker service provision for children with IMIDs

The study also found out that caregivers were generally satisfied with services at the rheumatology clinic, but raised concerns about the need for further education, counselling, and steady supply of long-term treatment drugs and vaccines.

"We have a shortage of drugs and nurses, and this will affect the vaccines. The disease of my son is very stressful, and long-term treatment tires the boy. We need support, counselling, and help to get the drugs and vaccines, these drugs are very expensive, but if they can be made freely available, that will help a lot." (Mother to a girl attending rheumatology clinic)

Theme 4: Community engagement and mobilization to accept vaccines and knowledge on vaccines

The study identified the need to engage communities (caregivers, health workers, and general public) to embrace and demand for additional vaccines and better support for children with IMIDs.

"Parents should be educated and sensitized on the dangers of not immunizing and the importance of immunization. The follow up service and clinic should buy the vaccines and drugs for the children. We can ask and look for the vaccines if we know they are needed. Mothers need to be told where else these vaccines can be found and reminded when to give them." (Caregiver of an affected child, who is a high school teacher)

"Health workers should educate people about the vaccines that available and how they help the children. We need outreach services and if possible, they can provide transport." Caregiver in follow up clinic)

Theme 5: Immunization Health Systems factors that may affect vaccine uptake and provision for patients with IMIDs

This study established that concerns around access to costly vaccines, costly treatments, transport to attend scheduled clinics are factors affecting vaccine uptake and attendance of routine follow up clinics

"The challenge why sometimes a mother fails to bring the child to the clinic is actually transportation, when someone does not have bus fare." (Caregiver with child at Rheumatology clinic).

"Sometimes we go to the clinic and they write for us drugs and the drugs are not available, so you are forced to buy the drugs. The vaccine also will require payment. Some are not freely available. This will be a big challenge to many parents." Caregiver to a child with RA

Discussion

To the best of our knowledge, this study provides the first documentation in the East African region of the perceptions and practices on the benefits of immunization among the population of children with IMIDs, by their caregivers and health workers. Children and adults with IMIDs are commonly immunocompromised and their treatment relies on immunosuppressive drugs for long periods predisposing them to infection (4, 10). This is a big concern especially given that vaccine coverage in this unique population of patients remains low (11). The view of caregivers and health care providers on the potential benefit and role of vaccines in IMIDs is therefore important. The study revealed the need for a clear approach to vaccinations in this population, alongside the need to address caregiver concerns regarding the importance of and access to vaccination in their children.

The European League Against Rheumatism (EULAR) and Paediatric Rheumatology European Society (PReS) published updated recommendations for vaccinations in children with rheumatic diseases (4, 6). Many regions have progressively initiated conversations about similar recommendations for their unique specific populations and contexts (11). In Kenya, vaccination with non-live vaccines is generally advised for all children regardless of immunomodulatory therapy. Live vaccines on the other hand are not recommended for patients on immunosuppressive therapies including high dose glucocorticoids. The study found that the caregivers are in support and largely willing to have their children vaccinated. Interviews with practicing paediatricians and child health practitioners revealed concerns around live vaccines and IMIDs. It is important however to point out that in situations where high-risk of infection is likely, vaccination could be considered on a case-by-case basis, weighing the risk of infection against the risk of the intended vaccination (4).

Immune-mediated inflammatory diseases are characterized by reduced immunity and increased inflammation. Their management is largely based on the administration of immunosuppressive or immunomodulatory therapies, worsening the immunosuppression and predisposing these patients to serious infections (11,12,13,14,15,16,18,19,20). Two comprehensive population-based retrospective studies that compared rheumatoid arthritis (RA) patients with matched controls revealed an almost doubled incidence of documented infections in RA patients (12, 13). In systemic lupus erythematosus (SLE), the infectious complications usually occur in 25–45% of SLE patients, and up to 50% of the mortality in SLE is attributed to infection. The increased infection and death rates in both SLE and RA patients are partly related to immunological defects such as complement deficiencies (14, 15). The infection risk in non-vaccinated individuals is not negligible. A recent study demonstrated that non-vaccinated children in the USA have a 35 times increased risk of contracting measles in comparison with vaccinated children (16). Clinicians therefore have an important task to advocate for greater access to vaccination, especially for patients such as those with IMIDs that have increased risk of infectious complications. (17-19).

This study found that the caregivers and paediatricians support additional vaccines aside from those given in the routine EPI program for children with IMIDs. However, concerns remain about the risk of AEFI and lack of access to the vaccines due to high cost. While the caregivers acknowledge the need for further education and caregiver mobilization around embracing the vaccines and exact benefits of the vaccines, they generally are supportive of strategies and approaches that improve the health of children with IMIDs. For sustainable provision of vaccines to this vulnerable population, it would be important to quantify the burden of disease. Unfortunately, there's currently no local prevalence data on these conditions and effort to determine the disease burden should be enhanced. Further, there is need for a more systematic approach to vaccinating these patients and therefore inclusion of specific vaccination recommendations in the national immunization policy guidelines would go a long way in standardizing care and increasing uptake of essential vaccines for this population group.

When considering how best to set up a programme to sustain the provision of vaccines for children with IMIDs in Kenya and the region, many factors need to be considered. Developing a repository or registry with all children with IMIDs, characterization of actual disease profiles, development of treatment protocols (including immunizations) and continuous engagement and mobilization of communities on role of vaccines are some of the important considerations.

Strengths and limitations of this study

This is in our view the first study in the region to look into the need for inclusion of guidelines in the national vaccination program for children with IMIDs and how the caregivers and health workers perceive need for additional vaccines. This study has highlighted the high acceptance rates of the vaccines among caregivers and need to have improved access to these vaccines to promote uptake. The study's limitations include the observational nature and the small number of participants partly due to the rarity of the conditions. This was partially mitigated by the mixed design which enabled us to further explore perceptions and attitudes through qualitative (FGD) methods. The actual immunization status of the vaccination status was based solely on care giver verbal report. It is acknowledged that the actual practices would greatly influence interpretation of some of the study findings. Additionally, the study was carried out in tertiary health institutions within an urban setting which limits generalization of the findings to other settings even within the country.

Conclusion

Caregivers of children with IMIDs and healthcare workers generally accept and support additional vaccines for children with IMIDs. Facilitators to uptake of the additional vaccines by caregivers of children with IMIDS include recommendation of the vaccine by medical practitioners, and positive perception of vaccines as being safe and effective. Inappropriate perceptions concerning benefit and safety of vaccination of children with IMIDs among some care givers and low access due to cost may be barriers in accessing recommended vaccines in these children.

Recommendations

- There exists the need for a clear approach to vaccinations in children with IMIDs, and this can be achieved through the inclusion of guidelines on vaccinating these patients in the national immunization policy guidelines.
- There is need to include the recommended vaccine antigens for children with IMIDs in the routine EPI program in Kenya to increase access by all the patients that require these vaccines for better health and treatment outcomes.
- It is important to ensure continuous engagement of patients with IMIDs and their care givers to educate them on the importance of life course vaccines for optimal treatment outcomes as well as for better overall health and wellbeing.

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