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Motivators and barriers to neurodevelopmental research enrolment

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ABSTRACT

Q5 Participant recruitment for studies investigating neurodevelopmental conditions can be difficult, limited, and resource intensive. In this study, caregivers were surveyed to learn about the factors influencing their decision to enroll their neurodivergent child in research. Data were collected through an online survey from caregivers of neurodivergent children who were signing up for a research recruitment database ($n = 46$). Participants indicated the most important motives were to help achieve better outcomes for other children and to contribute to scientific understanding. Personal curiosities, such as the caregiver or child learning more about their condition, were identified as important for some parents. The most influential barrier to enrollment noted by participants was a heightened possibility of a significant negative side effect. These findings provide essential insight that can inform study design and associated research support that could overcome barriers and ensure families are aware of the benefits of participating in research.

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Neurodevelopmental conditions; recruitment; research enrollment; research participation; youth

Neurodevelopmental conditions (NDCs) are diagnoses describing developmental concerns which onset in early childhood.[1] These syndromes are broadly characterized by difficulties in covert (i.e., thought patterns) and overt behaviors (i.e., physical movements and social interactions).[2,3] These conditions include, but are not limited to, autism, attention-deficit/hyperactivity disorder (ADHD), and intellectual disability (ID).[1]

NDCs affect between 10% and 15% of children in North America.[4,5] Despite the widespread prevalence of NDCs, there are many unanswered questions relating to etiology, diagnosis, biomarkers, treatment, and prognosis for developmental concerns that can help to inform essential support for these individuals across the lifespan.[6,7] Unfortunately, it can be difficult to recruit participants for research related to NDCs.[8] To help address this issue, methods to successfully recruit families for studies have been evaluated. For example, research registries and databases have been developed to make information about research opportunities easily accessible,[9] and methods to inform and recruit families to relevant research opportunities have been studied.[8] Regardless of the promotion research projects receive, the decision to enroll in NDC research lies with the participant, or in the case of dependent children, their caregivers.[10] Understanding which factors contribute to caregivers' decision to enroll their children in research may help successfully recruit participants in future research.

Existing literature highlights altruism as the most reported motivator for research enrollment by caregivers of children with NDCs. Families reported enrolling in research to: (1) contribute to knowledge of NDCs,[3,11] (2) help those struggling with the same condition as their child,[12,13] and (3) support identifying future interventions to help people with NDCs.[14] These motives were more commonly reported by caregivers who identified as high-socioeconomic status (SES) individuals with one affected child.[15] Another commonly reported motive for enrollment in intervention-related research was the perception the intervention strategy or approach may have a direct benefit for their child.[16,17] This motive was higher among caregivers who identified as low-SES individuals.[15] Other identified motives included wanting to gain more knowledge about their child, or their child's condition,[18,19] receiving financial, or other incentives,[12] and connecting with other families.[20,21]

In comparison, previous research highlights the most common barriers or deterrents to study enrollment were related to time and logistical concerns.[10,16] These barriers included: (1) the time commitment required to participate, (2) the study location (i.e., distance too far away), (3) the number of required study appointments, and (4) appointments not aligning with participant schedule. Additional identified barriers included the risk of adverse side effects,[20] inadequate knowledge about study design,[14] and an incongruency between the study's aim and the child's area of difficulty (i.e., participation will not directly benefit the child).[16]

Despite this emerging evidence demonstrating commonly reported motives and barriers to study enrollment, previous studies have been limited in terms of the types of NDCs included, with most existing literature focused on caregivers of autistic children,[3,19] cerebral palsy (CP)[10,22] and fragile X syndrome,[20] or caregivers of children with other medical conditions.[14,16] To date, there are limited studies including caregivers of children from various NDC diagnoses.[13,14] Additionally, few studies have examined caregivers of children

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Q3 Supplemental data for this article can be accessed online at https://doi.org/10.1080/17518423.2024.2438969 from a wide age range (e.g., 0–18).[16,23] Most prior studies have been conducted in the United States,[14,16] however, studies have also been done in Europe.[11,23] The current study will address the limitations of previous research by including caregivers of children with a wide range of NDCs, and a wide range of ages.

This study sought to answer the following questions: (1) Which motivators are important in caregivers' decision to enroll their child in research? (2) Which barriers are influential in caregivers' decision to enroll their child in research? and (3) How do the identified factors relate to key demographic variables? To address our research questions, we surveyed a group of families with children affected by NDCs who were registering for a dedicated neurodevelopmental research recruitment database. Participants were asked to reflect and report on barriers and motivators influencing their decision to enroll their child in NDC research. Based on previous research, we anticipated the most important motive for research enrollment would be altruism, while the most influential barrier to enrollment was expected to be time and logistical concerns. Findings from this study may strengthen researcher understanding of motivators and barriers influencing individuals' decisions to participate in research. This understanding may help inform future study design and associated research support, by allowing researchers to be mindful during study development of factors which affect one's inclination to participate in research. Common barriers to research enrollment for caregivers may be reduced, and studies may be designed to be more accommodating and accessible for research participants. Increasing study accessibility and removing, or addressing, deterrents to participation will ideally allow more pediatric NDC research to occur by ultimately facilitating greater participant recruitment.[10]

Method

Following ethics approval, participants were recruited to participate in this survey through the Owerko Neurodevelopmental Disorder Recruitment Database. Only individuals who registered for the database were asked to participate in this study. This is a database designated to NDC recruitment; families are broadly recruited to the database through a variety of different community and tertiary care medical clinics, as well as through community services and family support groups and online advertisements. The children of database members were required to be between the ages of 1–17 years, either diagnosed with, or being assessed for, an NDC such as autism, ADHD, global developmental delay, ID, CP, or fetal alcohol spectrum disorder (FASD). Participants were excluded if they were not fluent in English and/or were not a legal caregiver (i.e. parent or guardian) able to supply consent and contact information.

Caregivers completed a preliminary online form required to join the database. In this form, they filled out information confirming their eligibility (i.e., age of child, developmental and medical diagnoses of their child, home address). Caregivers also completed the Motivators and Barriers to Neurodevelopmental Research Enrollment Survey; a 23-item online survey which included three optional open-ended questions (see supplementary material). It was designed to be completed in less than 15 min. The survey contained four demographic questions regarding caregiver education, ethnic background, number of children per household, and number of children with a NDC in the household. The survey contained seven questions assessing participants' motivations to enroll their child in research; participants rated motivator importance on a 4-point Likert scale of 0 (not at all important) – 3 (very important). Additionally, the survey contained 12 questions assessing barriers to enroll their child in research that employed the same 0 (not at all influential) – 3 (very influential) Likert scale. Finally, three optional open-ended survey questions were administered to all participants to identify (1) other motivators that may encourage caregivers to enroll their child in research, (2) other barriers preventing them from enrolling their child in research, and (3) actions researchers can take to make it easier for participants to enroll their child in research. Aside from the open-ended questions, all survey items were mandatory. Of note, the term "caregiver" was used in the Motivators and Barriers to Neurodevelopmental Research Enrollment Survey instead of more traditional terms, such as "Mother" and "Father," to be inclusive of participants who assumed different caregiver roles (e.g., grandparents, stepparents, other kinship caregivers).

Participants completed all questionnaires online through the secure online Research Electronic Data Capture (REDCap) platform hosted at the University of Calgary.[24,25] All respondents filled out the questionnaire between January and March 2023.

Analysis

Statistical analysis was performed using IBM SSPS Statistics 26. Means and standard deviations were calculated for demographic variables. Exploratory analyses were performed to assess the association between demographic factors and reported motivators and barriers to research enrollment. Spearman rank order correlations were conducted to assess the influence of primary caregiver education level, and the number of children in the household, on caregiver ratings of barriers and motivators.[26] The Kruskal–Wallis H test was used to assess differences in ratings of barriers and motivators between caregivers with one child, and caregivers with two children with an NDC.[27] A one-way ANOVA was used to evaluate whether caregiver rating of the barrier "study location being too far away" was associated with the distance families lived from the research center.[28] The value for distance from the research center was obtained virtually by mapping the distance in kilometers from the research center to the subject's postal code reported in the survey (Table 1). Distances less than 200 km were used in the analysis.

To summarize results from the open-ended questions, we first identified unique responses from the motivators and barriers previously listed in the survey. These responses were then grouped by theme (e.g. "reduce stigma" and "be more accepted in our society") Responses reiterating motivators and barriers identified in the survey (e.g. "poses a risk") were reported if they were reported by more than one participant in the open-ended responses. Responses identifying action researchers can take to make it easier for participants to enroll

Table 1. Demographic characteristics of participants.

	Sample		
Characteristics	Mean	SD	Range
How many children or youth live in your household	2.13	1.02	1–6
How many children or youth live in your household with a NDC	1.20	0.40	1–2
Age of children with a NDC (years)	9.5	3.8	2.7–18.7
Distance from research centre (km)[a]	104	196	1.8–784
	n		%
Neurodevelopmental condition of children[b]			
Attention deficit hyperactivity disorder	32		47.06
Autism spectrum disorder	14		20.59
Motor deficit, motor delay, or cerebral palsy	6		8.82
Global developmental delay or intellectual disability	5		7.35
Genetic condition	3		4.41
Fetal alcohol spectrum disorder	1		1.47
Other developmental or learning concerns	7		14.58
Ethnic Background[c]			
North American	31		47.69
European	21		32.30
First Nations, Inuit, or Métis	3		4.62
Hispanic	3		4.62
East Asian	2		3.08
Southeast Asian	2		3.08
Would rather not say	1		1.54
Other	2		3.08
Caregiver education background			
Junior high (grade 7–9)	1		2.17
Highschool graduate	2		4.35
Some college, no degree	4		8.70
Post-secondary diploma (i.e., occupational, technical, vocational program)	5		10.87
Bachelor's degree	20		43.48
Master's degree	9		19.57
Professional school degree	2		4.35
Doctoral degree	3		6.52
Other caregiver education background[d]			
Junior high (grade 7–9)	1		2.38
High school (grades 10–12) – no diploma	1		2.38
Highschool graduate	1		2.38
Some college, no degree	1		2.38
Post-secondary diploma (i.e., occupational, technical, vocational program)	12		28.57
Bachelor's degree	17		40.48
Master's degree	8		19.05
Professional school degree	1		2.38

Demographic characteristics of participants *(n = 46)*. [a]Three participants were from out of the country and were excluded from average. [b]Participants were permitted to select more than one diagnosis for their child. [c]Participants were permitted to select more than one ethnic background. African, South Asian and Middle Eastern caregivers are not represented in Table 1 as no individual from those specific ethnic backgrounds chose to participate in this study. [d]42 participants total reported other caregiver education background.

their child in research were grouped by theme (e.g. "Zoom" and "online surveys" identified as "virtual options for participation").

Results

Demographics

A total of 49 caregivers consented to complete the survey. Three participants were removed as they did not complete the entire survey, and thus the final sample included 46 participants. Table 1 outlines demographic information for the final sample. Most caregivers identified as North American ethnicity and had attained some form of a post-secondary degree or diploma. Families had between one and six children with one or two affected by NDC. The most common condition among children or youth was ADHD. Most children were formally diagnosed with NDC by a clinician, with one child who was currently in the process of being assessed for ADHD. Children were between the ages of 2.7 and 18.7 years.

Motives for Enrollment

The most important motives to enroll one's child in research were to help achieve better outcomes for other children and contribute to general scientific understanding (Figure 1). All caregivers believed both these motives were either "important" or "very important," except for one caregiver who believed these motives were only "slightly important" (2.17%). No caregiver believed these motives were "not at all important." In comparison, receiving a financial benefit or honorarium was less important to caregivers when choosing to enroll their child in research. No caregivers considered this motive "very important"; caregivers mainly specified it was "not at all important" (39 caregivers total; 67.39%). Most caregivers considered learning more about their child and child's condition

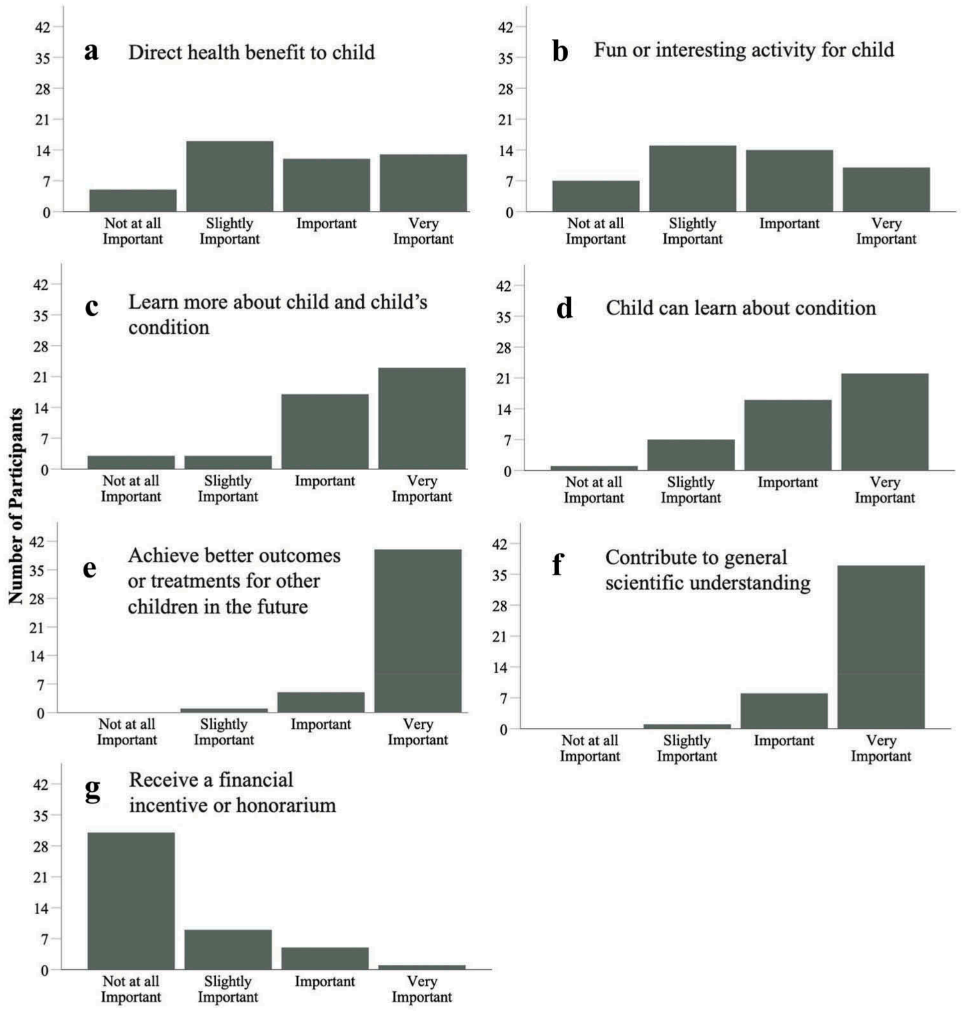

Figure 1. Motivators of research enrollment. The number of caregivers rating the importance of motivators on a 4-point scale, from "1: not at all important" to "4: very important." Survey questions: A. Direct health benefit to child; B. Fun or interesting activity for child; C. Learn more about child and child's condition; D. Child can learn about their condition; E. Achieve better outcomes or treatments for other children in the future; F. Contribute to general scientific understanding; G. Receive a financial incentive or honorarium.

to be "very important" or "important," with only two caregivers considering it "not at all important" (4.35%). Similarly, most caregivers also considered having their child learn more about their condition to be a "very important" or "important" motive. Only one caregiver considered it "not at all important" (2.17%). Direct benefits to the child such as providing (1) a direct health benefit" or (2) an interesting activity for child, had mixed results with caregivers providing responses across the full range of responses (Figure 1).

Barriers to Enrollment

Most participants reported the most influential barrier to enrolling one's child in research was a good chance their child would experience a large negative side effect (e.g., injury; Figure 2). Thirty-eight caregivers (82.61%) considered this factor "very influential" in terms of their decision for study enrollment; only two caregivers considered it "not at all influential" (4.35%). Similarly, 39 caregivers (84.78%) reported even a small chance of their child receiving a large negative side effect was "influential" or "very influential." Only two caregivers considered it to be "not at all influential" (4.35%). A good chance their child would experience a small negative side effect was also considered either "very influential" or "influential" by most. Only four caregivers considered this "not at all influential" (8.70%). In comparison to the barriers described above, a small chance their child would experience a small negative side effect was considered less influential, with 29 caregivers considering this factor only either "slightly influential" (47.83%) or "not at all influential" (15.22%). Receiving no health benefit from research participation was identified as the least common influential barrier to research enrollment. Twenty caregivers (43.48%) believed this was "not at all influential" and 16 caregivers (34.78%) believed this was only "slightly influential."

Other barriers had more even spread across survey responses with some families considering them "very influential" and others rating these factors as "not at all influential" (Figure 2). Barriers including the loss of a child's privacy, and the study being too hard for the child were both considered "not at all influential" by seven caregivers (15.22%), while 39 caregivers considered them to be of some level of influence (84.78%). In

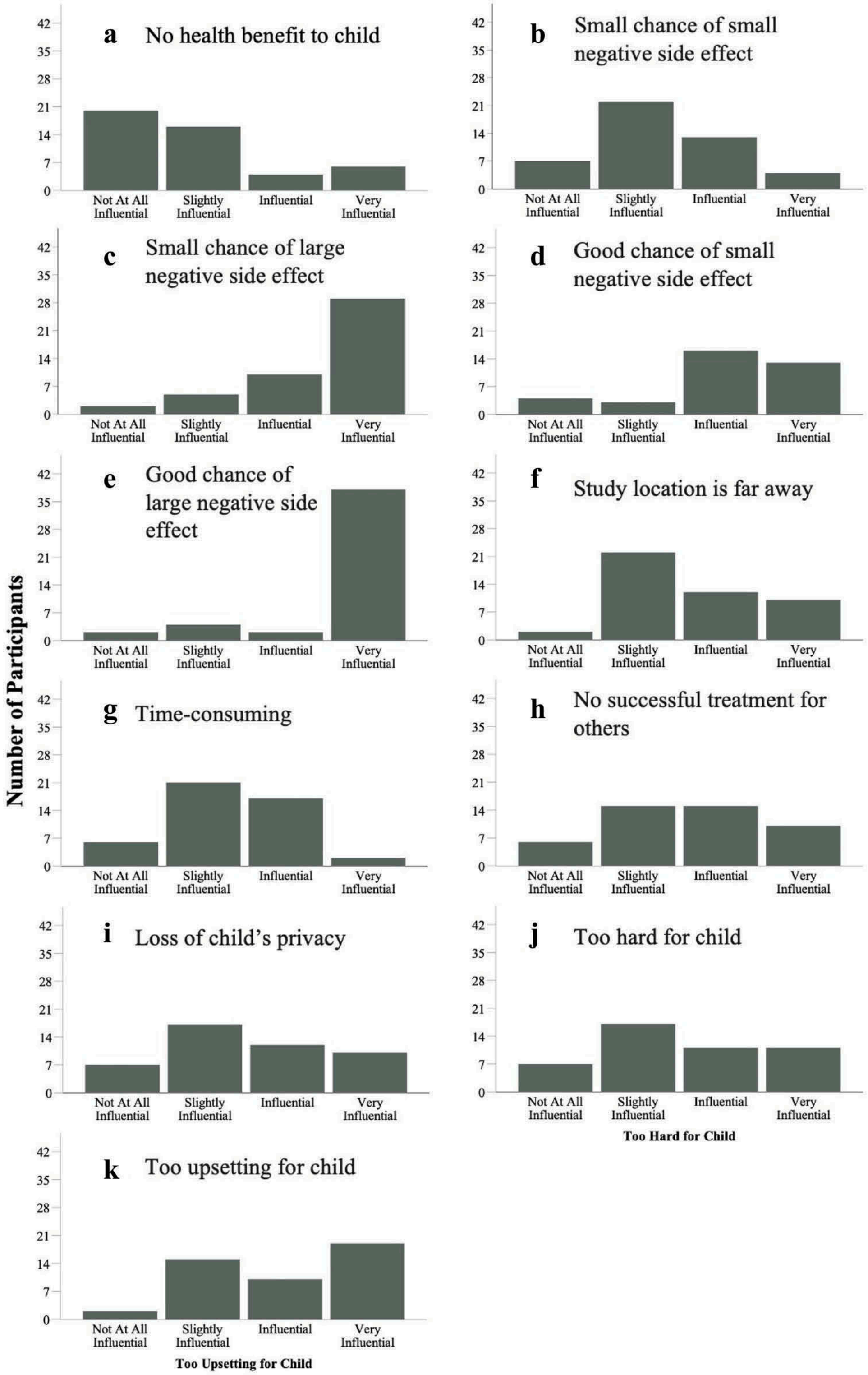

Figure 2. Barriers to research enrollment. The number of caregivers rating how influential they considered each potential research barrier from "1: not at all influential" to "4: very influential." Survey questions: A. No health benefit to child; B. Small chance of small negative side effect; C. Small change of large negative side effect; D. Good chance of small negative side effect; E. Good chance of large negative side effect; F. Study location is far away; G. Time-consuming; H. No successful treatment for others; I. Loss of child's privacy; J. Too hard for child; K. Too upsetting for child.

comparison, the study not leading to successful treatment options and the study being too time-consuming, were both considered "not at all influential" by six caregivers (15.00%), while 40 caregivers considered them to be of some level of influence (86.96%). Lastly, barriers including the child finding the study too upsetting, or the study location being too far away were both considered "not at all influential" by two caregivers (4.35%), while 44 caregivers considered them to be of some level of influence (95.65%).

Association Between Barriers and Motivators and Family Factors

Caregiver Education

Spearman rank order correlations between primary caregiver education level and caregiver rating of barriers and motivators were conducted. Education level was positively associated with the research study being too time-consuming ($r = 0.34$; $p = .020$) and having a good chance of experiencing a small negative side effect ($r = 0.33$; $p = .026$). Additionally, education level was negatively associated with motivator "Child learns more about their condition" ($r = -0.31$, $p = .036$) where caregivers with higher levels of education ranked the child learning about their condition as less important.

Number of Children per Household

Spearman rank order correlations between the number of children per household, and caregiver rating of barriers and motivators were conducted. No significant associations between variables were found, with one exception. The number of children in the household was positively associated with barrier "the research study may be too upsetting for my child" ($r = 0.523$, $p < .001$). The Kruskal–Wallis H test was used to determine differences in rating of barriers and motivators between caregivers with one child, or two children with a NDC. No significant differences were found.

Distance from Study Location

One-way ANOVA revealed caregiver rating of the barrier "study location being too far away" was not significantly associated with distance families lived from the research center ($p = .083$).

Age of Child

Associations between age of child and barriers and motivators were examined, however no significant trends in the data were found.

Open-Ended Survey Responses

Caregivers had a chance to share additional motivators (19 out 46 participants responded) and barriers (14 responded) to research enrollment through two open-ended survey questions. Additional motivators of research enrollment highlighted by caregivers included: 1. the child receives their choice of honorarium (1/19); 2. the study is a length of an hour or less (1/19); 3. study appointments are available at convenient times (e.g., late afternoon, evening, weekend; 1/19); 4. the research may help others in society (i.e., general public) understand and accept the NDC (2/19); 5. the study design and purpose appeal to the child (2/19); 6. receiving a summary of study results (1/19); and 7. reduce stigma (1/19). Like other studies, many caregivers (9/19) also reiterated altruistic motivations including wanting to help other children, wanting to learn about their child, or child's condition, and contributing to science, as previously rated in the quantitative questionnaire.

In comparison, other potential barriers to research enrollment identified by caregivers included: 1. the worsening of preexisting symptoms (1/14); 2. missing work, or their child missing school (2/14); 3. the requirement of financial inputs (i.e., paying for parking; 2/14); 4. poor, not well thought out, study designs (1/14); and 5. the type and purpose of study was not appealing to the child (2/14). Caregivers also reiterated barriers such as negative side effects from the intervention (5/14), the study requiring an excessive time commitment (2/14), study appointments being too far away (2/14), and loss of privacy (2/14).

Finally, through an open-ended question caregivers had the opportunity to provide researchers with suggestions that may increase their likelihood of enrolling their child in future research ($n = 11$). These suggestions included: 1. providing virtual options for long-distance study participation (2/11); 2. making the study engaging for the child (e.g., provide entertainment for child while participating, or honorariums (2/11); 3. scheduling shorter duration study appointments (1/11); 4. informing the children of the reason for, and potential impact of the studies they participate in (2/11); and 5. helping caregivers have a stronger understanding around the risks of the study from researchers (2/11).

Discussion

As seen in other studies of pediatric enrollment in research, the most important motives to enroll one's child in research were altruistic, such as contributing to knowledge of NDCs,[3,11] helping others with the same condition as their child,[12,13] and helping identify future NDC treatments.[14] Most caregivers identified contributing to scientific understanding and helping achieve better outcomes for other children as the most important motives for research participation. The importance of these motives of research enrollment was also supported by open-ended survey responses. In comparison, receiving a financial benefit or honorarium was less important to caregivers when choosing to enroll their child in research, though flexibility and making the research engaging to the child was identified on open-ended questions as ways of improving acceptability of research studies. In prior research, financial incentives and honorariums were also less commonly identified as important motives for enrollment.[10,15] However, it was identified as a motive in a qualitative study by Owen-Smith et al.[12] This could be explained by SES differences of study participants. While we did not collect family income data, most caregivers completed some form of post-secondary education indicating they may have higher SES. A participant in the study by Owen-Smith et al. [12(p126)] described financial incentives and honorariums as a motive, because they allowed the caregiver to purchase items for their child they otherwise couldn't "give him out of my pocket." As such, this participant may have been experiencing more financial strain compared to our study participants, thus making financial incentives and honorariums more appealing and therefore important motives. Receiving a direct health benefit was a less commonly identified motive in our study. This contradicts findings from Chechi et al.[14] where almost two-thirds of the study population endorsed it as a motive. This may be related to the type of study caregivers were enrolling their child in.

In our survey, the study type was left relatively broad and up for interpretation from study participants (see Online Supplemental Material). For comparison, Chechi et al.[14] examined caregiver ratings of factors specific to enrollment in a clinical trial. Intervention studies are more closely tied to identifying efficacious treatment options (i.e., in comparison to survey research for example), and therefore individuals may have enhanced awareness and preoccupation with the potential for health benefits, and perceive these outcomes as more important. Additionally, intervention studies can include specific and oftentimes costly clinical procedures; participants may enroll their child in studies specifically to obtain a direct health benefit. Findings from Eley et al.[20] also identified a direct health benefit as a motive for participation; however, this study also examined participation in intervention studies.

In comparison, the most influential barrier to research enrollment identified in our study was their child having a good chance of receiving a large negative side effect (e.g., injury). While risk of injury has been an influential barrier recognized in prior literature,[20] the most identified barriers to study enrollment from other studies were time and logistical concerns (e.g. study location too far, study appointments conflict with the caregiver or child's schedule).[10,12,16] This discrepancy may be due to the methods used to collect data. Some studies conducted semi-structured interviews, only administered open-ended survey questions to identify barriers[3,10,12] or did not include the potential for injury among the barrier options in their survey.[14] In these cases, participants may not have been prompted to recall or consider side effects as a barrier. Additionally, this discrepancy could have arisen due to the caregiver population participating in each study. Many participants in our study were caregivers of children with ADHD, whereas in other studies the participants were primarily caregivers of children with other NDCs, such as cerebral palsy[10] or autism.[3,12] Different NDCs may uniquely influence families' ability to travel for research, or a caregiver or child's availability, making it a more pronounced barrier for some.[10] In prior research, where risk of negative side effects was identified as a barrier, few participants identified it as the most influential, with the exception of a study by Eley et al.[20] This, again, could be related to the methods used to collect data, or the NDC of the child.[16] The phrasing of our survey items and distinguishing large and small negative effects may have affected participant rating of influence. Our survey items specified their child would have "a good chance of a large negative effect," compared to potentially experiencing general or less severe side effects, likely leading more participants to select "very influential." Notably, a participant in our study suggested the use of clear descriptions and enhanced understanding of the possible risks of a study as important for recruitment, highlighting the need for trust and transparency when caregivers are considering research enrollment.

The least influential barrier to research participation participants reported was receiving no direct health benefit. While identified as influential in one known study (see ref. 16), receiving "no direct health benefit" was not a common barrier in prior literature. As described earlier, this may be related to the type of study caregivers were enrolling their child in (i.e., a clinical drug trial). Participants may perceive the absence of direct health benefits as more influential in interventional studies, where the risk of side effects may also be greater. Lastly, the study by D'Amanda et al.[16] where "no direct health benefit" was the most identified barrier, had a small sample and only 5 participants reported it. Further, this study examined enrollment in a specific population of caregivers of children with fragile X syndrome; the target population may have had implications in caregivers' selection of barriers.

While time and logistical concerns were not the most influential barriers, many motives and barriers identified through open-ended survey questions were related to logistics. For example, motives for enrollment included "a study length of specifically an hour or less" and "study appointments available at convenient times." In comparison, potential barriers to research enrollment included missing work or school, excessive time commitment, or distant research location. Additionally, the suggestions provided to increase research enrollment were related to improving convenience of study participation.

There were some potential limitations of the present study that may have influenced our results and the generalizability of the findings. Primarily, all participants expressed an interest in research by enrolling in a research recruitment database.[10] Therefore, they are likely inclined toward a favorable view of research and research participation. As a result, these participants may be more inherently motivated to participate in research, than those who did not agree to be part of the database. However, they are also representative of the population most likely to participate in future studies. Secondly, it is possible we missed some potential motivators and barriers listed in the survey. Although, many barriers and motivators included in the survey were those discussed in the previous literature,[10,13,16,20] we may not have captured all potential factors, particularly those affecting groups underrepresented in research.[3] We attempted to minimize this limitation, by including open-ended responses to learn about other motivators and barriers potentially not included in the survey. Additionally, to limit the survey length to 15–20 min, we limited the collection of demographic information. Previous research experiences and family income were not collected, yet these factors may have been influential in caregivers' ratings of barriers and motivators. Furthermore, survey research raises potential concerns surrounding biases. Primarily, the Likert scales used for the closed questions were not symmetric, as there were more response options reflecting "influentiality" or "importance," compared to response options reflecting "unimportance" or "lack of influentiality."[29] This may have incidentally led to participant response bias and contributed to more participants selecting positive response options. Secondly, due to social desirability bias individuals may have been more likely to rate certain survey items differently to appear more socially acceptable, such as rating altruistic motives as "very important." Lastly, the type of research study the participants were asked to consider enrolling in was vague, and largely left to participant interpretation. As a result, we cannot determine if the ratings of barriers and motivators vary depending on the study design or purpose (e.g. observational or survey research may differ from interventional or clinical trial studies.[30]

Conclusion and Future Directions

This study investigated motivators and barriers to caregiver enrollment of their child in NDC research. These findings may be useful in informing researchers investigating NDCs of guidelines and suggestions for successful future recruitment of caregivers of children with a NDC. For example, by knowing altruism is an important motive for caregivers, when applicable, studies should highlight how participating in their research may benefit other children or contribute to a greater scientific understanding. Researchers should consider articulating this information in recruitment materials (i.e., posters, flyers), so caregivers are well informed when the study is first introduced to them. Further, by understanding an influential barrier to caregivers is a good chance of their child experiencing a large negative side effect, researchers should clarify and help strengthen caregivers' understanding of the study risks, and describe actions undertaken by researchers to minimize risk. Researchers should ensure they clearly communicate risks to caregivers when describing the study verbally, and when appropriate in writing prior to consenting to ensure there are opportunities to ask questions and reduce any ambiguity around study risks. Lastly, caregivers are more likely to enroll their child in research when study designs are more logistically convenient. If feasible, researchers should tailor study design to better accommodate caregivers (i.e., provide virtual testing options, shorten study appointments, and provide appointment times outside work and school hours).

Certain barriers and motives may not only be influential to recruitment, but also participant retention. For example, caregivers may be less likely to withdraw from studies that better accommodate their needs, have desirable outcomes (i.e., helping others) and reduce logistical barriers. Future studies should consider examining how the various barriers and motivators impact study retention. As stated earlier, each of our participants had expressed an interest in research by enrolling in a research recruitment database. Further research is needed to investigate barriers and motivators specific to potential participants who are not actively seeking out research opportunities. Past caregiver research experience may also influence caregiver ratings of factors. As this data was not collected from participants, future research may benefit from exploring this relationship. Additionally, it may be important to further investigate whether the level of motivators and barriers vary for caregivers when enrolling the child in different types of research. Future research should also examine whether implementing the suggestions provided by participants or addressing influential barriers improves research recruitment. With successful recruitment, more data surrounding NDCs may be collected, and more answers for unknown aspects of these conditions may be uncovered.

Disclosure Statement

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