Assisting children and youth with completing self-report instruments introduces bias: A mixed-method study that includes children and young people’s views

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ARTICLE INFO

Keywords:
Children and youth
Quality of care
Self-report
Response bias
Questionnaires
Surveys
Assisted assessment

ABSTRACT

Many children and youth struggle to complete surveys and questionnaires by themselves. They are often assisted when asked to give their opinion. From discussions with youth from the client council at a residential treatment facility for youths in The Netherlands, the notion emerged that interaction factors may impact the results of surveys, especially when sensitive topics are addressed.

Using a mixed methods design, we explored the question if and how survey results are influenced by the presence of an assistant during assessment. 120 children and youth that reside at one of the treatment facilities of Koraal, a Dutch multi-site care facility, completed a survey about the perceived quality of care at the facility. They were randomly assigned to one of three conditions: (a) unassisted, (b) assisted by their care worker, or (c) assisted by a research assistant. The resulting scores in each condition were compared quantitatively. In successive focus groups with children and youth, the results and possible explanations were discussed.

Participants: in the Assisted by care worker condition exhibited significantly higher satisfaction scores than participants in each of the other two conditions. Results from the focus groups indicated that complex client-carer interaction dynamics contribute to these differences. Several explanatory mechanisms and implications for practice were suggested by the participants.

These results suggest that bias may be introduced when children and youth need assistance to complete surveys or diagnostic measures. This requires careful consideration on the part of researchers working with these vulnerable participants.

1. Introduction

Despite worldwide efforts to prevent out-of-home placements, millions of children and youth continue to move to live in residential group care settings because the preconditions for growing up at home cannot be met satisfactorily (van IJzendoorn et al., 2020). Children and youth admitted to group care are at risk of physical and emotional abuse, and might have unmet medical needs (Desmond et al., 2020). Potential adverse consequences include delays in physical growth, cognition, attention, socioemotional development and difficulties with mental health (Van IJzendoorn et al., 2020).

One potential way to mitigate the potential adverse effects of living within residential group care settings is to explicitly consider the views of children and youth about the quality of care in participative research and care improvement programs (Goldman et al., 2020; ten Brummelaar et al., 2018). An example of an instrument that was purposefully designed to this end is the My Opinion (Wissink and Kooijmans, 2020) survey. The My Opinion survey was constructed to accommodate the challenges associated with self-report measures for vulnerable populations, including children, persons with reading problems and persons...
with intellectual disabilities (ID; Kooijmans et al., 2022). Examples of ’ID-inclusive’ features include Easy Read language, 3- to 5-point Likert scale options with supportive visualisations and digital assessment with a read-aloud function for questions.

At Koraal, it is standard practice for staff and children to engage in joint reflection upon the results of the My Opinion survey. Recently, survey results were discussed with the Koraal client council, incorporating youth, and it was noted by council members that reported satisfaction with care was high. This seemed to contradict the council members’ perception of how children and youth generally expressed their views on the quality of care at the facility. Consequently they expected the results to be much less rosy than those reported via the survey. The Koraal client council suggested that the survey may have been biased in a positive direction because care workers assisted many children and youth with completing the survey. As a consequence, the council recommended (a) the completion of a brief literature review to explain why biased responding may occur with reference to acquiescence, social desirability and dependency effects, and (b) an exploration of mechanisms that may introduce bias within self-report assessments leading to the generation of hypotheses and an associated methodology which informed the development of the current study.

1.1. Factors that May explain overreporting of satisfaction in self-report client surveys

There are numerous potential sources of bias that threaten the reliability and validity of self-report measures (Havercamp et al., 2021). It has been suggested that as much as 40% of the variance in self-reported data can be explained by response biases (McCrae, 2018). These biases may be more marked amongst vulnerable populations, including children, whose cognitive, communicative and social skills have not fully developed (Bell, 2007) and persons with limited cognitive abilities (Nicolaidis et al., 2020). Difficulties with understanding may lead to incorrect or incomplete responses, while the introduction of support from another person when completing self-report measures may introduce certain types of bias, such as socially desirable responding, as a consequence of respondent-assistant dynamics (Finlay and Antaki, 2012; Kramer et al., 2010).

1.1.1. How misunderstanding can inflate satisfaction scores

A variety of different sources of bias may affect responses to self-report measures when used with vulnerable populations. Research on children, people with ID, and low literate persons suggests that sources of bias may include (a) acquiescence which is the tendency to say yes to questions regardless of content, (b) recency bias which is the tendency to select the last option mentioned in multiple-choice questions, irrespective of one’s true opinion, (c) nay-saying which means saying no to every question, and (c) suggestibility (Bell et al., 2018) which refers to willingness to change answers following suggestions from another person. These response biases are more prevalent when individuals do not know the answer to the question (Emerson et al., 2013). For children, the variance that can be attributed to acquiescent responding can be twice as large than for adults (Soto et al., 2008).

Returning to consider the My Opinion survey (Wiisink and Kooijmans, 2020), acquiescent responding may have occurred as all questions are positively phrased; negatively worded questions or questions using double negatives were not used as they tend to be confusing and lead to more errors (Payne and Jahoda, 2004). Acquiescent responding can occur when positively phrased questions are misunderstood leading to an increase in the frequency of affirmative answers.

1.1.2. Interaction as a source of bias

The My Opinion questionnaire was designed to be accessible for those who have difficulties with reading and understanding information, and while it is recommended that children and youth should be given the opportunity to complete the survey by themselves, in practice this happens rarely. This is because many children and youth may seek help from others or are offered unsolicited help by adults involved in their day-to-day care.

It cannot be assumed that unassisted completion will yield the same results as assisted assessment. Pioneers in research on complex carer-client interactions, such as Antaki and Rapley (Antaki, 2013; Rapley and Antaki, 1996), have demonstrated conclusively that these interactions can heavily influence the outcomes of discussions about support needs. Garton and Copland (2010) showed that any prior relationship between interviewee and interviewer turns objective accounts of the interviewee’s reality into an interactional event where meaning is constructed jointly. Interviewers may willingly or unwillingly direct respondents towards certain answers by the way they react to respondents’ verbal and nonverbal expressions. For instance, by nodding to favorable answers or frowning upon criticism.

Answers are also shaped by the respondent’s expectations about how the assistant will react to their answer. When the relationship is non-symmetrical, general submissiveness may contribute to acquiescent responding (Finlay and Lyons, 2002). Submissiveness is the tendency to conform to the opinions of people with authority (Finlay and Lyons, 2002).

Social desirability may occur when questions on sensitive or even taboo subjects are asked (Krumpal, 2013). The respondent may be reluctant to admit to socially or culturally unacceptable behavior in the presence of an authority figure (Bell, 2007; van de Mortel, 2008).

Pleasing occurs when people will answer the question in a certain way because they think it is the ‘right’ answer the interviewer would like to hear (Rapley and Antaki, 1996). Children may especially report more socially desirable behavior (or less socially undesirable behavior) when they fear that this information is shared with their parents or other adult authorities, a phenomenon that is known as ‘the bystander effect’ (Havermans et al., 2015). In residential facilities, despite efforts to create more egalitarian relationships between care workers and clients, children and youth are still taught to conform to their care workers’ expectations (De Valk et al., 2019). Children and youth who openly criticise care worker competence or other ‘sensitive’ aspects of quality of care may be seen as noncompliant or oppositional and may face repercussions as a consequence. This may lead to an increased chance of accepting suggestions and advice from others (Douma et al., 2012).

An important construct that may have an impact upon response style is the nature and degree of dependency children and youth have upon adults. They depend upon their carers to organize and provide support to fulfill their physical and psychological needs, while they are also the conduit to the “outside world”, including family and friends (Moonen, 2019). As a consequence, children and youth in residential care may work to maintain positive relationships with care workers and avoid offering any criticism.

1.2. The present study

In the current study we explore response bias that is introduced when children and youth with MBID are assisted completing a satisfaction questionnaire. To investigate this, we used a sequential explanatory mixed-method design (Creswell, 2016).

In the quantitative phase, participants were allocated to one of three groups and invited to complete the My Opinion questionnaire either (a) unassisted, (b) with assistance from a care worker, or (c) with assistance from someone unknown to the participant. Group differences were analysed using inferential statistics. Based on the literature and the input from the client council we hypothesised that the participants in the assisted conditions would return higher satisfaction scores than those in the unassisted condition.

In the qualitative phase, the findings from the quantitative study were followed up within a series of online focus groups with children and youth from the target population. In line with a participatory research approach (Groundwater-Smith et al., 2014), we regarded our
participants as coresearchers who were actively involved in the explanatory process. Participants discussed possible explanations for the findings from the quantitative study, to provide first-person views on the topic of response bias.

The aim of the integration of quantitative and qualitative results in an explanatory sequential design was to advance the knowledge on the occurrence and nature of response bias in survey research, leading to recommendations for future practice.

2. Methods

2.1. Mixed-method research design overview

An explanatory sequential design (Creswell, 2016) was used to guide the methodology of this study. In such a design, quantitative data are analysed statistically, but limited inferences are made from the data. The qualitative part of the design is used to explore possible explanations for the quantitative results (Walker and Baxter, 2019). First, we performed quantitative analyses on the results from the survey, comparing the three experimental conditions. We then followed-up the quantitative survey analysis with online focus group interviews because (a) we could not adequately explain the results from the quantitative analyses by referring to the extant literature, as the explanations offered in the literature were diverse and inconclusive; and (b) because we as researchers did not want to make inferences about the subjective justifications of children and youth. Instead, we wanted participants to explain the results to us themselves and in their own words.

For the quantitative study, a randomized experimental design was used. Participants were randomly assigned to one of three conditions, using simple randomisation with an online random number generator (www.random.org). In the first condition, participants completed the My Opinion survey unassisted, in the second condition they were assisted by a care worker, and in the third condition they were assisted by a research assistant. The results were analysed to test if satisfaction scores differed between conditions.

To explore explanations for the results found in the quantitative study, children and youth participated in online focus groups and individual interviews. In the structured focus group interviews, participants reflected on the quantitative study results and explored possible explanations for the results.

The Journal Article Reporting Standards (JARS) for Quantitative (JARS-Quant; APA, n.d.) and Qualitative (JARS-Qual; APA, n.d.) Research were used to guide the reporting of the quantitative and qualitative study components respectively. The Mixed-Method Article Reporting Standards (MMARS; APA, n.d.) were used to report the integration of quantitative and qualitative data.

2.2. Quantitative study

2.2.1. Participants

An a priori power analysis using the G-power computer programme (Faul and Erdfelder, 2007) indicated that a total sample of between 66 and 159 respondents would be needed to detect medium to large main effects ($\eta^2 = 0.06$ to 0.14) with 80% power using an ANOVA with alpha at .05. We set out to include a minimum of 160 participants, but despite efforts to motivate more participants for inclusion and higher attrition rates than expected (see Participant Recruitment and Sampling) we had to settle for a final study sample of 120 participants. This meant that the minimum population sample requirements to detect a large effect were met, but in case the main effect proved to be in the direction of a medium-sized effect, the design was slightly underpowered.

Participants were children and youth aged 11–23 years that temporarily resided in one of three residential treatment facilities of Koraal, an organisation for care and education based in the south of The Netherlands. Most of the children and youth admitted to these facilities have a mild intellectual disability or borderline level of general intellectual functioning (MBID) and were admitted to the facility by formal referral. Of participants for whom a recent Full Scale IQ was available, 50% of participants had a total IQ score below 70, 49% had a total IQ score between 70 and 84 and one participant had an IQ score of 86. The level of adaptive functioning was not formally assessed for any of the included participants.

There were no group differences in terms of demographic characteristics across conditions. For Age, $F(2, 117) = 0.233, p = .792$, for IQ, $F(2, 61) = 1.396, p = .255$. For Gender, $X^2(2, 120) = 2.129, p = .445$.

Participant characteristics are displayed in Table 1.

2.2.2. Participant Recruitment and Sampling

For the purpose of the present study, potential participants received a flyer, information letter, consent form with study details and requirements for participation. Because all participants are part of a vulnerable low-literate target group, information and consent forms were formatted according to Easy-Read guidelines. Of 355 children and youth that were approached, 134 (38%) consented to participate in the research. Parents and guardians of children and youth under 16 years of age were asked to consent to the participation of their child. No parent denied participation for their child. All participants were rewarded with a gift card to the value of €5.

During the actual survey period, due to rising numbers of Covid-19 infections, the enforcement of strict limitations in contact between clients and persons from outside the institution limited the access of research assistants to participants. As a result, nine participants were dropped from the Assisted by research assistant condition. They were offered to complete the survey unassisted or assisted by a care worker, and their results were omitted from the analyses. Participant recruitment and sampling flow can be found in Fig. 1.

The quantitative part of this study was reviewed and approved by the Ethics Review Board from the University of Amsterdam (registration number 2019-CDE-10133).

2.2.3. Instruments and procedures

2.2.3.1. My Opinion client satisfaction survey. The My Opinion questionnaire measures a client’s satisfaction with aspects of received care and quality of life on 17 items. Assessment results in scores on the subscales client-carer relation, autonomy, leisure & physical environment and group climate and in a total satisfaction score. The questions are presented in a digital format, one question per page. The language for items and responses are formatted according to Dutch Easy-Read guidelines (Moonen, 2021). Responses are given on a 5-point Likert scale. A read-aloud function and visualised response options assist participants who are less able to read. The My Opinion questionnaire has been validated in samples of children and youth with MBID (De Meyer, Van Dam and Delsing, 2016) and adults with mild to moderate intellectual disabilities (Wissink and Kooijmans, 2020). The internal consistency of the My Opinion questionnaire is satisfactory (Cronbach’s α’s

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Characteristics of quantitative study participants.</th>
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<tbody>
<tr>
<td></td>
<td>Unassisted</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(N = 49)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean (SD)</td>
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<tr>
<td>Gender</td>
<td>Female (%)</td>
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<tr>
<td></td>
<td>Male (%)</td>
</tr>
<tr>
<td>IQ</td>
<td>Mean (SD)</td>
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a Total N for IQ is 64. For 56 participants (47%) their recent total IQ score was unknown or they or their parents did not consent to share recent IQ scores.
range from 0.78 to 0.83 across populations). Adequate convergent validity was observed when comparing My Opinion results to the results of a comparable youth client survey, the so-called C-test (Dutch: C-toets; Franssen and Jurrius, 2005).

Cronbach’s Alpha for the My Opinion 17-item total score in this study was 0.84.

2.2.3.2. Assessment procedure and conditions. After randomisation, all participants and their care workers received instruction on how to complete the survey.

In the Unassisted condition participants were instructed to choose a quiet room where there was minimal chance of disruption and completed the questionnaire by themselves. Follow-up contact with respondents indicated that all participants in the Unassisted condition had indeed managed to complete the survey without help.

In the Assisted by care worker condition, care workers were instructed to schedule a moment for the assessment with the participant and complete the survey together at the appointed time. The care worker read aloud every question and the participant was subsequently invited to answer the question. The care worker was instructed to stick to the procedures outlined in the survey manual, which are meant to standardise the assessment as much as possible.

In the Assisted by research assistant condition, the same procedure as in the Assisted by care worker condition was followed. The research assistant was not familiar to any of the participants beforehand.

2.2.4. Quantitative data analysis

For all analyses, the independent variable was the assessment condition and the dependent variable was the mean client satisfaction score across all items.

Homogeneity of variance was tested using Levene’s test. The error variance of the dependent variable was equal across all groups in the model $F(17, 102) = 1.47, p = .122$. A Shapiro-Wilk test of normality revealed that scores in the Unassisted and Assisted by researcher conditions were distributed normally, $W(49) = 0.96, p = .059$, and $W(31) = 0.98, p = .834$, respectively, but the scores in the Assisted by care worker conditions were not, $W(40) = 0.91, p = .005$. Because the assumptions about normality of the distribution of scores could not be met, a Kruskal-
Wallis test was performed to assess differences in the total satisfaction scores under the three conditions. Dunn’s post-hoc tests were performed to further explore any statistical differences in group means.

2.3. Qualitative study

2.3.1. Participants

Participants for the qualitative study were children and youth that lived in group care homes at Koraal. Seventeen children and youth participated in individual or focus group interviews. Characteristics of the interview participants are comparable to the quantitative study participants in terms of age and general cognitive capacities (Table 2).

2.3.2. Participant Recruitment and Sampling

Participants were recruited from the three facilities’ respective client council members. Participants were asked to participate in a small (maximum of 6 participants) focus group. At their own request or for logistic reasons, some of the children and youth participated in individual interviews. After the first interviews and focus groups, the data were analysed. In a series of iterative steps more interviews and focus groups were conducted until no new information was put forth by the participants. The final sample consisted of 17 participants. Of these, 13 were members of the client council. Four more participants were not council members but requested to participate voluntarily. Interview participants did not receive a monetary remuneration, but were given drinks and treats during the interview as a token of appreciation.

The focus group study was approved by the University of Amsterdam Ethics Review Board (registration number 2019-CDE-11604).

2.3.3. Instruments and procedures

2.3.3.1. Online focus groups.

Due to COVID-19 contact restrictions, opportunities for organizing in-person focus groups were limited. As an alternative to in-person focus groups, we resorted to online meetings using Teams (Microsoft, 2018) as an online platform. In comparison with in-person focus groups, richness of data and themes that emerge in online focus groups are comparable. Researchers comparing both modalities even suggest that participants may be more candid when they discuss sensitive topics online than they would in-person (Woodyatt et al., 2016).

The main goal of the focus group meetings was to let participants reflect on the outcomes of the quantitative study. Before presenting the results, probing questions were asked to engage the participants and help stimulate the process of reflection. They were asked to predict outcomes using the online Mentimeter web polling application (www.mentimeter.com). Upon sharing the actual results, the participants were then asked if the results fitted their preconceived ideas. Mentimeter questions were further used to ask a multi-response question about possible mechanisms underlying the results (e.g. “Why do you think this result is observed? Because explanation a., explanation b., etc.”). They were then asked to use their own lived experience of everyday life in the facility to elaborate on their explanations and forward examples to illustrate. Three main questions were the subject of study in the focus groups:

- Satisfaction scores proved to differ between conditions. In what condition do the survey results reflect the children and youth’s ‘true’ opinions?
- Why do results differ between different conditions? Does the presence of a person assisting you distort the answers you give? What cognitions, feelings and expectations account for these distortions?
- Knowing that assistance influences results, and acknowledging that many children and youth require assistance to complete the survey, how should researchers adjust survey assessment procedures to optimally reflect children and youth’s true opinions?

These questions were broken up into sub-questions and reworded to take into account the verbal understanding skills of the children and youths under study. Questions were presented on screen and read aloud by the researchers. Each question was addressed by first asking “How does this work for you?”, then “How do you think it might work for others (and why?)” and finally “Knowing this, what should we do with the outcomes?”. In case participants had different viewpoints on topics, they were encouraged to challenge each other’s opinions through respectful discussion. The researchers served as mediators. When all questions surrounding a topic were answered, the researchers concluded by providing a summary of the participants’ responses and asked them to corroborate or correct the proposed conclusions.

The interview procedure was scripted in detail to ensure a high level of standardisation. The scripts for individual interviews and focus groups were identical. The interview structure and online focus group format were pilot-tested with representatives from the client council (who were not part of the eventual study sample). Minor revisions to the script were made to clarify language, visualisations of survey results and the Mentimeter questions.

Three focus groups were held, one at each participating location, with four, six and two participants respectively, and a further five participants were interviewed individually at their own request. Each session lasted between 32 and 53 min and was recorded and transcribed verbatim. All sessions were moderated by the first author (RK) and a research assistant.

2.3.4. Qualitative data analysis

To analyse the transcripts from the focus groups and interviews, thematic analysis was applied following the steps outlined by Braun and Clarke (2012). The first author (RK) and a research assistant familiarised themselves with the data by viewing and reviewing the recorded interviews, comparing notes on the interviews and reading and rereading the transcribed interviews. The data were then restructured in a data charting form, where all relevant citations were arranged under the corresponding interview topic. The answers to the closed Mentimeter questions were seen as sensitising questions and were not formally analysed. Next, all text fragments, arranged per topic, were uploaded in Atlas.ti 8 for initial coding by the first author and a research assistant. A behavioral scientist with extensive clinical and research experience working with MBID adolescents was added to the coding team. She was not involved in any part of the design or implementation of the survey or focus groups and was therefore seen as an ‘impartial outsider’, with no preconceived notion of the topic.

For the purpose of additional external validation, a second ‘impartial researcher’ was asked to review the raw data and the inferences that were made from them. This researcher was a seasoned qualitative research expert in the field of youth care research, working in an unaffiliated university. Her findings were used to corroborate, refute or finetune our own conclusions.

2.4. Integration of quantitative and qualitative data

The thematic analysis resulted in a set of tentative explanations for the results and recommendations for future practice, all forwarded by the children and youth themselves. In the Discussion, the results from...
the quantitative analyses were integrated with the explanations and recommendations offered by the participants. Conclusions were mapped against the interaction factors mentioned in the Introduction, to connect their observations and opinions with the extant literature. Recommendations and implications for practice were formulated based on the integrated results.

3. Results

3.1. Results of the quantitative analyses

Because non-parametric tests were used to test differences between conditions, both median and mean total scores are presented. Median and mean total satisfaction scores per condition can be found in Table 3. There was a significant difference between the three groups on satisfaction scores, H(2) = 12.2, p = .002, η² = 0.09. Post-hoc testing revealed that children and youth assigned to the ‘assisted by care worker’ group exhibited significantly higher satisfaction scores than children and youth in the ‘unassisted’, p = .009, and ‘assisted by researcher’ groups, p = .006, while there was no significant difference between the ‘unassisted’ and ‘assisted by researcher’ group, p = 1.00.

3.2. Findings from the interviews and focus groups

All participating children and youth expressed that they had enjoyed discussing the findings with the researchers and with each other. Participants shared some differing but also very similar experiences of daily life in a treatment facility and gave very powerful insights in the complex dynamics between those receiving and providing care. Below, the results from the interviews and focus groups are summarised under the three questions that were mentioned in the Methods section under Online Focus Groups. Per question, emergent themes from the thematic analyses are discussed.

3.2.1. Under what conditions do children and youth voice their ‘true’ opinions?

When discussing this topic, a notion emerged that was replicated throughout all interview topics: many respondents tended to make a distinction between what they themselves would think and do and how their peers might think and act. Specifically, some participants suggested that they would be honest under all conditions and that it wouldn’t matter if someone was present. But others might find it difficult to give honest answers in the presence of an assistant. M (20 yrs, female): ‘I’m always honest, doesn’t matter who’s there … I expect others to be honest too, no matter what... but maybe your answers aren’t truthful if you feel it’s something to be embarrassed of...?’.

When the results of the quantitative experiment were presented, demonstrating that participants assisted by a care worker showed higher satisfaction scores, most participants said they were not surprised. Next, we presented the participants with two options as to what the ‘true’ value of the mean population satisfaction scores was: either respondents give unrealistically high scores in the presence of their care worker or they give unrealistically low scores in the other conditions. On the one hand, participants expected respondents to feel free to offer open and honest criticism in the ‘unassisted’ condition, whilst being hesitant to open up to their care workers. On the other hand, some participants stressed that children and youth may be tempted to exaggerate their criticism of the facility when they are alone or with a stranger, hence deflating ‘true’ mean satisfaction scores across conditions. J (17 yrs, male): “For one like to be honest. I don’t like lying. I really dislike it… but when they are on their own, I think they might give very low scores on purpose.” In this case, the respondents’ scores in the ‘assisted by care worker’ condition would more truly reflect the population satisfaction scores. One respondent stressed that there was really no way of knowing if the scores in the ‘unassisted’ condition are true scores as there is no one to follow-up on their answers to see if they understood the question and check if this is really how they felt: “They can answer just about anything, just to get it over with”.

3.2.2. Why do results differ between conditions?

We further explored underlying mechanisms that could account for the observed difference between scores. Some very plausible, yet not conclusive nor mutually exclusive, explanations emerged that provide insight into how children and youth experience the complexities of carer-client dynamics in residential care. After sensitising the participants with multiple-choice Mentimeter question, three main explanatory mechanisms emerged from the reflective discussions on the results: (a) avoiding tension and conflict; (b) empathic reactions; and (c) dependence. A fourth theme pertaining to (d) the quality of the relation of children and youth with their care worker as a mediating factor.

3.2.2.1. Avoiding tension and conflict. Almost all children and youth indicated that providing open and honest critical feedback in the presence of a care worker can be quite daunting. In the perception, and occasionally the direct experience of participants, being critical about the quality of care they receive can easily be mistaken as insolence by care workers. J (15 yrs, male): “… for instance, if you had an argument with this person before, you may not want to tell the truth. Because you’re scared that the person gets angry with you.” Sometimes expressing an opinion will even be seen as a testimony of a youth’s ignorance - ‘they don’t know what’s good for them’. A (17 yrs, female): “Once, I made a decision that did not agree well with what my care worker thought was smart and then he and everyone around me got mad at me. And then I thought I should have been compliant with what they think is best. So that sort of thing makes me quite insecure about answering these kinds of questions with my care worker, they might get mad again.” Most participants stated that they can imagine that their peers may be apprehensive to provide negative feedback. But when asked if they had experienced at first hand that care workers reacted angrily if they expressed criticism, very rarely could they provide examples. On the contrary, many examples were put forward of care workers encouraging children and youth to be open and honest. A (15 yrs, male): “… generally they will remain calm, you can just give your honest opinion. They will say it’s okay to be honest.” So this apprehension to provide critical opinions because of a fear of retribution on the part of the care worker seems to be quite generic, while there does not seem to be a direct justification for this fear.

3.2.2.2. Attunement. Participants made it very clear that completing a questionnaire is more than answering questions in a social vacuum. Children and youth consider the perceived expectations, thoughts and feelings of the person assisting them when thinking about what answer would be the most appropriate. Often, they may choose a response that aligns with what they think is expected of them, compromising between what they themselves feel and what they think is ‘the right answer’ in the eye of the care worker. A (17 yrs, female): “When you’re on your own you just think ‘this is it!’ But when you’re with your care worker you might think ‘Will she be ok with this?’ And then you’re considering what she may think, so it’s much better when you’re on your own.” J (17 yrs, male): “When you are with your care worker, you usually agree with him, you sort of say what the care worker wants you to say.”

Table 3

<table>
<thead>
<tr>
<th>N</th>
<th>Median</th>
<th>Minimum – maximum</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unassisted</td>
<td>49</td>
<td>2.53</td>
<td>0.65–3.71</td>
</tr>
<tr>
<td>Assisted by care worker</td>
<td>40</td>
<td>2.00</td>
<td>1.18–3.59</td>
</tr>
<tr>
<td>Assisted by researcher</td>
<td>31</td>
<td>2.41</td>
<td>1.18–3.88</td>
</tr>
<tr>
<td>Total</td>
<td>120</td>
<td>2.71</td>
<td>0.65–3.88</td>
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* Possible minimum total score = 0, maximum total score = 4.
3.2.4. How to optimise survey assessment procedures?

In a final reflection exercise, the participating children and youth were asked how the results should be translated to practice. How should the next survey be organized, knowing that many children and youth need assistance on the one hand, and seeing that it really does matter who is assisting you on the other? Not surprisingly, most participants asserted that children and youth should be offered a choice as to who assists them. There are many different preferences across children and youth. The defining factor is perceived to be the level of trust they have in their care workers. If the youth is not sure if he can trust his care worker, or is uncertain as to how the care worker will react to criticism, assistance from an impartial assistant can help them to give an honest opinion without feeling pressured into giving socially desirable answers. If there is trust and a general positive bond between youth and care worker, participants think assistance from their care worker is the best option. Mainly because of the opportunity to directly act upon the feedback, transforming complaints into an opportunity to make things better for the youth. Participants stressed once more that if staff invites children and youth to give an opinion, this means that they should be prepared to do something constructive with the results.

What was somewhat surprising to the researchers, was that not many participants advocated that it should be made possible for all children and youth to complete the survey unassisted. When asked why this option was not appealing to them, participants observed that many of their peers were unable to read and struggled to voice their opinions unaided. Although unassisted completion of the survey would minimize the chances that bias distorts the results, it was not deemed to be feasible for a large part of the population of MBID children and youth. This highlights the need to use measures that are adapted to accommodate for literacy problems and cognitive impairments.

Some participants mentioned that they would prefer trained peers to help them. Peers share the same perspective and may therefore better understand what children and youth are going through. They can be trusted, because they are ‘on the same side’.

In regard to the ‘other’ category, one participant expressed that he thought parents could help as well. They are the persons many children and youth trust the most, and who generally have a natural position to advocate the youth’s interests.

4. Discussion

In survey studies with children and youth, respondents are often in need of assistance to complete the survey. In this study, we set out to explore whether the results of a client satisfaction survey were influenced by the presence of an assistant. Based on the literature and the input from a client council we assumed that the respondents who were helped would return higher satisfaction scores than those who were not. In a subsequent focus group study we aimed to explore possible mechanisms underlying the results.

The quantitative analyses of the survey data showed that those who were assisted by a care worker had the highest satisfaction scores relative to children and youth who completed the survey unassisted or those who were helped by an assistant unequipped to the participant.

Results from the focus groups and solo interviews revealed that several mechanisms might have contributed to the difference between conditions. Conscious deliberations and subconscious processes contribute to biased answering tendencies, reflecting both functional and empathic components.

In terms of functionality, most considerations for children and youth to choose an answering strategy refer to the possibility that offering open and honest criticism may have negative consequences for their stay at the facility. Some children and youth fear that care workers may get mad when they are told that they are not ‘doing it right’. They perceive that it is in their best interest to keep the relationship positive at all times. This seems to reflect elements of a power dynamic; participants expressed that they feel they depend on the care worker to maintain
contact with friends and relatives and to organize support to meet current and future support needs. Being positive about the quality of care at the facility in the presence of a care worker, may contribute to presenting a positive image of oneself (Van de Mortel, 2008), which may be beneficial for creating a positive working alliance. A positive working alliance in turn contributes to achieving adolescents’ goals (Osr et al., 2010). Children and youth who experience warm and trusting relationships with their care worker on the other hand, assert that they have nothing to fear and being critical is seen as an opportunity to improve care by both youth and care worker.

Aside from the functional aspect of the youth-carer relationship, some children and youth let empathetic deliberations weigh in on their satisfaction ratings. They may report favorable satisfaction ratings because they may feel sorry for the care worker if they are being critical. As far as we know, empathy as a source of response bias has not been noted before in research on response biases (e.g., see Finlay and Lyons, 2002). The qualitative design, in which participants were asked to reflect on their motivations directly, may account for the emergence of this finding. This finding is somewhat surprising given the difficulties with mentalizing abilities – i.e. the ability to recognize and reflect on mental states of others and self, such as feelings and thoughts – that are observed in many children and youths with MBID (Allen et al., 2008). A general submissiveness is also observed, where children and youth may provide the answers they think care workers will want them to give (Borgers et al., 2000).

The extent to which these factors influence scores is subject to two moderating variables: (a) interpersonal variance; and (b) the quality of the relationship. Many participants acknowledged that they adjusted their answers to the person who happened to sit by them. Others maintained that they were not affected by these factors at all, and that they had no problem being open and honest in any situation. Regarding the quality of the relationship, the presence of a care worker at assessment generally inflates satisfaction scores, but predominantly so if children and youth are in a non-trusting relationship with their care worker. In that case, bias factors mentioned in the Introduction manifest themselves most clearly.

### 4.1. Strengths and limitations

Complex client-carer interactions have been observed to influence the outcomes of dialogues between those who receive and provide care (e.g. Finlay and Antaki, 2012). To our knowledge, the current study is the first that attempts to quantify the effect of assistance on survey outcomes in a population of children and youth. A marked strength to this study is the use of a mixed method design where qualitative methods were used to help us understand our results jointly with our participants.

An important limitation of this study is that the absence of a ‘gold standard’ for satisfaction limits the inferences that can be drawn from the results. Because the scores in the three conditions cannot be compared to an undisputed ‘true’ satisfaction measurement, there is no conclusive answer to the question if scores in the ‘assisted by care worker’ condition can be regarded as unrealistically high, or if the scores in the other two conditions are lower than they should be. Objectively, the scores can only be compared relative to one another, without referring to one as ‘right’ and the other as ‘wrong’. Most explanations for the observed differences seemed to indicate that the impact of interpersonal dynamics is greatest in the presence of the care worker. For several reasons, participants expressed that most children and youth would be hesitant to be critical when assisted by their care worker, as opposed to being assisted by an impartial assistant or on their own. The proposed mechanisms suggest that scores in the ‘assisted by care worker’ condition are subject to inflation, as a result of submissive responding tendencies. But the current qualitative design does not permit this conclusion to be drawn with any undisputed certainty and this requires further exploration.

As always, qualitative analysis calls for careful reflection of the process of making inferences from statements by a limited number of participants to general statements and even theories. We have tried to ensure a certain degree of methodological integrity by letting several unaffiliated researchers participate in the process of analysis and perform checks on the conclusions we drew from the data. This has not led to major adjustments in our conclusions but helped to nuance some findings. It was especially helpful in that we were constantly reminded by the ‘outsiders’ to stay close to the data and be wary to make inferences from reading between the lines.

Another limitation in regard to the qualitative phase of this study relates to our decision to sample our participants from members of the client board. They may be more invested in the research than others living in the facility, thus raising the question of representativeness. On the other hand, the very reason that they were elected member of the board is that they are deemed (and trained) to represent the opinion of their constituency. When discussing topics, they are generally more prone to take into account different perspectives from their own than other residents of the facility. Regarding the transferability of our results to more general populations, we cannot be sure that the results from our study with MBID children and youth in a residential setting will be applicable to all children and youth that are asked to complete surveys. The cognitive impairments associated with MBID may have magnified the impact of some of the response biases. A greater tendency for acquiescent responding is observed in both cognitively impaired study populations (e.g. Finlay and Lyons, 2002) and children (Havermans et al., 2015) and there may be a confluence in this study. In a direct comparison of children with and intellectual disabilities, Ramirez (2005) did not find evidence for differential acquiescent responding. Further, children and youth with MBID in residential care may be especially sensitive to client-carer dynamics as a result of their dependency of carers to provide for their everyday needs (Harder et al., 2013). Obviously, the client-carer dynamics in residential care facilities do not apply directly to children and youth living with their parents or independently. Nevertheless, dependencies exist for these children and youth too, and the assistance from parents or social workers may unwittingly shape responses to surveys for children and youth outside residential care as well.

### 4.2. Directions for further research

This study offers some interesting yet experiential insights in the way children and youth take various interpersonal considerations into account when completing a survey with assistance. Many possible mechanisms are proposed by the participants, leading to tentative conclusions and recommendations, but these mechanisms were not tested empirically. Specifically, throughout the accounts of the participants, the quality of the client-care worker relation emerged as a possible mediator for the impact of bias. It is presumed by the participants that more valid scores are obtained if the respondent has an open and trusting relation with the care worker.

Similarly, the current design has allowed us to only make statements about relative differences between conditions. Scores in one condition were higher than in the other two. But no inferences could be made about which scores more accurately reflect true satisfaction. In subsequent studies, we intend to use cognitive interviewing techniques (Miller et al., 2014) to gain further insight into what is actually happening when a respondent completes the survey.

In this study, respondents were assigned to a condition randomly, receiving assistance on the basis of their allocated condition, rather than an observed or expressed need for assistance. In practice, many children and youth, especially with MBID, receive help unsolicited, often because they are deemed incapable of completing a survey by themselves. To promote a sense of autonomy, and reduce possible bias from interaction factors, unassisted completion could be beneficial in many instances. In order to allow more children and youth with MBID to complete surveys
by themselves, more research on the boundaries of giving valid self-reports is needed. What can they do by themselves, how can inclusive design features support them and where is assistance really needed?

4.3. Implications for practice

From the results of this study, it is very likely that it matters who provides assistance. Researchers conducting a survey should not assume that helping children and youth to complete a survey is always beneficial if they want to elicit the true opinion of children and youth. When thinking about conducting a survey, especially children and youth that are placed in residential care, the option of letting respondents themselves choose who can assist them might be considered. However, this study has demonstrated that pairing participants to different modes of assessment based on their preference might lead to different results for different participants (i.e., those not assisted versus those who are assisted). In the design stage of a study, researchers should at least be aware of the possible distorting effect of offering assistance. They should carefully balance out the added value of tailoring assistance to the needs and preferences of participants and the value that is put on standardized research procedures. The first maximizes the validity of answers, especially self-reported information on sensitive topics, while the second may be essential if reliability requirements call for standardized procedures. Where research designs involve offering respondents assistance, and there is a pre-existing relationship between a pair, then researchers may need to take this into account when designing studies and analyzing findings.

If for logistic or other practical reasons this is not feasible, it would be preferable to arrange for ‘impartial outsiders’ to assist if needed. If there is no alternative to letting care workers assist participants, they should at least be offered the opportunity to choose the person they trust the most – or distrust the least.

Another suggestion that was offered by participants was to use trained peers as assistants. This might be especially helpful for children and youth who have a history of adverse life experiences involving adults and who have developed a general distrust against adults. Careful consideration is warranted, as peer assistants are usually not in the position to help turn results into actions and may struggle to provide after-care in reaction to strong emotional and behavioral reactions to the assessment, especially when covering sensitive topics.

The most reliable way to minimize interaction factors and ensure that participants will answer truthfully however, is to stimulate that as many children and youth as possible can complete the survey unaided. This calls for an effort to make the survey and the survey procedure as inclusive as possible. Evidence-based guidelines for adapting self-report instruments to persons with intellectual disabilities are provided by Kooijmans et al. (2022). These include the use of Easy Read guidelines, visualization, modified response options and the use of digital media such as text-to-speech and speech-to-text options. These recommendations extend beyond the field of intellectual disability research and are applicable to other vulnerable populations that benefit from inclusive research practices.

Further efforts are needed to connect survey outcomes from unsupervised assessments to quality improvement measures that benefit the individual respondent. When children and youth experience that they are asked to give their opinion, but the results are not followed-up by tangible actions, they may be reluctant to contribute the next time we ask them.

The implications of this study may reach well beyond research with children and youth to other vulnerable populations. Generally, our results suggest that the nature of a relationship between a respondent and the person asking questions may introduce bias. While this has implications for research involving children and young people, it also has implications for others who struggle to complete questionnaires by themselves, including those with intellectual disabilities, reading difficulties, non-native English speakers or those with physical disabilities.

‘Dependency’ appears to be a major contributing factor to the occurrence of response bias, and other vulnerable populations may be equally dependent on maintaining positive relations with caregivers or other helpers. Although our study does not permit us to draw conclusions about the applicability of the results to other marginalized populations, there are implications for other studies where a respondent is asked questions by an interviewer.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Credit statement

Roel Kooijmans: Conceptualization, Data curation, Formal analysis, Methodology, Validation, Visualization, Writing – original draft, review and editing, Peter Langdon: Conceptualization, Methodology, Supervision, Writing – review & editing, Xavier Moonen: Conceptualization, Methodology, Supervision, Writing – review & editing.

Data availability

Data will be made available on request.

Acknowledgments

The authors wish to thank all children and care workers at Koraal who chose to participate in this study. They further thank Annemieck Meys and Geke Klapwijk for their invaluable work in helping us interpret the focus group results.

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