Clarivate Consulting Services

Understanding the Participant Experience of Qualitative Interview Studies to Inform Future Study Design: Analysis of Feedback Forms

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Introduction

Qualitative interviews are vital for obtaining in-depth understanding of the lived patient or caregiver experience.

The design of qualitative studies should be patient-centric - involving active, meaningful patient and researcher collaboration – but access, timeline and funding restrictions all influence decision making.

Post-interview feedback was therefore obtained to understand patient and caregiver experiences of participating in a qualitative interview study.

Objective

To understand the patient/caregiver experience of participating in a clinical outcomes assessment (COA) qualitative interview study to inform future study design.

Methods

Participants in COA studies from 2018 to 2023 were asked to complete a brief, optional feedback form after their concept elicitation and/or cognitive debriefing interview.

Feedback forms included free text questions analyzed using qualitative content analysis in ATLAS.ti v9 and multiple-choice questions analyzed descriptively in Microsoft Excel.

Free text questions asked how participants felt about the way they were invited to participate in an interview, how they felt before participating in the interview, how they felt after participating in the interview, how they would describe their overall experience and if they had any advice/suggestions on how to improve the interview process.

Multiple choice questions asked participants how they felt about the length and format of the interview, who they would have been happy to be interviewed by, who they would most like to be interviewed by and how likely they would be to participate in other research interviews.

Results: Sample

Feedback forms, that included permission to use/publish, from 106 patients, across 14 COA studies were analyzed; see Table 1 for sample and study characteristics.

Table 1: Sample and study characteristics

| Characteristic | N (%) | |
|--|--|--|
| Participant type | | |
| Patient Caregiver of child/adolescent Caregiver of adult | 89 (84%) 13 (12%) 4 (4%) | |
| Interview type | | |
| Remote (online/telephone) Face-to-face | 59 (56%) 45 (44%) | |
| Interview length | | |
| 90-minutes 75-minutes 60-minutes 45-minutes 30-minutes | 77 (73%) 1 (1%) 19 (18%) 3 (3%) 6 (6%) | |
| Participant location | | |
| US Germany China Japan | 71 (67%) 13 (12%) 11 (10%) 11 (10%) | |
| | 11 (| |

| Japan | 11 (10%) | |
|--|----------------------------------|--|
| Indication based on International Classification of Diseases 10th revision (ICD-10) | | |
| Certain infectious and parasitic diseases Diseases of the digestive system Congenital malformations, deformations and | 33 (31%) 23 (22%) 15 (14%) | |
| chromosomal abnormalities Diseases of the nervous system Neoplasms | 9 (8%) 9 (8%) | |
| Diseases of the musculoskeletal system and connective tissue Endocrine, nutritional and metabolic diseases Diseases of the circulatory system | 6 (6%) 6 (6%) 5 (5%) | |
| | | |

Multiple choice interview preferences and feedback

Participants would most like to be interviewed by a researcher over their doctor/nurse or a patient/caregiver peer or had no interviewer preference (Figure 1).

Most participants felt:

- Interview length was appropriate (Figure 2)
- ✓ Interview format was appropriate (Figure 3)
- Participation in other research interview studies was very likely based on their present study experience (Figure 4)

Figure 1: Interviewer preferences (n; %)[†]

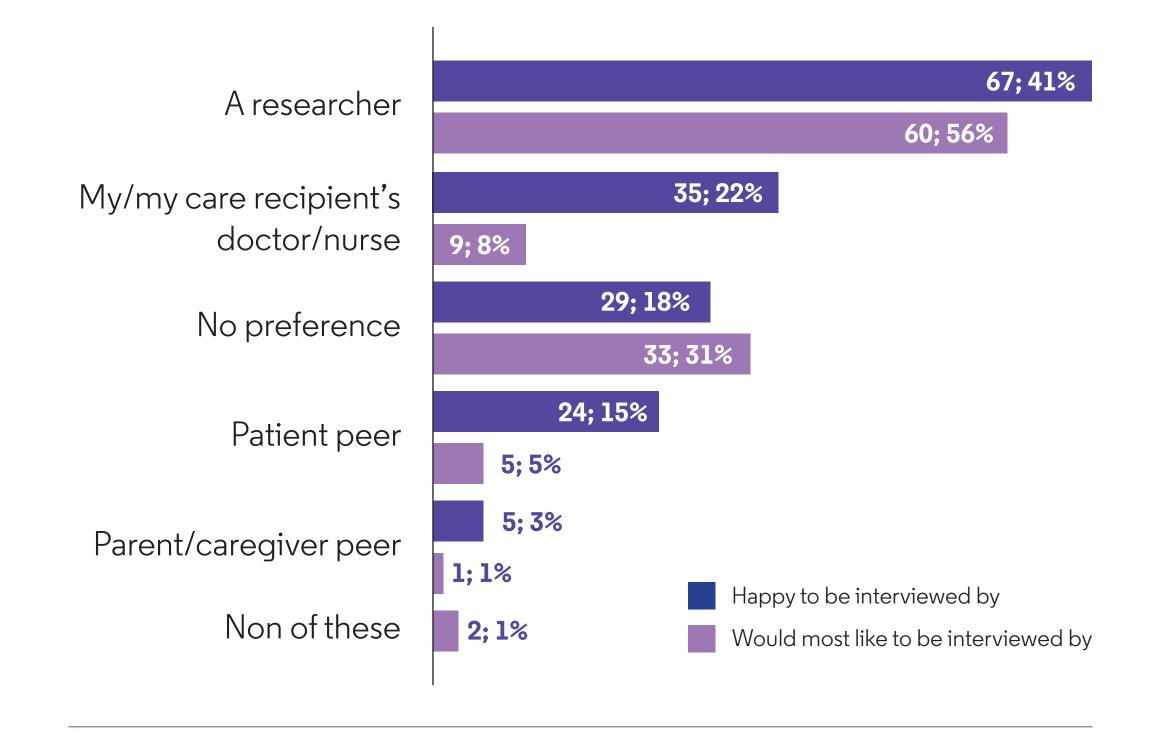


Figure 2: Interview length feedback (n; %)

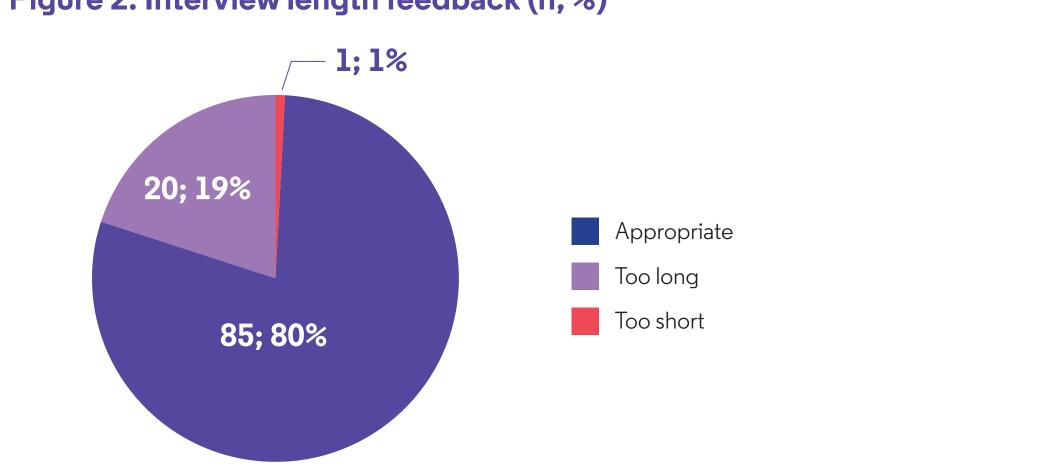


Figure 3: Interview format feedback (n; %)[†]

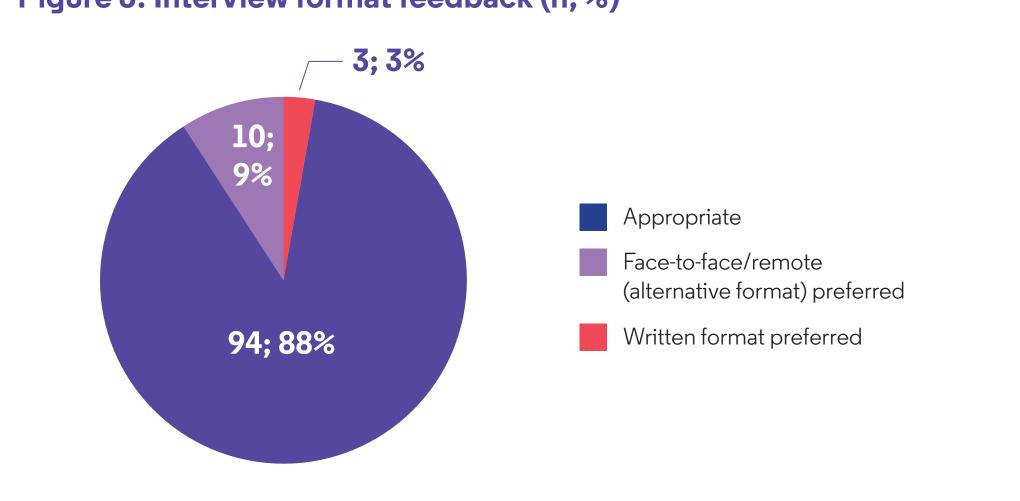
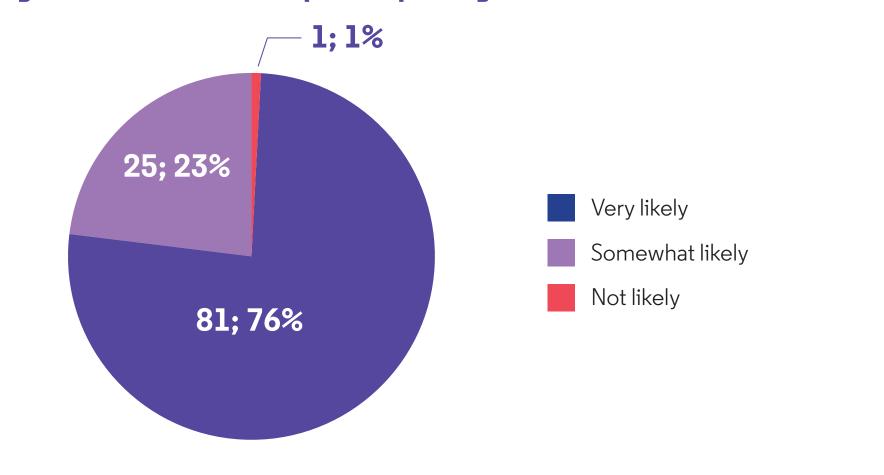


Figure 4: Likeliness of participating in other research interviews (n; %)[†]



Free-text feedback

The invitation and interview processes were described as good, easy, comfortable and professional; some participants commended their interviewer for being considerate in handling sensitive topics.

"It was excellent. I felt welcomed and comfortable."

"It was well done and felt very professional. The questions asked were stated kindly and without judgement."

"It was well conducted, the interviewer was very clear and put me at ease. I enjoyed participating. It was nice to be asked for input on the nature of the questions and I was able to make suggestions."

Positive feelings and nervousness or curiosity were felt before participation and, afterwards, participants felt happy to have contributed to research.

"I felt nervous, not knowing what to expect. Excitement was part of this experience"

"I feel good about having participated. It was one of the most well laid out and thought-out surveys I have ever done. It made me feel like my thoughts were very important to the overall design of the survey."

Problems and suggestions for improvements were few and varied but predominantly related to methodology (e.g. less repetition, technical difficulties with video conferencing, shorter duration, advanced content information) and accommodations for children (e.g. simplifying questions).

"There are many similar questions, and it would be better to be a little more selective in the type and number of questions."

"Shorten the interview process for children."

"I would have the subject fill out the questionnaire in advance and then review it with the interviewer."

"I had trouble with Microsoft Teams. I like zoom better. [...] What I did like was we ended up splitting the interview in 2 parts. [...] With my condition it's hard to concentrate on be on the phone or computer screen for long periods of time. It's nice to have breaks."

Conclusion

Participants felt positive about their overall experience, were happy with their interview and valued contributing to research.

Additional explanation regarding COA interview methodology (e.g. importance of item-by-item debriefing and thus the potential for repetitive questioning) and mitigating potential remote interview technical difficulties may be beneficial and appreciated.

† Participants may have provided multiple responses.