

Development of the Adelphi Caregiver Experience Questionnaire© (ACARE):
A Novel Tool Designed to Measure and Understand the Burden and Quality of
Life Impacts of the Caregiver Role

Gavin Dickie (MSc)¹, Kaelyn Rupinski (BS)¹, James Piercy (PhD)², Jonathan DeCourcy (BSc)², Victoria Higgins (BA Hons)², Lily Settel (MPH)¹, Nina Sankriti Kumar (BA)¹, Maggie McConnell (MMS)¹, Alan Shields (PhD)¹, Leighann Litcher-Kelly (PhD)¹

¹ Adelphi Values, Boston, MA, USA, ² Adelphi Real World, Bollington, UK

Background and Objectives

> The burden and impact of caring for individuals with health conditions are rarely well understood or quantified, with the availability of existing defensible caregiver burden assessments lacking in clinical research.¹

> This deficit poses challenges for understanding how treatments may reduce burden and enhance sustainability in the caregiver role.

> Based on a previously conducted concept-focused literature review¹ and review of existing caregiver assessments,² we developed the novel Adelphi Caregiver Experience Questionnaire (ACARE©) to better quantify the burden and associated impacts across different caregiver settings.

> This study describes the results from meetings with caregiver experts to elicit feedback on the draft ACARE questionnaire, and describes the subsequent revisions made.

ACARE

Adelphi CAREgiver Experience Questionnaire

Methodology

Draft questionnaire development

> Selection of concepts (i.e., impacts associated with caregiving) for the draft questionnaire was based on appropriateness across caregiver settings, measurability across multiple contexts, and frequency/importance from the literature

Concepts were included in the questionnaire if they were:

> Important and relevant across multiple caregiver populations (e.g., caregivers of children, caregivers of adults)

> Frequently reported or deemed important to measure in the literature

> Some concepts (e.g., independence), although infrequently reported, were included as they were considered more relevant for general caregiver groups

> Appropriate for a caregiver self-report

Concepts were excluded from the questionnaire if they were:

> Only relevant to specific caregiver populations (e.g., spouse/partner relationship)

> Redundant with other included concepts

> Infrequently reported in the literature

> May be more comprehensively assessed by pre-existing questionnaires

> Not appropriate for a subjective caregiver self-report (i.e., would be best measured via another type of assessment)

Overall, 12 concepts were identified for inclusion in draft questionnaire

Draft questionnaire used a seven-day recall period

Response options were on a five-point verbal response scale ranging from “Not at all impacted” to “Extremely impacted”

Definitions were developed to explain the purpose, intent and conceptual content of the draft questionnaire, including the instructions, response options and items

Caregiving expert advice meetings

Qualitative meetings were conducted with ten caregiving experts comprised of patient organization members, non-professional caregivers and professional caregivers

Feedback was elicited on the relevance, comprehensibility and appropriateness of the draft ACARE questionnaire

Questionnaire refinement

Qualitative data from the interviews were analyzed and the draft ACARE questionnaire was revised based on the feedback received

Table 1: Relevance and Appropriateness of the Item Concepts

> At least 80% of experts reported that each of the item concepts were relevant and important to caregivers and were measured appropriately by the questionnaire (Table 1).

> Experts reported that the most important concepts on the ACARE questionnaire were emotional wellbeing (70%), physical health (50%), sleep (40%), and worry for financial wellbeing (40%).

Item concept:	80%	90%	100%
Relevant to caregiving?			
Appropriately measured?			
Ability to care for yourself			
Work or education			
Sleep			
Ability to participate in social activities			
Relationship with the person you care for			
Worry for financial well-being			
Physical health			
Emotional well-being			
Other relationships (e.g. family / friends)			
Recreational activities			
Independence			
Household responsibilities			

Table 2: Revisions made to the ACARE questionnaire

> All experts reported the ACARE questionnaire to be clear and understandable to caregivers.

> While suggestions were provided to reword item concepts for clarity, most suggestions were raised by only one or two experts.

> All feedback were compiled. While most of the draft questionnaire remained unchanged, components of the ACARE questionnaire were refined based on expert advice (Table 2).

Component	Revisions made to ACARE questionnaire based on expert advice
Title	The term “burden” was removed from the questionnaire and title, to soften language and avoid potentially upsetting caregivers who do not consider caregiving as a burden
Instructions	The term “burden” was removed from the instructions and replaced with the term “challenges”; added acknowledgement that caregivers may experience positive impacts of caregiving despite questionnaire measuring negative impacts
Response scale	Response option updated to “not at all negatively impacted”, to have an applicable option for responders who only experienced positive impacts
Work or education item	The item and response anchors were modified to measure “ability to work or pursue education”, to expand applicability to responders who are not working (e.g., due to caregiving responsibilities, retired), avoiding need for “not applicable” response option
Independence item	The item was modified to help clarify the meaning of the concept of measurement (i.e., control over your life, choices, and time)

Conclusions

> Meetings with professional and non-professional caregiving experts demonstrated the value of measuring caregiver burden and helped refine the ACARE questionnaire for future use.

> Next steps will include gathering evidence of content validity (e.g., cognitive debriefing interviews), psychometric validation, and administration of the questionnaire in observational studies to obtain real-world data.

> Future work on the ACARE questionnaire may also involve adapting it into specific caregiver groups (e.g., modules, group-specific items, etc).

“It covers a nice wide range of the burden of caregiving, not only looking at the individual that’s been caregiving for, obviously it’s focused on the caregiver, which is actually quite rare in my experience and nice to see. And it also looks at things like financial, but also more of the broader things, which in a lot of ways is equally important. So yeah, the recreational and the social, the sleep, I think it’s really nice actually.”

– Professional caregiving expert (United Kingdom)

Results

> Experts were located in the United Kingdom (80%) and the United States (20%).

> In total, 70% of experts identified primarily as an informal caregiver, 20% identified primarily as a formal caregiver, and 10% were associated with patient advocacy groups. In addition, one informal caregiver was also part of a patient advisory group.

> Experts commonly reported providing care/support for activities of daily living (70%)

> The majority (>60%) reported the questionnaire to be comprehensive. Of the additional concepts that experts suggested might be missing from the questionnaire, none were mentioned by more than one expert.

> Most experts (70%) reported the seven-day recall period as appropriate although some (20%) suggested a longer recall period was preferable. * Developers retained the seven-day recall period so the questionnaire would remain applicable across different contexts of use.

> All but one expert (90%) reported a preference for the five-point verbal response scale over an alternative 11-point numeric rating scale (0 [Not at all] – 10 [Extremely impacted]).

* One expert (10%) did not provide a clear response to whether they considered the recall period to be appropriate

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> GD, KR, LS, AS and LL-K are employees of Adelphi Values, Boston, MA, USA.

> NSK and MM were employees of Adelphi Values, Boston, MA, USA at the time the study was conducted.

> JP, JdC and VH are employees of Adelphi Real World, Bollington, UK.

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References

[1] Rupinski *et al.* (2025) [PCR76 - Do Existing Caregiver Assessments Measure What's Important to Caregivers?](#) Poster presented at ISPOR 2025, Montréal, Quebec, CA. Abstract published in Value in Health, Volume 28, Issue S1

[2] Dickie *et al.* (2025) [PCR66 - Understanding the Caregiver Experience Through an Exploration of the Literature.](#) Poster presented at ISPOR 2025, Montréal, Quebec, CA. Abstract published in Value in Health, Volume 28, Issue S1

