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## ORIGINAL ARTICLE

## SURVEY ON CAREGIVERS' BURDEN OF CARE PATIENTS WITH CHRONIC STROKE AND CONSIDERATIONS ON THE ROLE OF THE PHYSIOTHERAPIST

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## ABSTRACT

**Background:** The role of caregivers in the rehabilitation process is crucial, yet the impact of caregiving on their well-being is not fully understood. This study aims to analyze the psycho-physical load on caregivers of chronic stroke patients, evaluate the variables affecting their health, and assess the significance of physiotherapists in improving patient rehabilitation outcomes.

**Materials:** A sample of 30 chronic stroke patients and their caregivers involving home-based rehabilitation services was examined over eight weeks. The study utilized various scales such as the Short Form Health Survey 36 (SF-36), Barthel Index, Stroke Impact Scale 3.0, Modified Rankin Scale, and Caregiver Burden Inventory to assess the health status of patients and the burden on caregivers before and after the intervention.

**Results:** The study found significant improvements in patient health metrics (SF-36, Barthel Index, Stroke Impact Scale, Modified Rankin Scale) post-rehabilitation. Similarly, a notable reduction in caregiver burden was observed, highlighting the effectiveness of targeted physiotherapy interventions in alleviating the psycho-physical stress on caregivers.

**Keywords:** Caregivers; Stroke; Chronic Disease; Physiotherapist; Burden.

## Introduction

Stroke is a leading cause of disability and poses significant challenges not only to patients but also to their caregivers, who often experience considerable psycho-physical burdens. In Italy, stroke is the third leading cause of death, represents the leading cause of disability, and is the second leading cause of dementia.<sup>1</sup>

It is shown that within one year after the acute event, 1/3 of ischemic or hemorrhagic stroke survivors have a high degree of disability<sup>2</sup>.

After the hospital period, in which the patient is cared for in the emergency and acute phases, the patient's post-acute care pathway continues with an integrated post-hospital and home care process.<sup>3</sup>

The World Health Organization defined home care as an array of health and social support services provided to patients in their residence. Such coordinated services may prevent, delay, or be a substitute for temporary or long-term institutional care.

Home care is a crucial aspect of the recovery process as it improves the patient's morale and well-being by involving them in their home decision-making.

Thus, it maximizes the patient's independence. It reduces hospital admission days, thereby reducing the cost of care, and with an earlier discharge, more patients can be treated in the same number of beds.<sup>4,5</sup>

With a total amount of €4 billion in investment, "Home as the First Place of Care: Home Care Assistance" has three primary objectives: improving the number of patients assisted in their homes to over a million and a half by 2026 (10% of >65 years old population); implementing a new organizational model by creating local operational hubs, to ensure the continuity, accessibility and integration of healthcare; and promoting and financing the development of new telemedicine projects for remote assistance by regional healthcare systems.

In the home care setting, the caregiver of stroke survivors is involved in in-home care and can actively collaborate in the rehabilitation process, which guides the patient to attain the motor skills necessary for performing activities of daily living.<sup>6</sup>

The caregiver's involvement in the rehabilitation process and proper knowledge of the most appropriate management strategies related to the patient's pathology can favor functional recovery and the degree of disability.<sup>7,8</sup>

The motor complications can occur following a stroke, and they face reintegration of the patient into the home environment, guiding them in acquiring new motor strategies to achieve better autonomy. Additionally, during the rehabilitation process in the

home setting, taking charge of the patient and caregiver, the physical therapist can help the process of functional recovery of the patient and improve the quality of life of the caregiver, as the rehabilitator can take care of providing the caregiver with adequate skills in knowledge of the characteristics of the pathology, suitable strategies for the management of the patient, education to cope with difficulties, and participation in the process of reintegrating the patient into daily life.

However, several studies have confirmed that caregivers experience psychophysical overload in terms of high anxiety, perceived stress, loneliness, reduced social activities, and overall quality of life. There is also an increased risk of depression in caregivers of stroke patients after the stabilization of functional impairment, as caregivers often face difficulties such as a lack of support in the knowledge of the disease and a lack of skills in managing the paperwork necessary to provide care in the home environment.<sup>9-11</sup>

A deflection of the caregiver's mood tone and the lack of appropriate tools to cope with the problems of the patient's reintegration into the home environment can result in negative implications by unfavorably influencing the rehabilitation process and social inclusion, increasing the patient's degree of disability.<sup>12</sup>

A weak positive correlation was discovered between caregiver burden and patient's age, level of disability, socioeconomic status, and more excellent caregiving hours, particularly among female and male caregivers.<sup>13</sup>

In an analysis that used caregiver reaction assessment (CRA) to evaluate burden, they highlighted that caregivers faced difficulties paying for the patient's health needs and services.<sup>14</sup>

Others reported that they did not have the strength to care for the patient and were mainly tired from caring for their relative.

The present study was conducted to determine fluctuation in the levels of stress influenced by variables such as the characteristics of the caregiver and the patient himself, and also to describe the role of the physiotherapist within this context and discuss the reduction of the caregiver's care load through his intervention, and the patient's autonomy improved, which presented the need for the study. In line with the above observations, our study aimed to detect, describe, and evaluate the caregiver burden perceived by caregivers in the home management of people with ictus.

**MATERIALS AND METHODS**

**Sample**

The study examined 30 chronic stroke patients and the same caregivers caring for them. The patients were recruited in the Agrigento area through the rehabilitation service offered by integrated home care (ADI), which is prescribed by the specialist or family doctor and provides the patient with health care at home. The project lasted eight weeks, with a cadence of 3 weekly accesses lasting 60 minutes. A total of 24 accesses were performed. With a margin of error of approximately 9% and a confidence interval of 95% on a population of 30 individuals the sample size is sufficient for 24 individuals.

**Inclusion and exclusion criteria**

Participants had to meet the following criteria to be eligible for the study: Stroke patients must be diagnosed with a stroke by brain computed tomography or magnetic resonance imaging and have no cognitive or speech impairment. Caregivers must be 18 years of age or older, may or may not have consanguinity ties with the patient, and must comply with the execution of the guidelines issued by the physical therapist for the conduct of the study. Participants were excluded if The patient resided in a long-term care institution or died during the study. The caregiver is not interested in participating in the study.

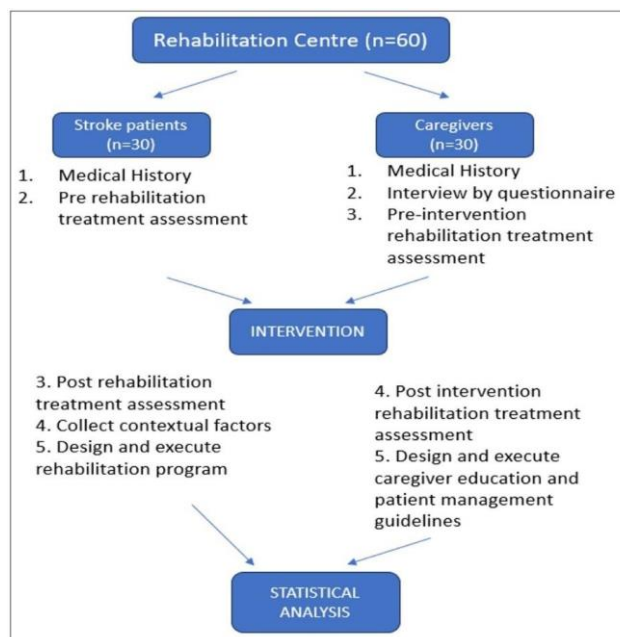
**Procedure**

The study conducted by the research team was split into two phases of data collection and intervention aimed at the patient and caregiver of the patient, respectively. According to the Council for International Organization of Medical Sciences (CIOMS-2016), approval by an ethical committee is not required because “the research poses no more than minimal risk to participants” with his non-invasive practice. The patients were selected among candidates already for rehabilitation; no personal data are shown, and this method could not have caused any damage.

**Sample selection**

The patient study consisted of taking a detailed medical history collection, including age, gender, marital status, household number, education level, employment status, diagnosis of pathology (ischemic or hemorrhagic stroke), and the onset of pathology. A pre-and post-rehabilitation treatment assessment by administering the following rating scales: Short Form Health Survey 36 (SF- 36)<sup>15</sup>, Barthel Index<sup>16</sup>, Stroke Impact Scale 3.0<sup>17</sup>, Modified Rankin Scale (MRS).<sup>18</sup>

Contextual factors were collected. Based on the data, a rehabilitation program was designed and executed (Figure 1).



**Figure 1. Flowchart of the stud**

Short Form Health Survey 36 (SF- 36).<sup>15</sup>  
 The "SF-36" questionnaire is a brevity and precision survey of the patient's state of health. It is divided into 36 questions that allow you to assemble eight different scales and two indices that summarize the overall assessments concerning Physical Health (ISF) and Mental Health (ISM). The higher the score, the better the perceived level of health.

Barthel Index<sup>16</sup>  
 The Barthel Scale or Barthel Index (BI) is a measurement instrument based on an ordinal scale, commonly used to assess Activities of Daily Living (ADL), i.e., all the fundamental activities that an adult individual performs independently and without the need for assistance to survive and take care of himself. Daily living activities like nutrition, ability to bathe or shower, grooming skills, ability to dress, control of intestinal transit, urination control, use of the toilet, mobility, etc., are measured. Each component of ADLs is assessed by deepening the patient's ability to perform independently, with assistance, or dependent on the activity under examination. Depending on the need for help, a score of 0, 5, 10, or 15 points is assigned.

Stroke Impact Scale 3.0.<sup>17</sup>  
 The stroke impact scale (SIS) is a self-report questionnaire that assesses disability and health-related quality of life after stroke consisting of 59 items, divided into eight domains like Forza, Hand

Function, ADL/IADL, Mobility, Communication, Emotion, memory, and Participation/role function. Each item is rated on a 5-point.

Likert scale regarding the difficulty the patient encountered in performing each item. The final score ranges from 0 to 100, adding up each item from each domain.

Modified Rankin Scale (MRS).<sup>18</sup>

The Modified Rankin Scale is used to assess the level of total disability. Its field of use is mainly Stroke, both in the acute and post-critical phases. It consists of 6 items, with a score from 0 to 5 (where 0 indicates the absence of disability and five the maximum of disability).

The caregiver study consists of collecting caregiver biographical and care history collection, filling out a questionnaire on knowledge and skills in disease management, and a pre-and post-intervention rehabilitation assessment by administering the Caregiver Burden Inventory rating scale.<sup>19</sup> Caregiver Burden Inventory (CBI) measures five dimensions of burden-time dependence, developmental, physical, social, and emotional burden. It only consists of 24 items and is easily administered in a personal interview or self-administered format. Based on the data, caregiver education, and patient management guidelines were designed and administered.

### Caregiver registry and care history collection

The first phase includes a registry collection and the caregiver's care history. Detailed information was collected regarding age and gender, marital status, nationality, employment relationship or degree of connection with the caregiver, and the number of work hours or the type of work other than caregiving.

Questions were administered to the caregiver in a second assessment phase, investigating the degree of knowledge of the characteristics of the condition, motor complications that may occur after stroke, and the degree of competence in managing the patient in the home setting. The following is the interview proposed by the physical therapist during the cognitive and informative interview dedicated to the caregiver.

- Has it been explained what stroke is?
- Are you aware of the motor complications that can occur after a stroke?
- Has it been explained what is meant by spasticity?
- Has advice been given on the management

and reintegration of the caregiver to be performed in the home environment to provide the best functional recovery and prevent the onset of motor complications?

The rating scale administered during the last stage of data collection to assess the physical and mental caregiver burden borne by the caregiver was the Caregiver Burden Inventory.<sup>19</sup>

### Collection of contextual factors

The personal contextual factors collected concerning the patient were marital status, household number, degree of education, and employment status.

The personal, contextual factors collected related to the caregiver were degree of kinship or employment relationship, hours worked, nationality, marital status, and degree of education. The environmental factors collected were the type of dwelling (condominium / independent villa), presence of architectural barriers, and aids possessed in the home.

### Rehabilitation protocol:

Following the assessment, a rehabilitation treatment was proposed to the patient to improve their residual abilities and help them reach a higher level of autonomy. The proposed exercises exploit the following concepts:

- **Functionality:** exercises that aim to achieve a goal or purpose through active participation by the patient relating to the external environment;
- **Problem-solving:** exercises that stimulate an active process in solving a proposed problem;
- **Dual-tasking:** activities that aim at the possibility of performing two tasks simultaneously;

The rehabilitation protocol carried out and proposed by the same group of experimenters included Active mobilization, stretching, muscle strengthening, static gaittraining, balance, and sensorimotor stimulation.<sup>3,20-23.</sup>

### Guidelines intended for the caregiver

An educational phase was dedicated to the caregiver, where the physical therapist explained the main characteristics and complications that characterize stroke in simplified language. The focus was defining the motor complications that characterize stroke in the chronic phase, such as spastic hypertonia. Helpful aids were recommended for the patient's reintegration into post-hospital life and social reintegration. During the sessions, the physical therapist trained the caregiver to prevent



spasticity and pathological radiation by positioning the patient in bed with postures maintained in stretching in the various positions: lateral, supine, prone, and sitting.

Guidance was given to the caregiver to involve the patient in activities of daily living in the home environment, such as dressing and personal hygiene, housekeeping activities, or cooking. The caregiver was educated on the performance of aerobic exercise as a daily activity, with movements such as performing postural transitions, walking around the house or outside the home, climbing and descending stairs, and cardiorespiratory and balance exercises. Finally, leisure activities were proposed to be carried out daily, with the possible adaptations ranging from board games to walking outside the home, running small errands, playful activities, and socializing.<sup>24</sup>

**Statistical analysis**

Results are reported in terms of frequencies, means, and standard deviations. The association between contextual and environmental factors and caregivers' stress levels (CBI score) was assessed by linear regression analysis using the stepwise method. Any significant changes in clinical scales following the proposed interventions were evaluated by paired-sample t-test.

Spearman's bivariate correlation analysis assessed the degree of correlation between increases in clinical rankings and contextual and environmental factors related to caregivers' workloads.

All analyses were set at a significance level of 95% and power of 80%. Analyses were performed using IBM-SPSS software vers. 27.

**RESULTS**

**Patients**

Thirty subjects with stroke were included in the study. Eleven subjects had right hemiplegia, 19 left, by 8.83 ± 9.05 months. Eighteen patients were married, unmarried, or divorced, ten were widowed, and households averaged 3.53 ± 1.22 persons.

Of the patients, 33.3% possessed a high school education, 26.7% were college graduates, 16.7% owned a middle school license, and 23.3% had an elementary school license.

Regarding housing difficulties, 43.3% lived in an easy-to-manage situation (ground floor or presence of elevator), 30% at an average level (presence of stairs in the house), and 26.7% under challenging conditions (absence of elevators in condominium housing). 63.3% needed at least two motor aids, 30% required three aids, and 40% needed only one support.

**Caregivers**

Regarding the role of the caregiver, 43.3% were spouses, 40% were caregivers, 13.3% were children, 3.3% were the patient's mother, and 80% were female, aged 52.63 ± 11.44 years.

Nationality was predominantly Italian (73.3%), followed by Romanian (13.3%), Arab (6.7%), Moldavian and Albanian (3.3%). 46.7% of caregivers had at least a high school education, 30% a bachelor's degree, 16.7% an elementary school license, and 6.7% a middle school license. 60% of caregivers reported that they needed to be educated about what stroke is or the motor complications following a stroke.

70% said that they had yet to receive helpful advice on the management and reintegration of the caregiver to provide the best functional recovery and prevent the onset of motor complications to be performed in the home environment, and 76.7% reported not knowing what spasticity means. Stress load (CBI score) at initial assessment was associated with the increased number of aids needed to manage the patient and the degree of caregiver education (Table 1).

**Table 1. Variables associated with the caregiver's level of stress**

Model			Variables entered	B	t	p
R-square adapted	F	p	(Constant)	39.774	3.682	0.001
0.25	5.836	0.008	N. aids	10.9	3.203	0.003
			Caregiver instruction degree	4.006	2.131	0.042

**Clinical scales**

After rehabilitation treatment, a statistically significant increase was found for the SF36, Barthel, SIS, and MRS scales. A significant increase was also found for the CBI scale (Table 2)

**Table 2. CBI scale**

	Delta CBI	Delta SF36	Delta BI	Delta SIS	Delta MRS	Caregivers instruction degree	working hours	Home Difficulty	N. aids	Family
Delta CBI	r	1.00	0.32	-0.30	-0.11	0.11	0.23	0.56	-0.13	0.27
	p		0.04	0.05	0.29	0.27	0.11	0.00	0.24	0.07
Delta SF36	r	0.32	1.00	-0.59	0.38	0.27	0.41	-0.13	0.16	-0.11
	p	0.04		0.00	0.02	0.07	0.01	0.25	0.20	0.29
DELTA BI	r	-0.30	-0.59	1.00	0.04	-0.43	-0.21	-0.02	-0.03	0.03
	p	0.05	0.00		0.41	0.01	0.13	0.46	0.43	0.13
Delta SIS	r	-0.11	0.38	0.04	1.00	0.20	-0.04	-0.12	0.00	0.14
	p	0.29	0.02	0.41		0.14	0.42	0.27	0.50	0.23
Delta MRS	r	0.11	0.27	-0.43	0.20	1.00	-0.09	-0.17	-0.06	0.02
	p	0.27	0.07	0.01	0.14		0.32	0.19	0.38	0.46
Caregivers instruction degree	r	0.23	0.41	-0.21	-0.04	-0.09	1.00	0.03	0.18	-0.28
	p	0.11	0.01	0.13	0.42	0.32		0.43	0.17	0.07
working hours	r	0.56	-0.13	-0.02	-0.12	-0.17	0.03	1.00	-0.26	0.35
	p	0.00	0.25	0.46	0.27	0.19	0.43		0.08	0.03
Home Difficulty	r	-0.13	0.16	-0.03	0.00	-0.06	0.18	-0.26	1.00	-0.38
	p	0.24	0.20	0.43	0.50	0.38	0.17	0.08		0.02
N. aids	r	0.27	-0.11	0.03	0.14	0.02	-0.28	0.35	-0.38	1.00
	p	0.07	0.29	0.43	0.23	0.46	0.07	0.03	0.02	
Family	r	0.27	-0.11	-0.21	-0.16	0.11	-0.08	0.28	-0.24	-0.23
	p	0.07	0.29	0.03	0.20	0.29	0.35	0.07	0.11	

Ta A significant correlation was found between the decrease in CBI scale value and the improvement in patients' SF 36 scores ( $r=0.32$ ;  $p = 0.04$ ). The reduction in CBI scale value was also correlated with the caregiver's higher number of working hours ( $r=0.56$ ;  $p = 0.00$ ) and larger family composition ( $r=0.39$ ;  $p = 0.02$ ). A correlation was also found among the caregiver variables between higher education degrees and increased SF36scores (Table 3).

**Table 3. Correlations between clinical increases and environmental variables.**

	Average	SD	T	P	T0-T1 (average)	SD
SF36_T0	86.67	3.74	-9.06	0.00	9.40	5.68
SF36_T1	96.07	5.49				
Barthel_T0	48.50	19.66	-23.39	0.00	38.50	9.02
Barthel_T1	87.00	16.48				
SIS_T0	155.80	30.07	-34.69	0.00	84.53	13.35
SIS_T1	240.33	27.42				
MRS_T0	3.60	0.72	12.45	0.00	1.63	0.72
MRS_T1	1.97	1.07				
CBI_T0	75.73	11.43	19.55	0.00	32.63	9.14
CBI_T1	43.10	11.87				

**Fi-index tool**

To avoid any risk of bias regarding the reference list, this manuscript has been checked with the Fi-index tool and obtained a score of 0 on 20/02/24 according to Scopus® for the first author only.<sup>25, 26</sup>

**DISCUSSION**

From the analysis of the data collected, it emerged that most caregivers are not educated on the main characteristics of the disease, do not know the motor complications that can occur after stroke, and have not been educated or trained to manage the patient within their domicile.

A higher stress level at the initial assessment (CBI t0) documented in caregivers was related to the more significant number of aids needed for patient management and the caregiver's level of education. It is conceivable that a higher level of education in caregivers, who in our sample possessed relatively high levels of education, could generate a greater expectation of burden on the part of the latter due to a greater awareness of the physical and social problems of the pathology, and concerns about reconciling possible job positions with the needy condition of the family member. However, it is precisely the level of education that correlates with the improvement in the patient's quality of life that is associated with decreased stress for the caregiver. The education story helps to understand the educational and management intervention dedicated to the caregiver. The results showed a substantial

decrease in caregivers 'stress levels (CBI t1), correlated with a significant improvement in the patient's quality of life after the final evaluation.<sup>27-31</sup>

A comparable study conducted by Bugge C et al. revealed that the duration of care time was a significant factor impacting the mental health of carers, which is similar to the length of care time in the current study and thus positively correlated with anxiety and depression scores.<sup>32</sup> In another study by Bambauer KZ et al.<sup>33</sup>, extended periods of care were associated with an increased risk of unpleasant feelings, such as depression and anxiety. This could result from the carers' lengthy daily care schedules taking up too much of their own time, which lessens their time for work, socializing, and leisure. According to Lv LL et al., Low education levels lead to a lack of understanding about diseases and the capacity to learn about them, which has a negative impact on carers' ability to provide care to some extent and can result in anxiety, depression, and other negative emotional reactions in the caregivers.<sup>34</sup>

Our results are also in agreement with Hu P et al., who demonstrated that of the caregivers of stroke patients, anxiety symptoms were present in 43.9%, mild to moderate depressive symptoms were present in 26.5%, and severe depressed symptoms were present in 27.4% of cases. Anxiety and sadness were influenced by daily care hours and the way that medical payments were made, and there was a positive correlation between the two conditions and the overall care burden score.<sup>35</sup>

Compared to the contextual factors collected, sex and the type of home did not seem to significantly impact the perceived stress level and the patient's functional recovery. The improvement in the caregiver's load is also related to the more significant number of hours dedicated to the assistance and a higher number of members of the patient's family unit. The physical therapist can be the key to contact with the outside world for stroke sufferers who live at home with their caregivers.<sup>36-41</sup>

The rehabilitator, assuming a guiding role, can provide directives that give information about what the pathology is, what are its symptoms, what are the recurring problems, and provide practical strategies on patient management and the best reintegration in the home environment, thus ensuring personalized assistance based on the specific needs of the caregivers. Implementing communication with these people to provide helpful information for managing patient care at home can reduce the stress on the caregiver and increase her well-being. Furthermore, the physiotherapist can intervene in the patient by providing a rehabilitation

plan that aims to improve the residual abilities of the patient and help him reach a higher level of autonomy. These interventions can significantly reduce the subjective load perceived by the caregiver, which means that relieving the caregiver's stress not only improves the quality of life of the latter but also improves the relationship with the patient and their health.<sup>36-38</sup>

The strengths of the study were that as the duration of the study was short, the participants were compliant. As the study focused on a simple intervention, a bigger sample size can be taken in further studies. The knowledge gained in the intervention was helpful to all, thus, a similar scheme to brush up the knowledge and skills can be taken up by higher education bodies as initiatives.<sup>42</sup>

One of the limitations of this study is represented by the high number of family members in the caregivers and the average high level of education. This sample characteristic may have influenced the correlation analysis. The need to strengthen the family support network of this patient-caregiver dyad and recognize the value of multidisciplinary figures necessary for patient and family care was also noticed. Another limitation of the study is the need to have collected caregivers' daily access diaries. Although the latter declared their hours of assistance, the predominantly family composition of the sample, combined with the fact that the improvements in patients correlated with the number of family members, does not allow us to exclude that some assistance may have also been provided by other relatives of the patients, thus contributing to the reduction of the stress load of the caregivers regardless of the educational intervention administered.

## **CONCLUSION**

Caring for a stroke patient is a complex situation that challenges the family caregiver. The results of this study show high levels of uncertainty in patients' family caregivers. In addition, these levels of uncertainty are associated, in a mild but significant way, with the condition of the patient being treated and the symptoms presented by him, the duration of service as a caregiver, and the support that the caregiver perceives coming from health, family, and society professionals. These findings provide evidence of the importance of the professional physiotherapist in identifying needs and assisting the family caregiver of the stroke patient.

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Not applicable.

### **Consent for publication**

Not applicable.

### **Declaration of competing interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. None of the authors have any relevant financial relationship(s) with a commercial interest.

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“Not applicable”

### **Data Availability**

All data generated or analysed during this study are included in this article.

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