

①	②	③
Able to cry, smile, make sounds, and use body language to express themselves but unable to engage in deliberate communication	Cry, smile, make sounds, and use body language to engage in deliberate communication with a purpose	Use words, pictures, and sign language to engage in clear communication and exchange intentions

Q4) How is the current **physical ability of the pediatric patient**? Please select **all** that the **pediatric patient can do alone**.

①	②	③	④	⑤	⑥	⑨
Walk	Stand briefly	Sit independently	Sit with help	Roll over	Lift head	Unable to do none of the above

Q5) How do you assess the current **degree of physical and psychological difficulties** faced by the pediatric patient? Please select between 'A great deal (Very problematic)'(7) and 'Not at all (Not a problem)'(1) based on your assessment of the condition of the pediatric patient.

Variables	Not at all (Not a problem)							A great deal (Very problematic)
	①	②	③	④	⑤	⑥	⑦	
① Physical difficulties (Pain, discomforts, etc.)	①	②	③	④	⑤	⑥	⑦	
② Psychological difficulties (Anxiety, depression, stress, etc.)	①	②	③	④	⑤	⑥	⑦	

Q6) How often did the pediatric patient **visit the hospital in the past six months**? Please write down the **approximate number of days** the patient visited **this hospital, another hospital, or a clinic** and categorize them according to the nature of the visit. **(All days in hospitalization should be included.)**

Categories	No. of days in the past six months
① Outpatient department (including laboratory follow up, physical therapy, etc.)	_____ days
② Admission (general ward)	_____ days
③ Admission (intensive care unit)	_____ days
④ Emergency department	_____ days
Total	_____ days

Q7) What **method of transportation** do you normally use to **travel from home to this hospital** with the pediatric patient? Please select **all** the transportation methods you use normally.

- | | |
|----------------------------------|--|
| 1. Private car | 2. Intra-city bus / Subway |
| 3. Train | 4. Express bus / Intercity bus |
| 5. Private ambulance | 6. Public transportation support (Taxi for the disabled, etc.) |
| 7. Other (Please specify: _____) | |

Q8) **How long** does it normally take for the pediatric patient to **travel from home to this hospital** for treatment?

- | | |
|----------------------|----------------------|
| 1. Less than 30 min. | 2. 30 min. ~ 1 hour |
| 3. 1 ~ 2 hours | 4. 2 ~ 3 hours |
| 5. 3 ~ 4 hours | 6. 4 ~ 5 hours |
| 7. 5 ~ 6 hours | 8. More than 6 hours |

Q9) **How long do you wait** on average to receive **outpatient care** in this hospital? If the patient requires **outpatient services in two or more areas**, please select the **total waiting time**.

- | | | |
|-------------------------|---------------------|--------------------------|
| 1. Less than 15 minutes | 2. 15 ~ 29 minutes | 3. 30 ~ 59 minutes |
| 4. 60 ~ 89 minutes | 5. 90 ~ 119 minutes | 6. 120 ~ 179 minutes |
| | | 7. More than 180 minutes |

Q10) **How long** does **one outpatient appointment** with a doctor take on **average**?

- | | | |
|------------------------|--------------------|-------------------------|
| 1. Less than 5 minutes | 2. 5 ~ 9 minutes | 3. 10 ~ 14 minutes |
| 4. 15 ~ 19 minutes | 5. 20 ~ 29 minutes | 6. more than 30 minutes |

II. Questions on care of pediatric patients.

Q11) Who is currently **taking care of the pediatric patient at home**? Please write the number that represents **yourself or another individual who serves as the primary or secondary caregiver at home**.

Primary caregiver

Secondary caregiver

1. Mother
2. Father
3. Grandmother
4. Grandfather
5. Extended families
6. Activity assistant/carer
7. Neighbor
8. Others (_____)

Q12) How does the **pediatric patient behave at home** on a regular basis?

1. Always lies on the bed or floor
2. Usually lies on the bed or floor, but sometimes sits or rides the wheelchair
3. Carries out some indoor activities with help from a guardian
4. Carries out indoor activities without major challenges

Q12-1) Please answer only if you selected 1 or 2 in [Question 12].

How often does the pediatric patient take or is the patient repositioned to the following positions while he or she is awake at home? Please select the closest answer for each category. This includes not only the patient

taking the position by himself or herself, but also the **guardian or caregiver repositioning the patient.**

Categories	Frequency of taking the position or being repositioned
① Lying down	1. Never 2. Seldom 3. Sometimes (more than once a week) 4. Often (more than once a day)
② Lying down sideways (left or right)	1. Never 2. Seldom 3. Sometimes (more than once a week) 4. Often (more than once a day)
③ Sitting (Includes using tools to help maintain posture)	1. Never 2. Seldom 3. Sometimes (more than once a week) 4. Often (more than once a day)
④ Standing or walking (Includes using standing aids)	1. Never 2. Seldom 3. Sometimes (more than once a week) 4. Often (more than once a day)

Q13) What does the pediatric patient do at home on a **typical day**? Out of 24 hours in a day, how many hours does the patient spend on the following activities

Categories	Average hours per day
① Sleep (day and night)	_____ hours/day
② Receiving medical care (taking medicine, suctioning, changing tracheostomy tube, etc.)	_____ hours/day
③ Receiving physical care (eating, bathing, dressing, etc.)	_____ hours/day
④ Play and rest (watching TV, surfing the internet, play games, reading, etc.)	_____ hours/day
⑤ Social activities (school, meeting friends, etc.)	_____ hours/day

Q14) On a typical day, what **medical treatment or practices** does the pediatric patient **receive at home**?
How often does the patient receive (such medical treatment or practices) in a day?

Medical care		Average time or frequencies per day
① Home Mechanical Ventilator	1. Yes 2. No	_____ hours/day
② Home Oxygen support	1. Yes 2. No	_____ hours/day
③ Pulse Oximetry monitoring	1. Yes 2. No	_____ hours/day
④ Nutrition support (levin tube, gastrostomy tube etc.)	1. Yes 2. No	_____ times/day
⑤ Suction	1. Yes 2. No	_____ times/day
⑥ Administering medications	1. Yes 2. No	_____ times/day
⑦ Disinfection or cleaning of medical instrument/wound dressing	1. Yes 2. No	_____ times/day
⑧ Rehabilitation therapy	1. Yes 2. No	_____ times/day
⑨ Position change	1. Yes 2. No	_____ times/day

Q15) What is the **most challenging or difficult aspect** of providing medical treatment or practices to the pediatric patient at home? Please select the **two** most challenging or difficult aspects in order and **write down their numbers**.

First		Second	
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1. Assessing the pediatric patient's condition due to the lack of medical knowledge
2. Inexperience using equipment and providing medical practices
3. Making decisions during abnormal or emergency situations
4. Self-doubt or difficulty in confirming whether the correct care was provided
5. Providing the treatment alone without anyone's help
6. Show of discomfort or complaints of pain by the child
7. Other (Please specify ; _____)

Q18) What do you do when you have a **medical question while taking care of the pediatric patient at home**? Please choose **two** methods that you normally use in order and **write down their numbers**.

First		Second	
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1. Ask or search in web portals (Naver, Daum, etc.)
2. Ask or search in online patient associations or Internet forums
3. Ask a medical staff(doctor, nurse) via call or text
4. Ask another parent from a patient association or someone else via call or text
5. Look up professional literature or studies
6. Other (Please specify; _____)

Q19) Have you ever **asked a hospital staff member a medical question** via text, Kakao Talk, e-mail, etc. while taking care of the pediatric patient **at home in the past year**? Please select all the departments you have **asked at least once** in the past year.

1. Doctor in ward where child was previously hospitalized
2. Nurse working in the ward where the patient was hospitalized
3. Pediatric emergency department
4. Palliative care unit (Seoul National University Hospital)
5. Other (Please specify: _____)

9. I have not asked any hospital staff in the past year

■ Thee following questions are about **you, the respondent**.

Q24) What is the **most challenging or difficult aspect of taking care of the pediatric patient** for you today? Please select the **two** most challenging or difficult aspects in order and **write down their numbers**.

First		Second	
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1. Inconveniences in daily life (sleep, meals, lack of private time, etc.)
2. Financial difficulties (medical expenses, etc.)
3. Anxiety about the condition of the pediatric patient
4. Lack of professional knowledge or information on illness and nursing
5. Negligence of family (Negligence in taking care of other children, family relations, etc.)
6. Lack of psychological stability and rest for the caregiver (parent)
7. Other (Please specify ; _____)

Q25) How does your day look like on a **typical day**? **Out of 24 hours in a day, how many hours do you spend on the following activities?**

Categories	Average hours per day
① Sleep	_____ hours/day
② Taking care of child (supervision, suctioning, feeding via tubes, positioning, etc.)	_____ hours/day
③ Household chores (vacuuming, laundry, taking care of other family members, etc.)	_____ hours/day
④ Private time and rest (watching TV, playing games, surfing the internet, reading, etc.)	_____ hours/day
⑤ Social activities (school, occupation, etc.)	_____ hours/day

Q26) Have you ever **reduced your workload or quit work** (job or other financial activities) to **take care of the pediatric patient**?

1. I have taken leave of absence, resigned, or temporarily stopped working
2. I am currently working but reduced my workload
3. I am continuing to work without any change
4. I am originally a homemaker

Q27) What is the **degree** of physical, psychological, and economic **difficulty** you feel while taking care of the pediatric patient at home? Please select between 'A great deal (Very problematic)''(7) and 'Not at all (Not a problem)''(1) for each difficulty.

Variables	Not at all (Not a problem)						A great deal (Very problematic)
	①	②	③	④	⑤	⑥	⑦
① Physical difficulties (lack of sleep, fatigue, compromised physical health etc.)	①	②	③	④	⑤	⑥	⑦
② Psychological difficulties (Anxiety, depression, stress, etc.)	①	②	③	④	⑤	⑥	⑦
③ Economic difficulties (medical expenses, etc.)	①	②	③	④	⑤	⑥	⑦

III. Questions on difficulties in taking care of the patient(s) at home.

Q30) Reflecting on your experience taking care of the pediatric patient at home, **how did you usually feel when faced with the following difficulties?** Please select between 'A great deal'(7) and 'Not at all'(1) for each category.

Variables	Not at all	Somewhat			A great deal		
	①	②	③	④	⑤	⑥	⑦
① I have experienced an embarrassment at home because I did not know about the pediatric patient's condition or treatment method well	①	②	③	④	⑤	⑥	⑦
② I have experience failing to treat the pediatric patient because of inexperience with operating or managing equipment	①	②	③	④	⑤	⑥	⑦
③ I have experience not receiving help from the doctor or nurse for medical treatment	①	②	③	④	⑤	⑥	⑦
④ I have faced difficulties moving the pediatric patient when visiting the hospital	①	②	③	④	⑤	⑥	⑦
⑤ I have faced difficulties using hospital services (appointments, hospitalization/discharge, emergency room)	①	②	③	④	⑤	⑥	⑦
⑥ There is a medical treatment that I cannot administer alone (someone has to help)	①	②	③	④	⑤	⑥	⑦
⑦ I am always tired from taking care of the pediatric patient	①	②	③	④	⑤	⑥	⑦
⑧ I have been negligent in household chores due to the care for the pediatric patient	①	②	③	④	⑤	⑥	⑦
⑨ I have been negligent in caring for other children or family members from taking care of the pediatric patient	①	②	③	④	⑤	⑥	⑦
⑩ I have required someone's help in caring for the pediatric patient	①	②	③	④	⑤	⑥	⑦
⑪ I have required someone's help in finding stability and rest in myself and my family	①	②	③	④	⑤	⑥	⑦
⑫ I have had serious concerns regarding medical expenses for the pediatric patient	①	②	③	④	⑤	⑥	⑦
⑬ I have experience not providing required medical treatment or care due to financial burden	①	②	③	④	⑤	⑥	⑦

Q31) Did you ever feel that **medical treatment or practice was difficult or overwhelming** while taking care of a pediatric patient at home? (If so,) which medical treatment or practice is the **most difficult or overwhelming**?

1. Assessing the pediatric patient's condition
2. Administering medicine (oral administration, or needle injection)

3. Disinfecting/treating incisions or surgical sites
 4. Using and managing equipment
 5. Massaging, repositioning
 6. Other (Please specify ; _____)
-

9. None

Demographic Information

D 1) What is your gender?

1. Male
2. Female

D 2) What **age group** do you belong to?

1. 20s
2. 30s
3. 40s
4. 50s or older

D 3) Are you currently a **full-time homemaker**? Are you an **employed homemaker**?

1. Full-time homemaker
2. Employed homemaker (part-time job, freelance work, etc.)
3. Homemaker on leave of absence

9. Don't want to answer

D 4) What's the highest degree you earned?

1. Less than elementary school
2. Middle school
3. High school
4. Bachelor's degree
5. More than Graduate school

9. Don't want to answer

D 5) How does your **family structure** look like?

1. Parents + Underage child(ren)
2. Parents + Adult child(ren) + Underage child(ren)
3. Parents + Child(ren) + Grandparent(s)
4. Single parent + Child(ren)
5. Other (Please specify: _____)

9. Don't want to answer

D 6) How would you describe your **medical coverage**?

1. National Health Insurance
2. Medical Aid

9. Don't want to answer

D 7) Which of these categories best describes your family's level of economic status?

1. Upper
2. Upper-middle
3. Middle
4. Lower-middle
5. Lower

9. Don't know/Don't want to answer

D 8) Where is your current **region of residence**?

1. Seoul
2. Incheon / Gyeonggi
3. Busan / Ulsan / Gyeongnam
4. Daegu / Gyeongbuk
5. Daejeon / Sejong / Chungnam / Chungbuk
6. Gwangju / Jeonnam / Jeonbuk
7. Gangwon / Jeju