LONG-TERM EFFECT OF SHARING ILLNESS INFORMATION ON CHILDREN'S QUALITY OF LIFE DURING POST-HOSPITAL CANCER TREATMENT: A QUALITATIVE STUDY

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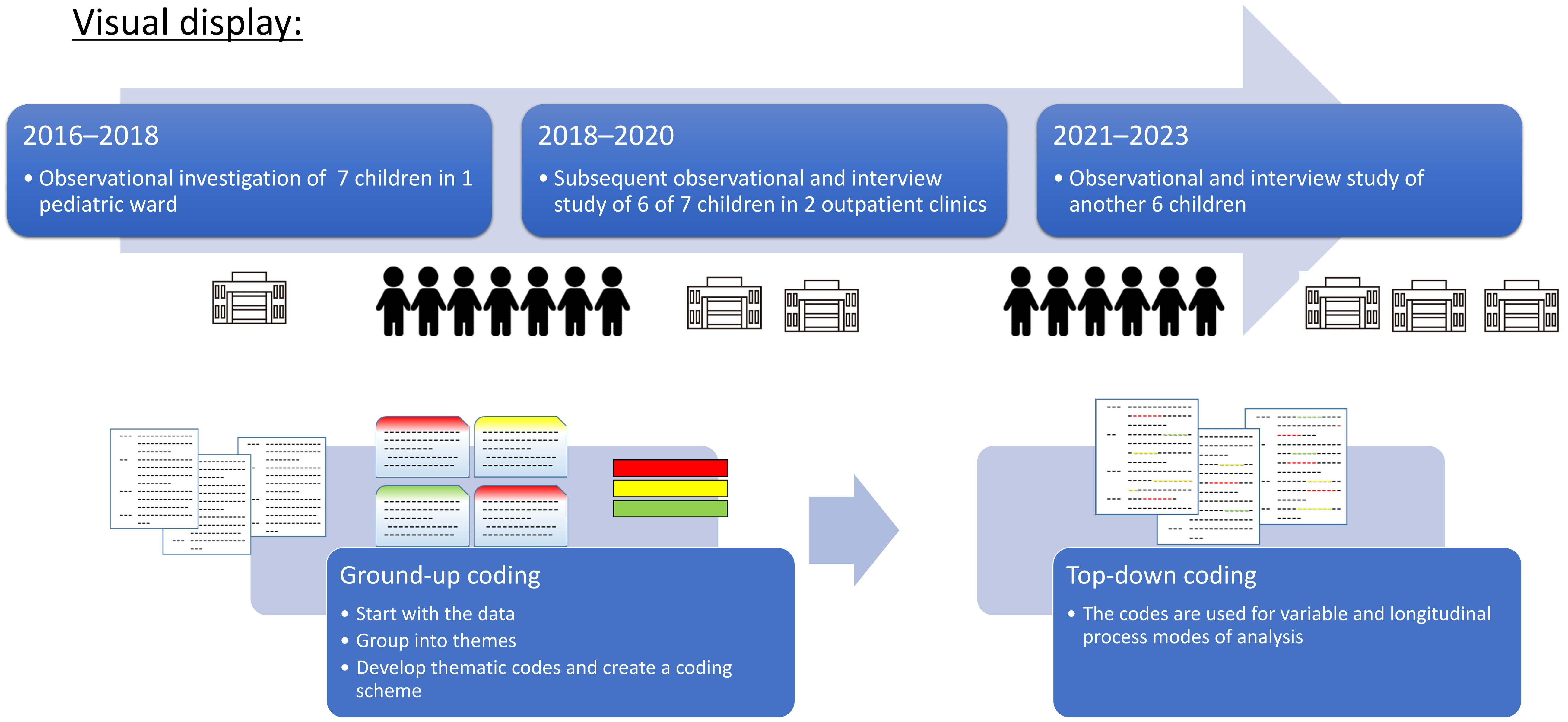
Background and Aims:

- Sharing illness information, such as disease name and treatment method, with children is an important aspect of child-centered care in pediatric oncology.
- However, its long-term effects on children's quality of life post-discharge remain under-investigated.
- Understanding how information sharing affects children's long-term quality of life could provide valuable information for clinical practice.

Methods:

- To examine this effect, we conducted qualitative interviews and observations with 13 children aged 5–12 years with hematologic cancer.
- Data were collected from 2016 to 2023 in one pediatric ward and two outpatient clinics in Japan.
- The interviews (which included children's parents) and observations provided extensive data on information-sharing among health professionals, children, and parents, and on children's thoughts, attitudes, and behaviors regarding their quality of life over time.
- Thematic data analysis and longitudinal process analysis were used to identify key themes.

Visual display:



2016–2018
- Observational investigation of 7 children in 1 pediatric ward

2018–2020
- Subsequent observational and interview study of 6 of 7 children in 2 outpatient clinics

2021–2023
- Observational and interview study of another 6 children

Ground-up coding
- Start with the data
- Group into themes
- Develop thematic codes and create a coding scheme

Top-down coding
- The codes are used for variable and longitudinal process modes of analysis

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Results:

The amount of data collected was **983,637** characters in Japanese.
The observation period was **272** days for **13** children.

Table 1 Selected characteristics of **13** children

	n	%
Sex		
Male	9	69%
Female	4	31%
Age (range: 5–10 years, median: 8 years)		
5–7 years	5	39%
8–9 years	6	46%
≥10 years	2	15%
Diagnosis		
Acute lymphoblastic leukemia	8	61%
Acute myeloblastic leukemia	2	15%
T-cell lymphoma	2	15%
Burkitt lymphoma	1	7%

Table 2 Information sharing with the 13 children

	n	%
Those who were informed that they had cancer upon hospitalization	7	54%
Those who were informed that they had cancer after hospitalization (follow-up period)	1	8%
Those who were not informed that they had cancer	5	38%

Two contrasting themes that characterized the views of children and their parents

Children focused on living in the present

Parents reminisced about past experiences related to their child's illness

This difference was apparent regardless of whether children were informed about their illness and regardless of the quality of information provided.

Conclusions

It is important to help children focus on the present to maintain a sense of normalcy and to support recovery. However, it is equally important in child-centered care to share information and understand the child's illness experience. Further investigations are needed on the long-term effects of information-sharing on children's quality of life.