

# FACTORS RELATED TO QUALITY OF LIFE IN HEMOPHILIA PATIENTS.

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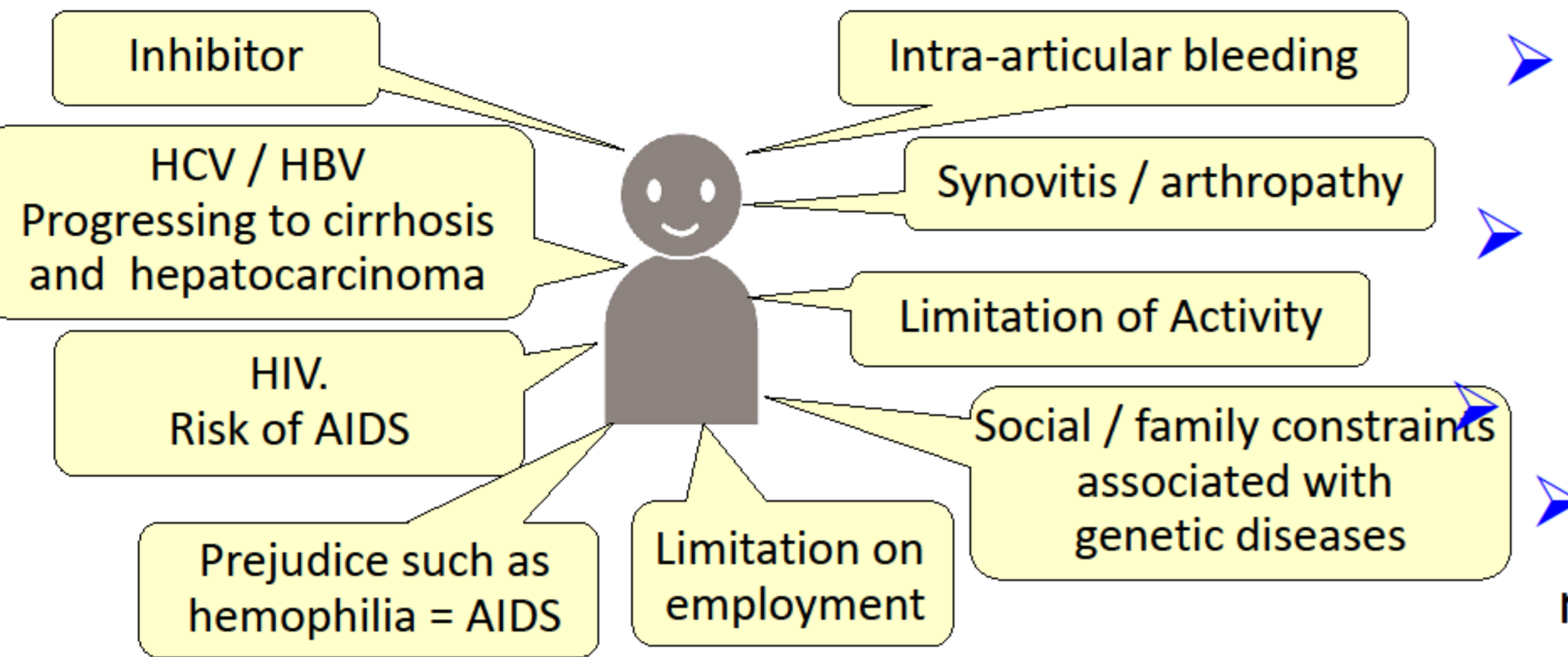
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## 【Hemophilia patients' problems】



## 【Back ground】

Base of treatment of hemophilia = Improvement of QOL in patients.  
 Hemophilia patients' QOL is affected by many factors.  
 Concept of QOL is used in many fields.  
 Assessment and rating of QOL is necessary in treatment of hemophilia.

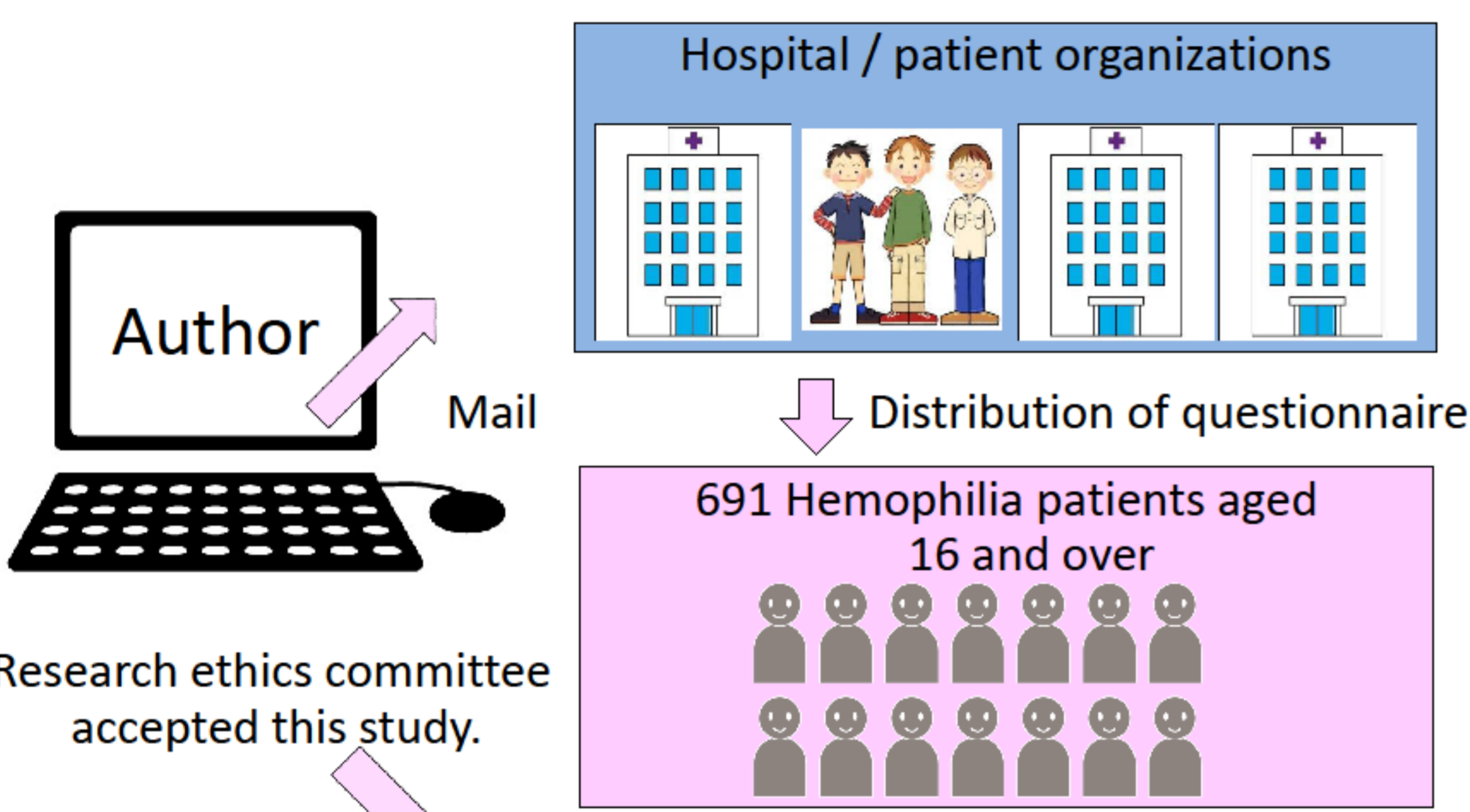
## 【Prior research about hemophilia QOL】

- ◆ Work provided a sense of identity and enabled patients to maintain their self esteem. Beeton K et al(2005)
- ◆ HIV / HCV positive patients' QOL is lower than HIV / HCV negative patients' QOL. TANAKA et al.(1999), Posthouwer (2005)
- ◆ HR-QOL of patients with severe hemophilia is lower than that of patients with moderate/mild hemophilia. Miners.(1999)
- ◆ Quality of life is linked to orthopaedic status. SCALONE et al.(2006)

There is much debate about QOL in hemophilia patients.

【Objectives】 This study aims to find a determinant of HR-QOL in hemophilia patients.

## 【Materials & Methods】



## 【Items investigated】

- 1) Subjects' biographical data : age, hemorrhage frequency during year (10 times or more / Less than 10 times), Severity of hemophilia (severe, or moderate, or mild), Complications (HIV, HCV, HBV, Inhibitor),
- 2) Social background: Working or Student (yes or no), Satisfied with physical and mental support from hospitals and patients, family, work place. (yes or no)
- 3) Level of ADL for different activities (easy or difficult or impossible)
- 4) Health-related quality of life (The RAND 36-item Health Survey 2.0 Japanese version: SF-36).  
**Physical (PCS) and Mental (MCS) component summary**

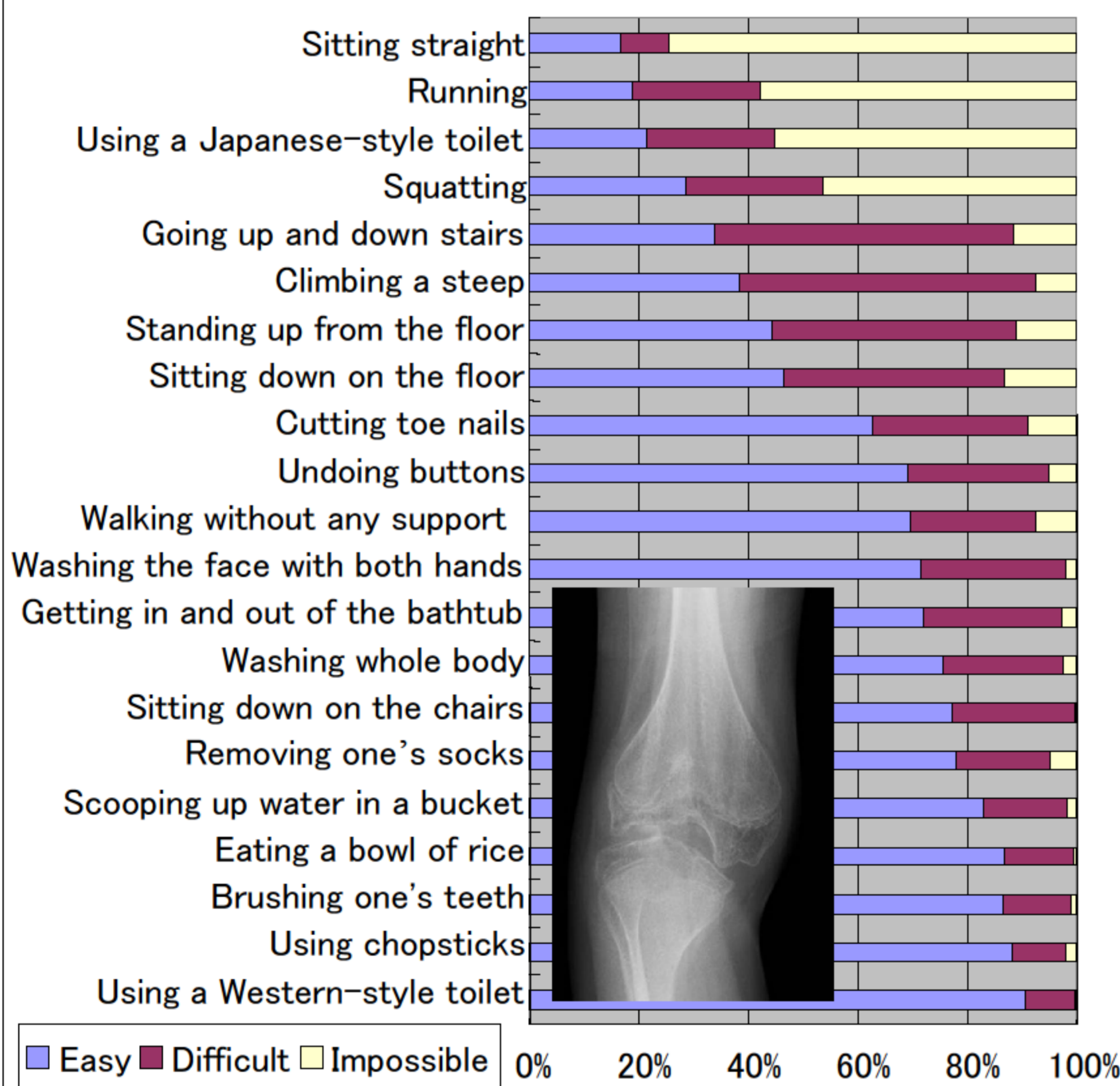
## 【Static analysis】

- 1) ADL: Quantification Theory Type 3
  - 2) Subjects' biographical data and PCS, MCS  
 Pearson correlation, unpaired t-test
  - 3) Binary logistic regression analysis (stepwise method)  
 \*Dependent variable: Significant factors by in the data(step2)  
 \*Independent variable: PCS, MCS(1: >average, 0: ≤average)
- ◆ Significance level: 5%  
 ◆ Data were analysed using SPSS software package version 19.

## 【Results】

259 patients(37.5%) gave valid responses. Average age was 40.9 (16~77) years old.  
 Severity of hemophilia: severe-167 patients (65%), moderate-47 patients (18%), mild-27 patients (10%),  
 Complications: HCV infection-204 patients (78.2%), HIV infection-92 patients (35.2%), Inhibitor-23 patients (8.8%)  
 Social background: employed or in full-time education 180 patients (69.4%).

### 1) Activities of Daily Living (ADL)



Reclassification: A group : easy, B group: difficult and impossible  
 ⇒ Quantification Theory Type 3  
 Eigenvalue: 1st.Axis 0.419 2nd.Axis 0.131  
 ⇒ 1st. Axis = ability for ADL

### 2) Relationships between subjects' biographical data and PCS, MCS.

FACTOR	PCS			MCS		
	t value	df	p value	t value	df	p value
Severity of hemophilia	1.254	239	n.s.	.301	239	n.s.
Hemorrhage frequency	3.412	253	**	1.641	249	n.s.
HCV	3.208	258	**	1.211	258	n.s.
HIV	1.232	226	n.s.	1.229	258	n.s.
HBV	1.934	258	n.s.	1.695	258	n.s.
Inhibitor	2.474	258	*	.834	258	n.s.
HCV+HIV	.558	142	n.s.	1.284	142	n.s.
Prophylaxis or on-demand	1.795	257	n.s.	.595	257	n.s.
Support from hospitals	3.519	252	**	2.825	252	**
Support from family	3.627	254	***	6.660	254	***
Participation in patients' meeting	.120	202	n.s.	1.976	255	*
Support from patients	1.960	212	n.s.	2.571	212	*
Working or Student (yes or no),	6.123	106	***	1.217	252	n.s.
Work-related problems	5.234	144	***	4.296	176	***
Support from work place	2.422	181	*	4.899	183	***
	correlation coefficient		p value	correlation coefficient		p value
Age		-0.416	***		.090	n.s.
ADL		0.739	***		.021	n.s.

3) The significant factors influenced by PCS and MCS. \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

### Binary stepwise logistic regression (stepwise methods)

	PCS	Regression coefficient	P value	Odds ratio	MCS	Regression coefficient	P value	Odds ratio
Work related problems		4.98	0.03	2.73	Work related problems	4.75	0.03	2.40
ADL		23.86	0.00	10.67	Physical and mental support from work place	6.31	0.01	2.72
Constant		9.41	0.00	0.12	Constant	17.89	0.00	0.05

## 【Discussion】

- Comprehensive intervention is necessary to improve the hemophilia patient's HR-QOL.
  - ◆ Management of HCV, Inhibitor, and bleeding.
  - ◆ Vocational assistance.
  - ◆ Improvement of ADL.
  - ◆ Both physical and mental support from hospitals, family, work place, and other patients.
- In particular, improvement of ADL is necessary in order to improve physical aspects of HR-QOL for hemophilia patients.
- And vocational assistance is necessary in order to improve mental aspects of HR-QOL.

## 【Conclusion】

- Determinants of HR-QOL in hemophilia patients are physical and mental support, ADL, work-related problems, hemorrhage frequency, HCV, inhibitor, age, and employment status.
- In particular, determinants of physical aspects of HR-QOL are ADL and work-related problems. Determinants of mental aspects of HR-QOL are physical and mental support from work places, and work-related problems.

