

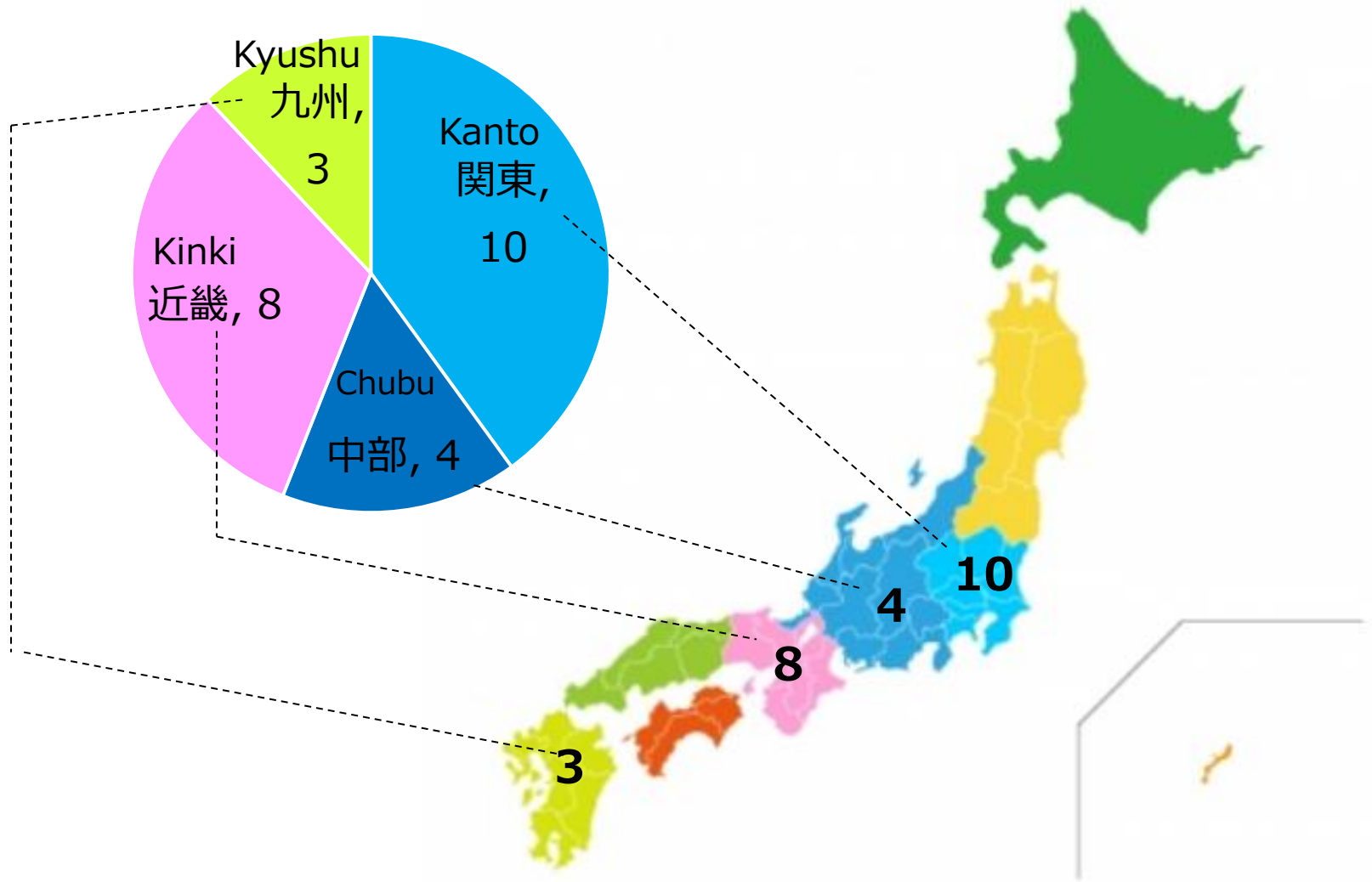
AHC親の会 国際交流会 発表資料

Japanese AHC Family Association (JAFA)
International Exchange Meeting
Presentation from Japan

September 21, 2017
JAFA: Noriyuki Matsuda

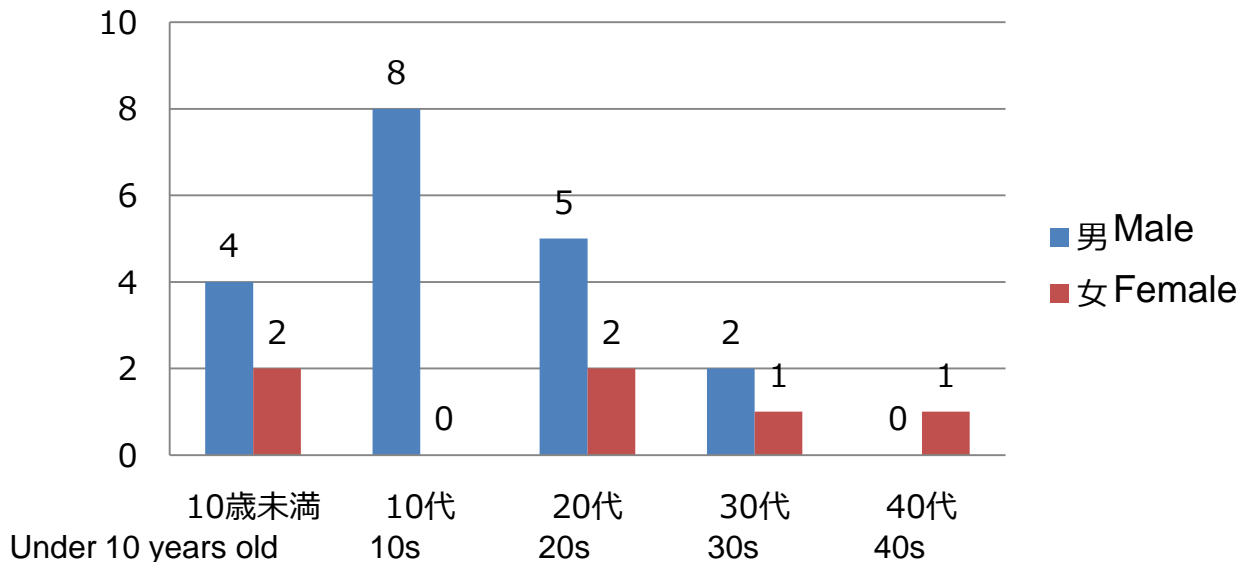
Basic Information
on JAFA (Japanese
AHC Family Association)

居住地 Place of Residence

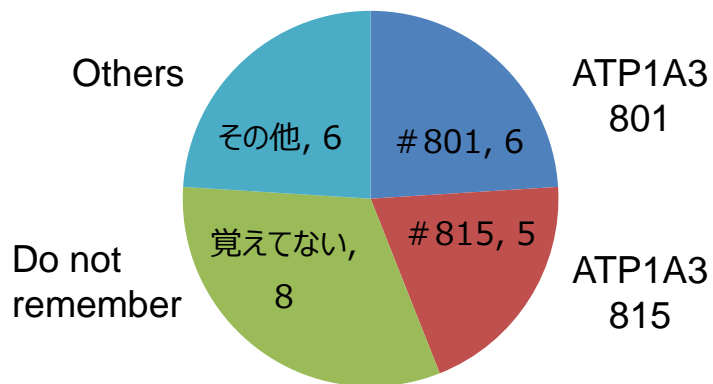


性別、遺伝子タイプ、フルナリジン Sex, Genotype, and Flunarizine

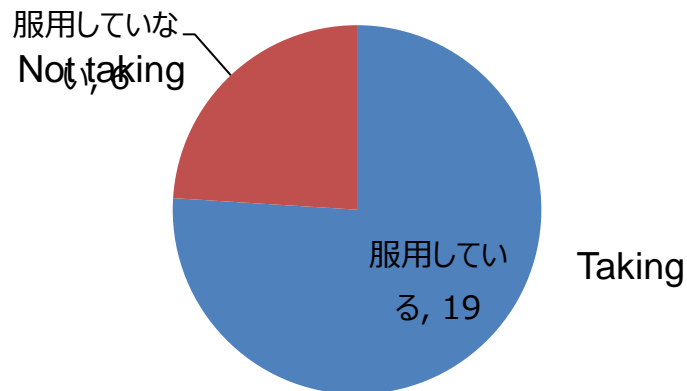
性別 Sex



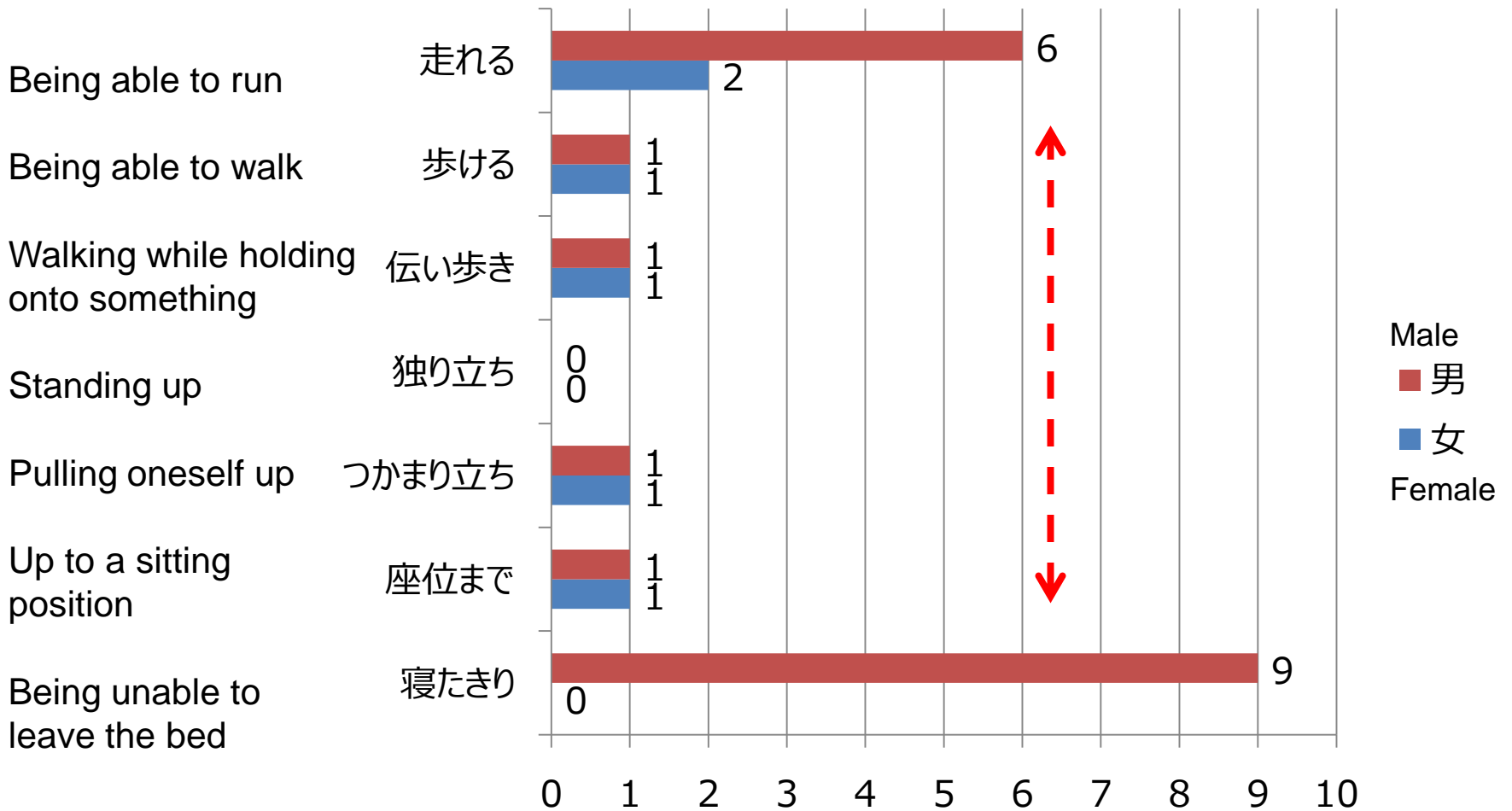
遺伝子のタイプ Genotype



フルナリジンは Flunarizine

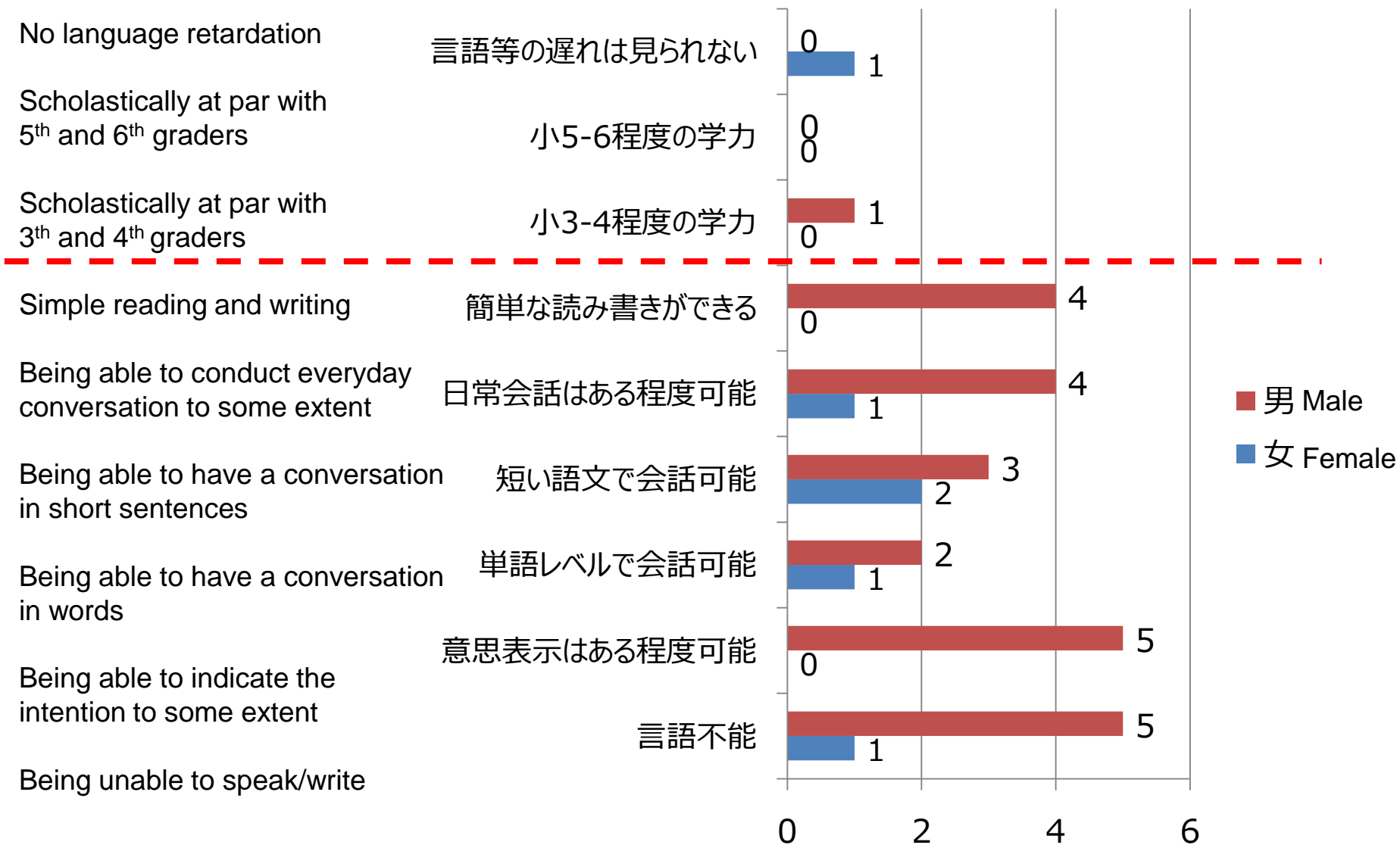


運動レベル Motor Performance Level

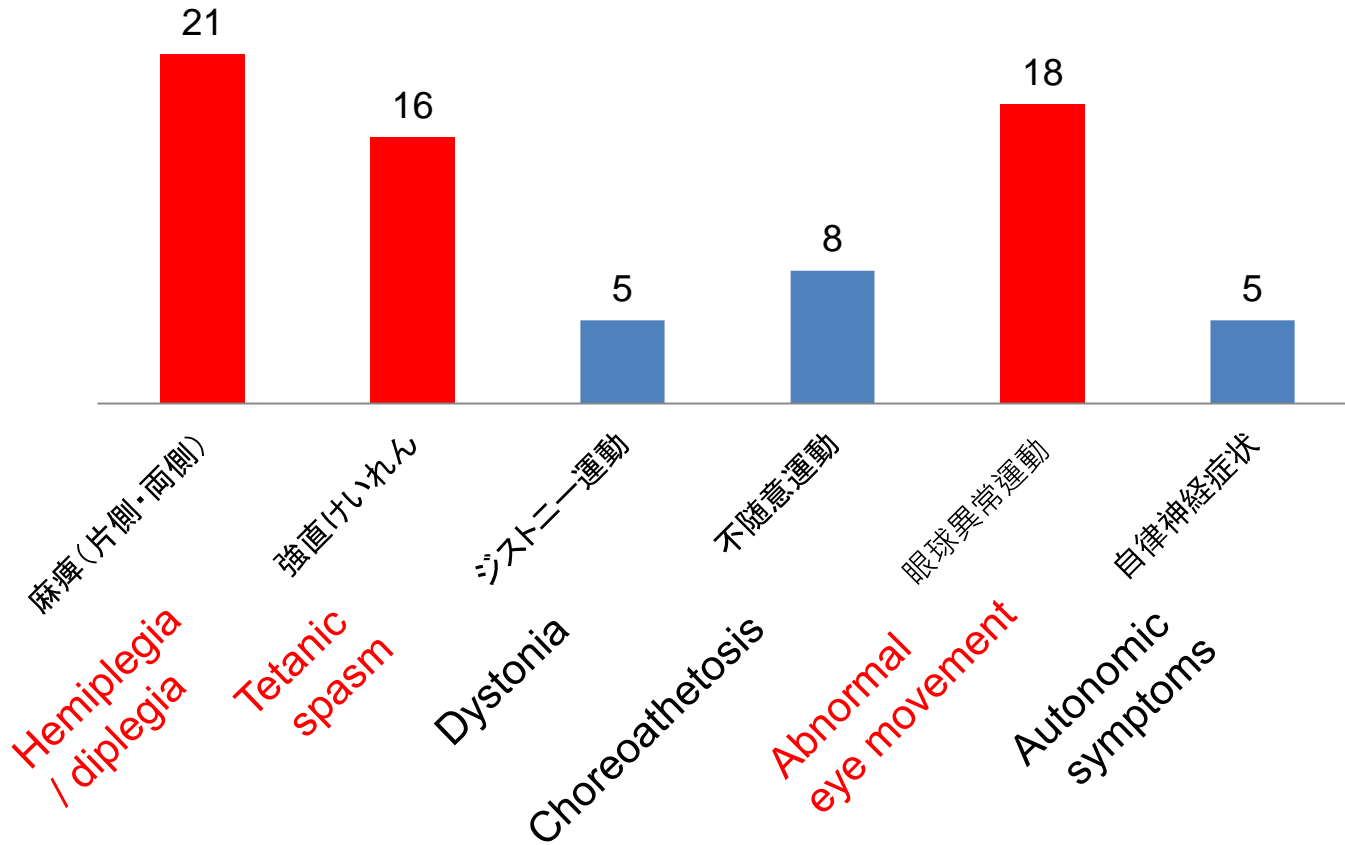


知的レベル（複数選択可）

Intellectual Performance Level (multiple answers)

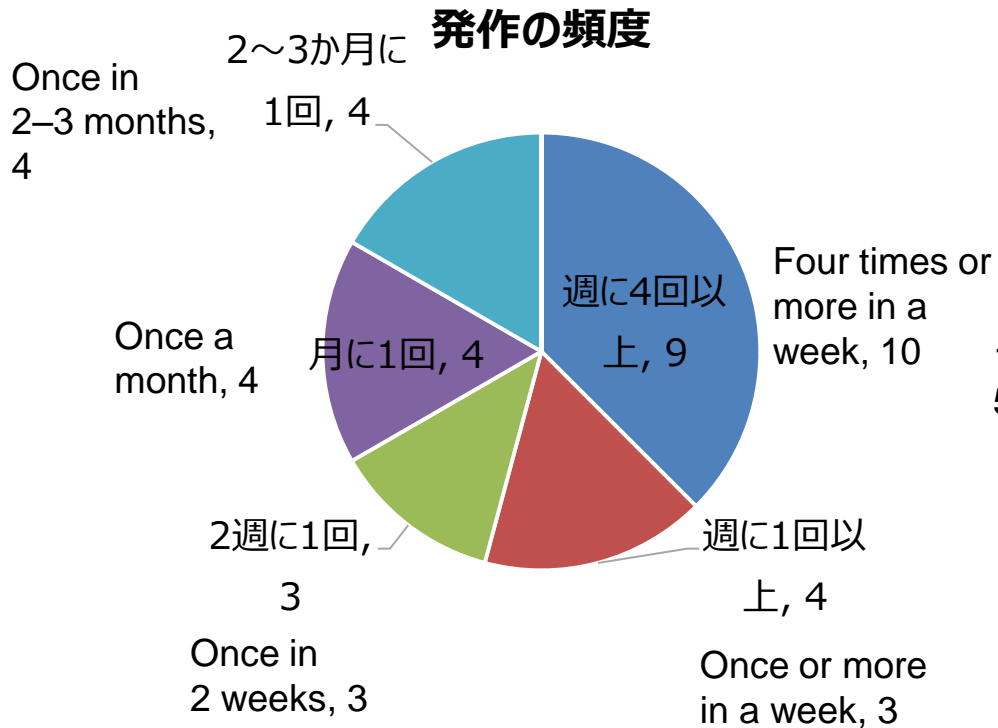


発作の症状 Symptoms of Episodes

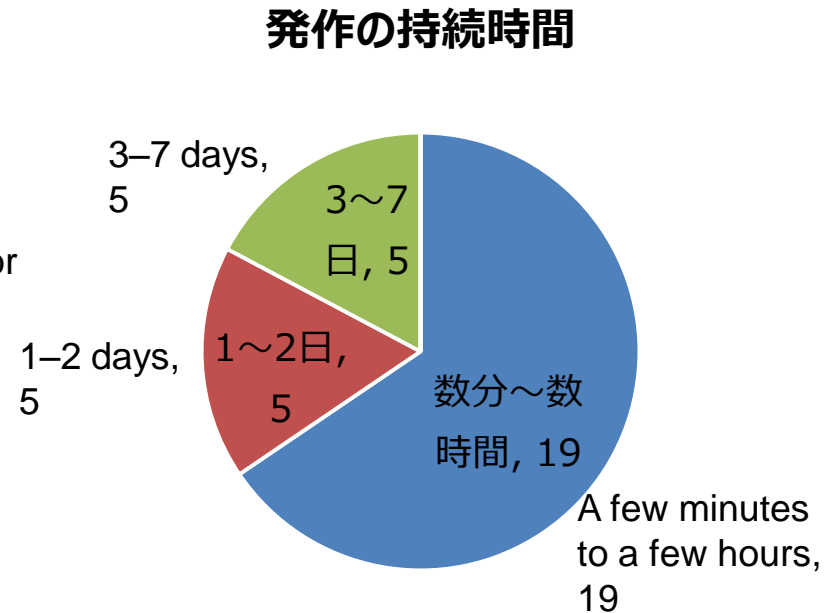


発作の頻度と持続時間 Frequency and Duration of Episodes

Frequency of Episodes

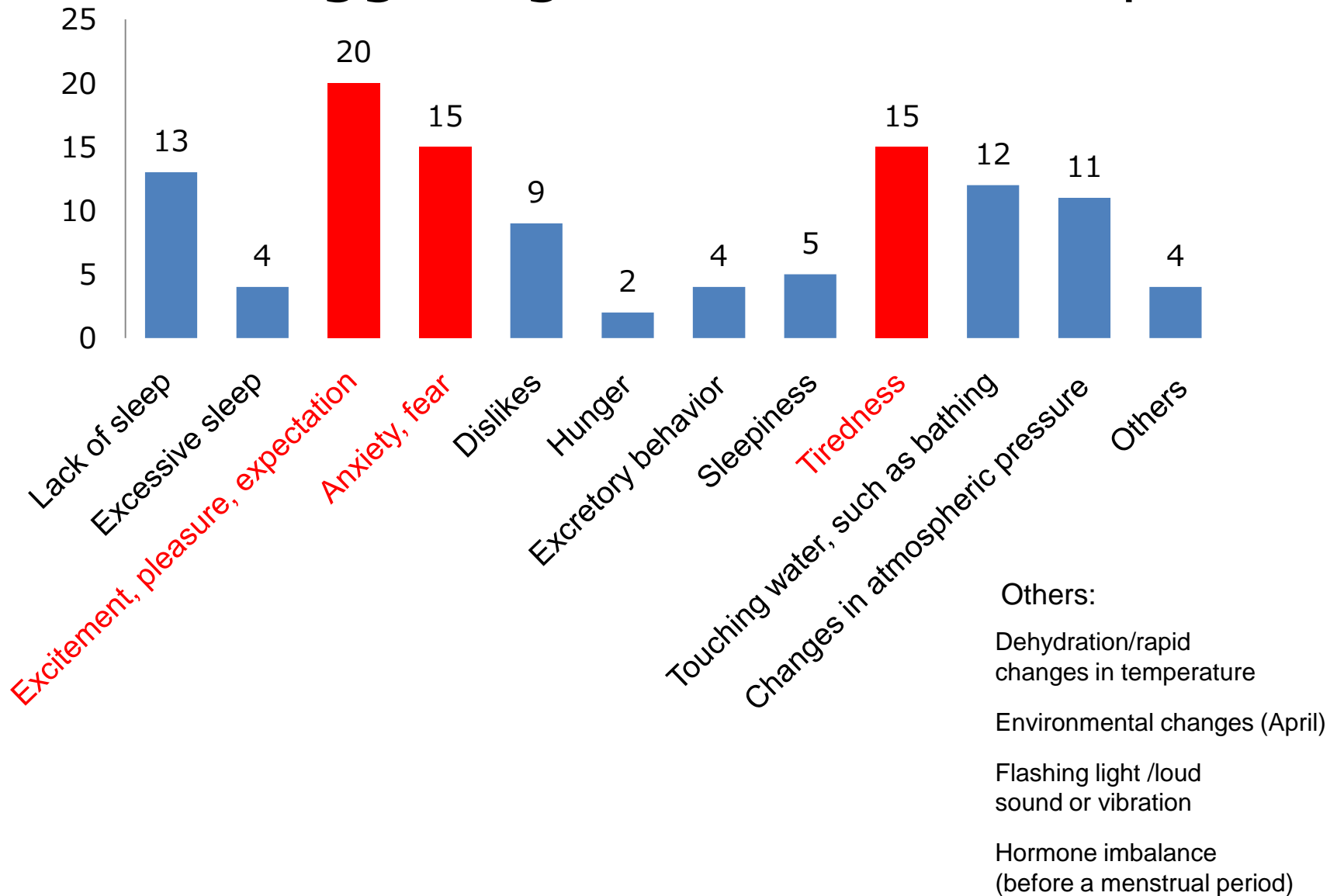


Duration of Episodes



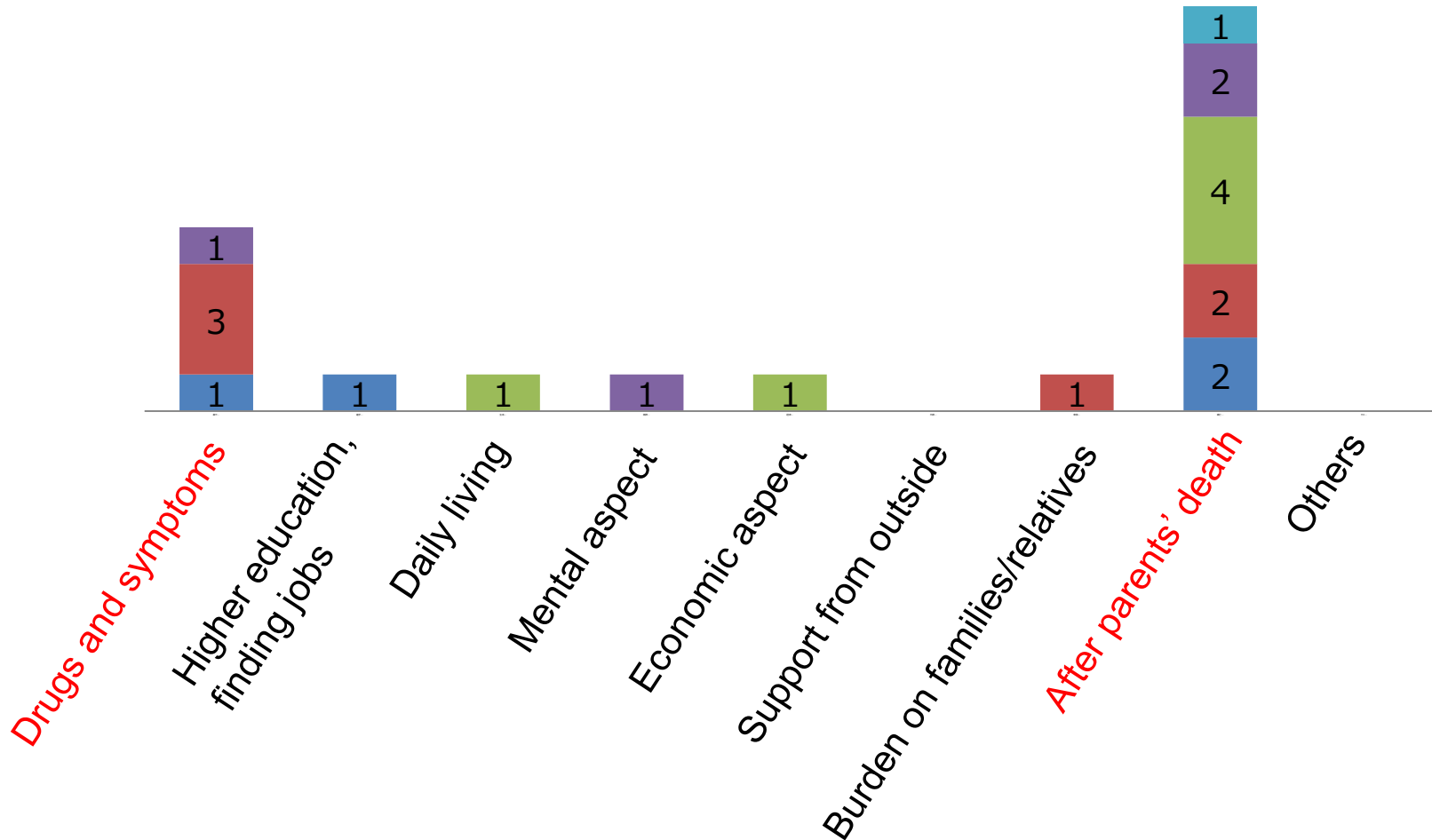
発作の引き金

Triggering Factors for the Episodes



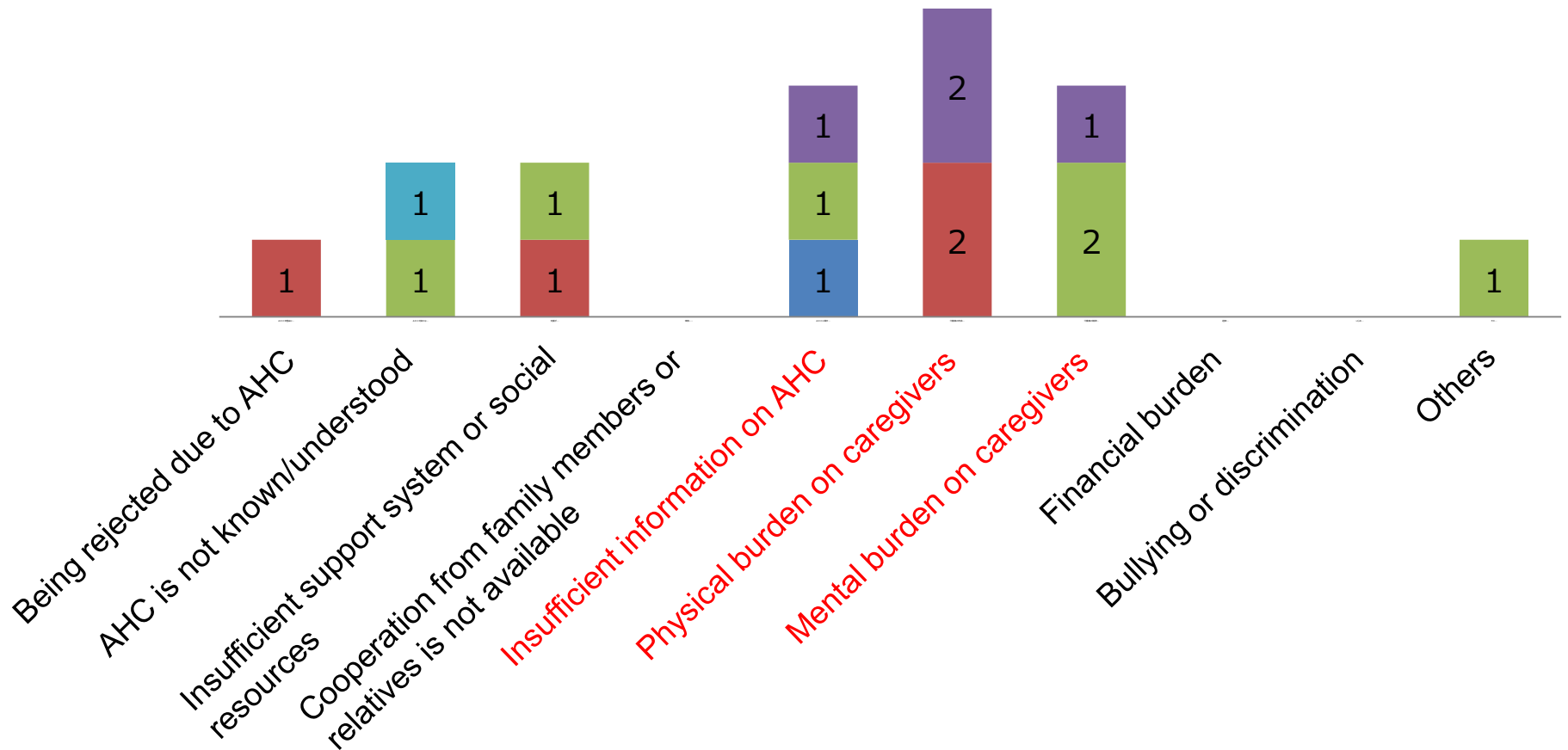
心配事（1つだけ選択） Concerns (single answer)

■ 10歳未満 ■ 10代 ■ 20代 ■ 30代 ■ 40代
Under 10 years old 10s 20s 30s 40s



困っていること（1つだけ選択） Difficulties (single answer)

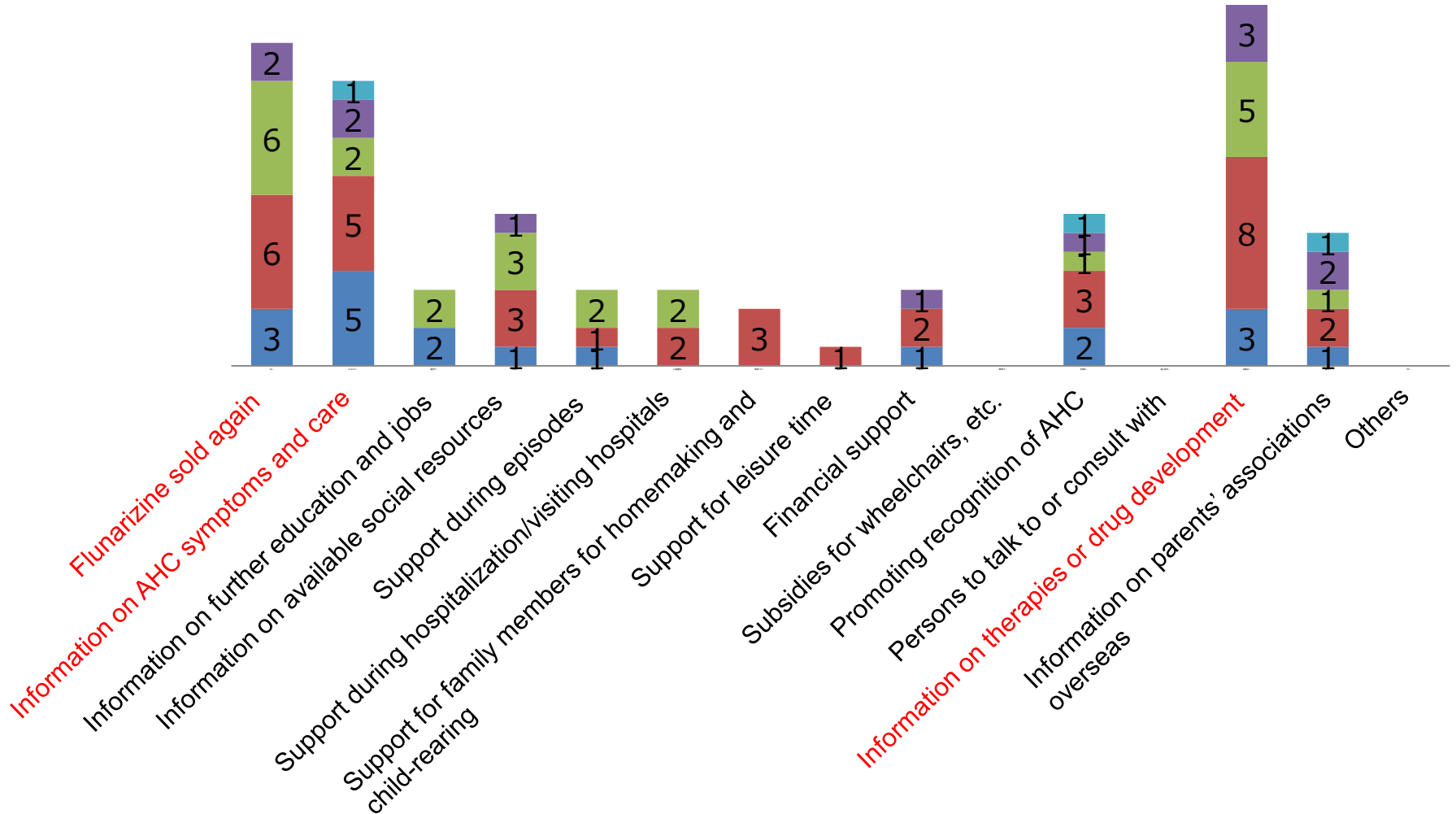
■ 10歳未満 ■ 10代 ■ 20代 ■ 30代 ■ 40代
Under 10 years old 10s 20s 30s 40s



必要な情報・支援（複数選択）

Necessary Information/Support (multiple answers)

■ 10歳未満 ■ 10代 ■ 20代 ■ 30代 ■ 40代
Under 10 years old 10s 20s 30s 40s



Personal Actions to Make People Understand AHC and Support AHC Patients

- Explain details of the disease of the patient, at the time of signing the contract with a supporting facility.
- Preparing a leaflet, containing information on how to support the patient under usual conditions and during episodes, and provide it to all persons concerned.
- Videotaping the patient during an episode to let people know about it, and using it as a reference.
- Participating in local meetings of the Physically Disabled and their Parents Associations to let the members know about AHC.
- Introducing the website prepared by the patients' family association (JAFA).
- Educating how to support the patient under usual conditions and during episodes.
- Delivering AHC leaflets to schools and companies where the patients are attending or working, and giving explanations about the disease (seven members).
- Delivering the patient's profile to people who look after the patient to inform them on how to take care including responses to episodes.

Questions that You May Want to Ask Members of Parents' Associations in Other Countries

- During paralytic attacks, how to bathe a patient/how far can a patient going out.
- What efforts do you make to increase the number of physicians/researchers who have an interest in AHC and AHC association?
- Activities of a parents' association in each country
- Further advancement of experimental studies on model mice
- Actual circumstances of living/family/financial status/future plan.
- Is public support such as pensions available? To what extent?
- What is the recognition level of AHC in each country?
- About physical changes/deterioration after the age of 20, because there are not many older (adult) patients in Japan.
- Average life expectancy of AHC patients
- Welfare systems in each country (facilities or support for caring after the parents' death, etc.)
- The public support scheme in each country
- What is the current focus of the parents' association?
- What activities are carried out by the parents' association to help studies of the disease?

Acknowledgements

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and by

Dr. Masayuki Sasaki (NCNP)

All JAFA Members