

How we address support needs and hereditary issues in Japanese hemophilic carriers? Narrative case study based on semi-structured interviews (A pilot)

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Background:

Likewise genetic disorders, hemophilia can considerably affect interpersonal relationship and disrupt their family life. Their circumstances are even more complicated due to HIV disasters caused in early 1980's. Through our dedication to both HIV victims and their families in Japan since our establishment in 1997, we had previously presented our study, addressing how and what we effectively support their life (Kakinuma et al, 2012 WFH congress in Paris).

Aim:

Our purpose is to find social support needs and authentic tactics extracted from hemophilic carriers in Japan, comprehending background of thorough their health history. Methods: Semi-structured interviews were conducted among women with carrier status or women having a family history of hemophilia with careful deliberation. In accordance with qualitative research, our survey was processed following qualitative method. An analysis of each case was comprehensively investigated among researchers, focusing on objective fact.

Interview Case

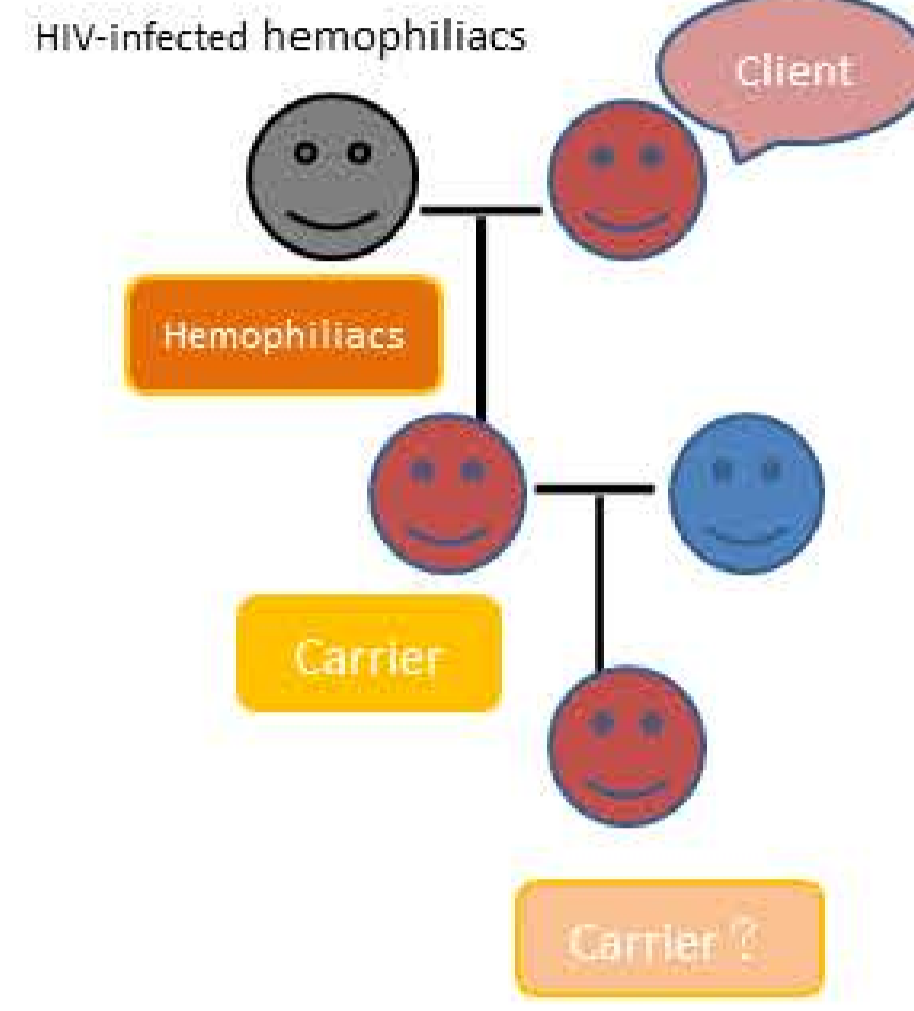
- e Notification of hereditary issues to her daughter on little background of hemophilia
- B Lack of genetic issues of hemophilia within families
- C Negative impact of HIV on her daughter's life style regarding marriage and giving a birth
- D A variety of conflicts in her family
- E No readiness for accepting hemophilia

Discussion and conclusion:

In a series of five interviews, we obtained these findings extracted from their families. 1) Lack of information sharing among their families. 2) Imperfect relationship between family and daughter with potentially carrier. 3) Hesitant attitude towards people with hemophilia among their families. Our studies suggest that comprehensive genetic counseling system is necessary for carriers.

Case 1: Ms. A's husband of HIV-infected hemophilic had already died out. Due to this reason, Ms. A's family faces difficulty of access to hemophilia test and knowledge

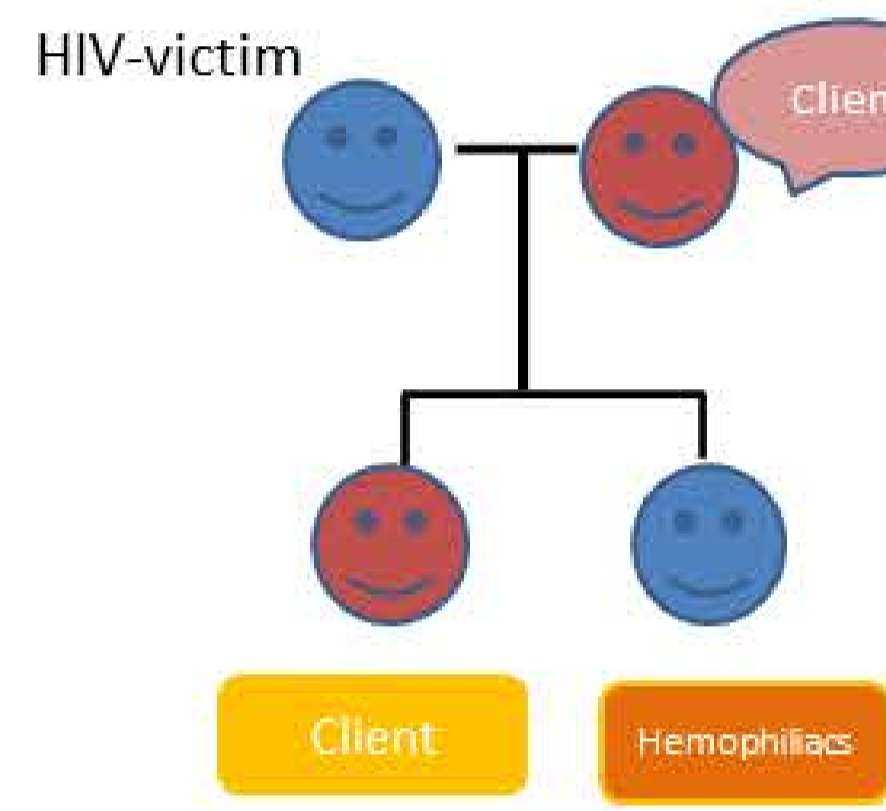
Counseling from Ms. A



- Ms. A's granddaughter becomes adult so she hopes her to check status of hemophilia.
- Her husband had already died out due to medical-induced HIV scandal.
- She has no knowledge, information and experience of hemophilia, much less imagine what it is.
- She would like to know what hemophilia test is.
- She was wondering how and what patient-oriented association and hemophilia treatment is going in recent days.

Case 2: Imperfect communication in family

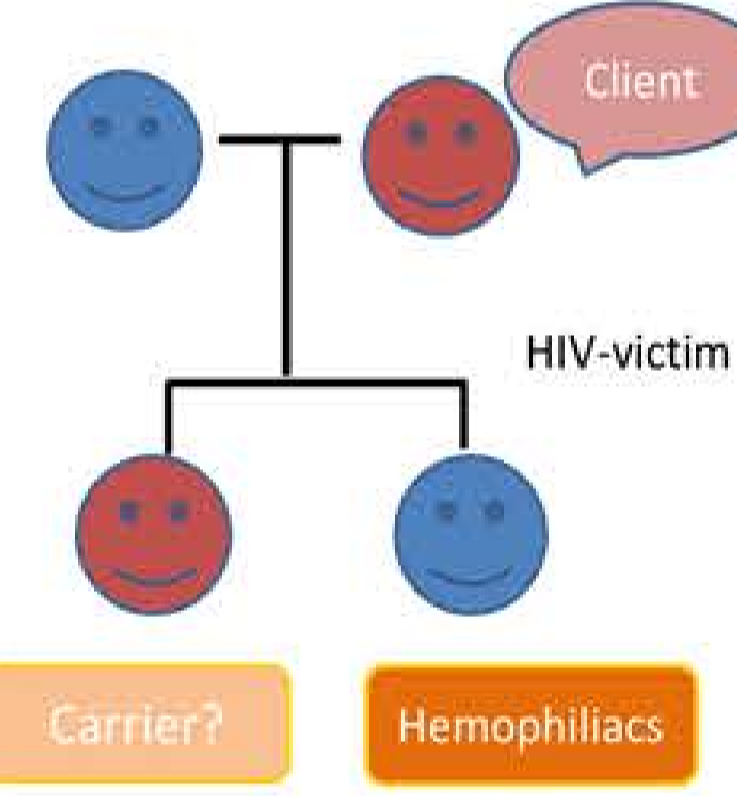
Counseling from Ms. B whose Husband is hemophilia



- Ms. B has relative with hemophilia. Nevertheless, she is concerned about carrier status of her daughter due to her lack of hemophilia knowledge.
- Since her daughter is possible carrier, she needs an accurate knowledge of hemophilia and hereditary.
- Ms. B (Mother) is worried about how to tell her daughter about possible carrier and knowledge of hemophilia.

Case 3: Ms. C makes her own assumption due to lack of knowledge of hemophilia

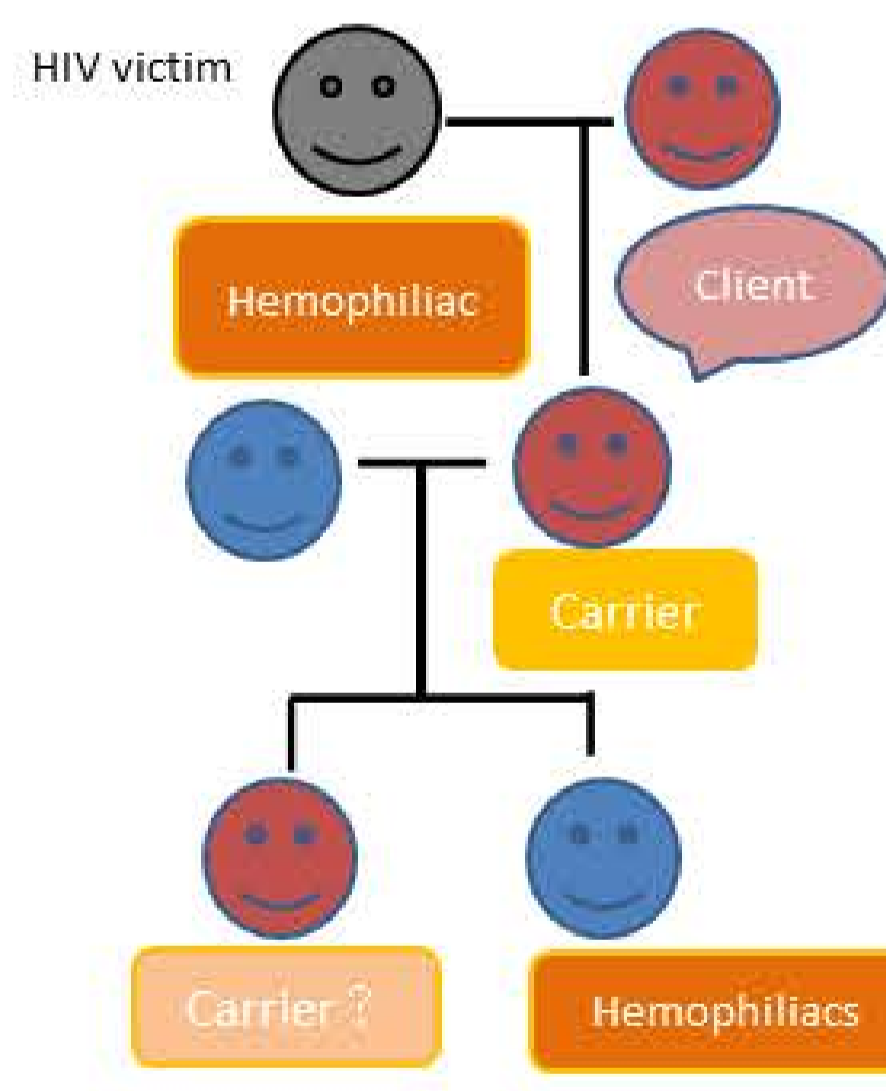
Counseling from Ms. C having child with hemophilia



- Ms. C has no relatives with hemophilia. At that time, she had a tough time due to lack of knowledge and information of hemophilia. Ms. C and her husband were seriously worried about as to whether they had another female child.
- We often told her that she could have child with hemophilia. As a result, she has not married yet. We are wondering she has been watching difficulties of her brother. However, her brother gets married.

Case 4: Contradiction in family role: Family D's Case

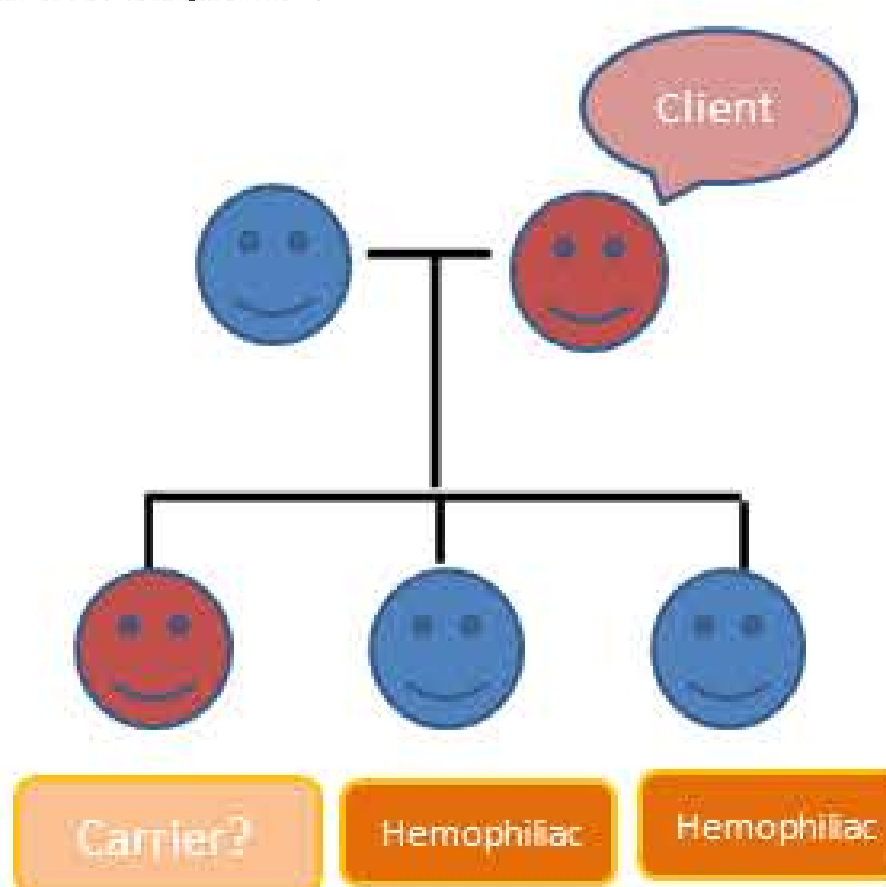
Counseling from daughter (Ms. D's daughter) and mother (Ms. D)



- My father was self-reliant person so D's daughter has never worried about carrier status, much less negative image of hemophilia. However, she thinks that both her father and her family had a severe time in the past.
- Ms. D has no intention of recommending hemophilia test though. It is her business whether her daughter will receive hemophilia test.

Case 5: Ms. E having child with hemophilia, faces difficulties such as hemophilia and medical-induced HIV scandal

Counseling from Ms. E having children with hemophilia



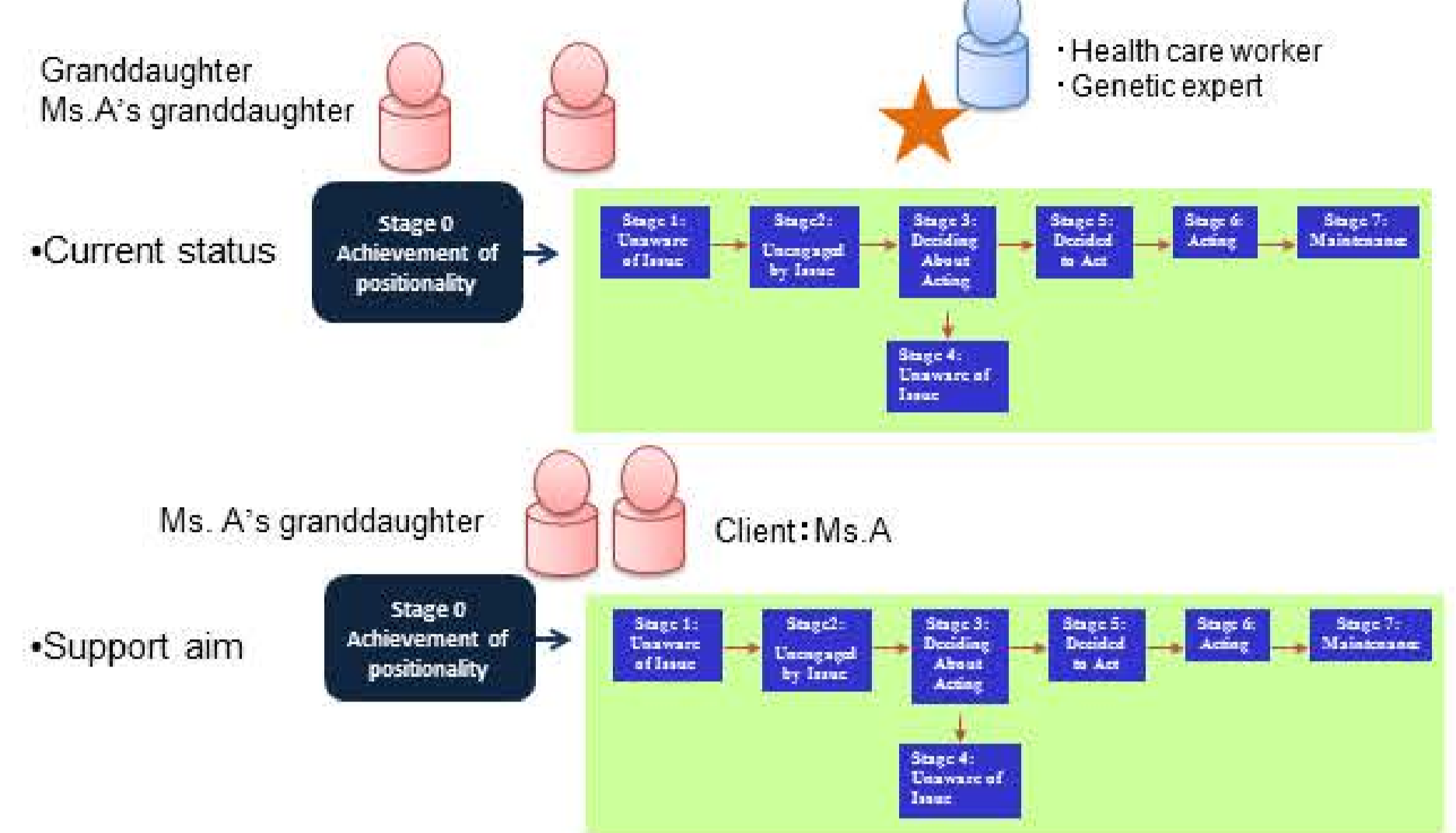
- Ms. E has no relatives with hemophilia. After her son was diagnosed as hemophilia, she was explained by her physician, "If your son uses this safe product, he should avoid the risk of HIV". She felt very embarrassed to hear his comments and was wondering why hemophilia is related to HIV.
- Since it is likely that her daughter could be carrier, she would like to let her know a precise information and knowledge of hemophilia. She hopes her daughter has a variety of choices with the use of these resources.
- Her hope is to have settings where her daughter has no hesitation to talk with peers and friends without concerning about her mother and siblings with hemophilic. Ideally, other facilities except medical institution should be associated with these issues if possible.

Ethic Policy

In accordance with ethic policy of epidemiological research, we conducted this research after obtaining an agreement of ethic committee of social welfare corporate Habataki welfare project on April 12th Heisei 21 (2009). Regarding questionnaire survey, we comply with ethic policy of research and on biology and medicine at special committee of Ochanomizu women's university. We implemented our research on December 13th Heisei 24 (2012). Notification of number 24-20.

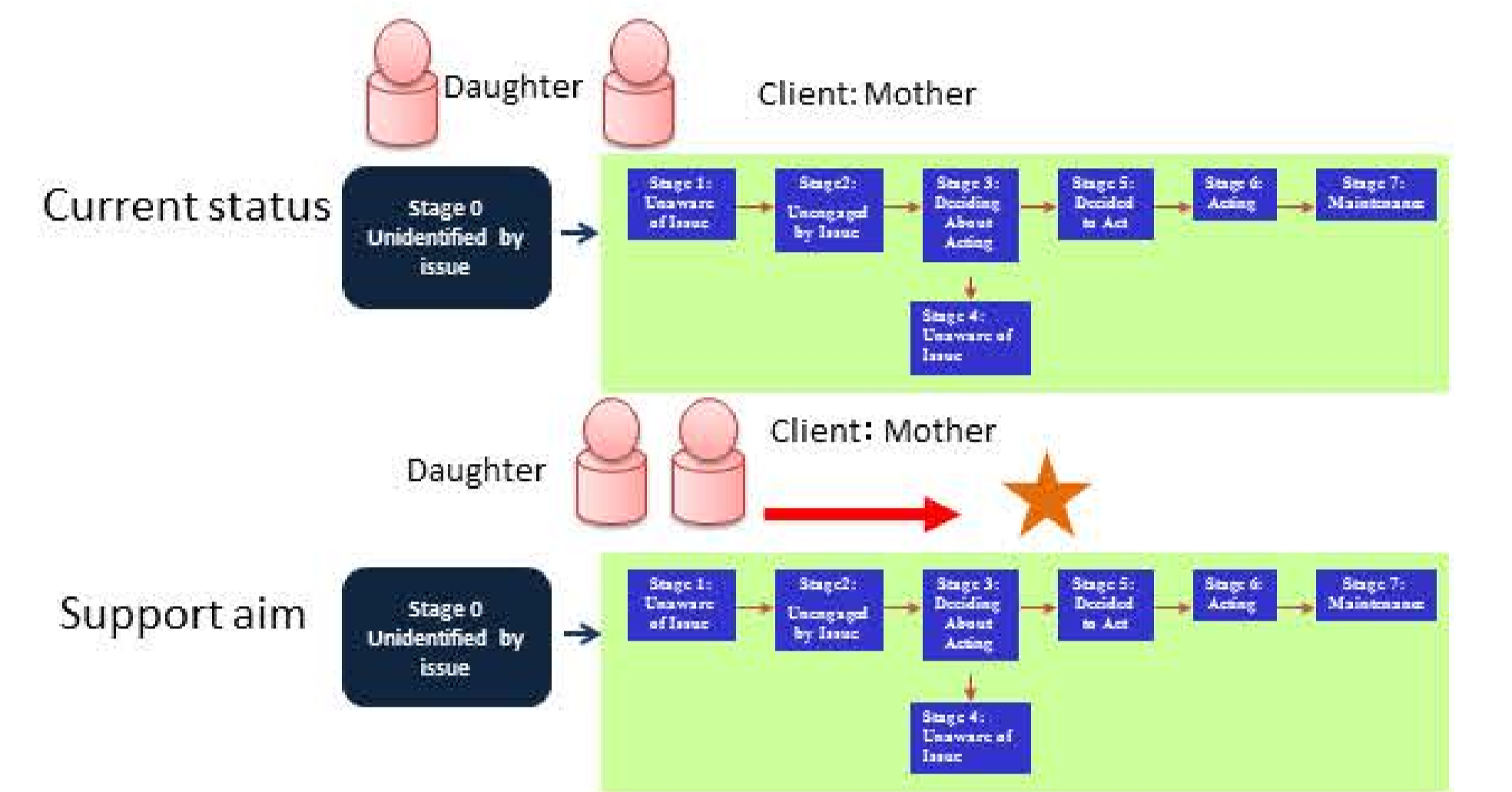
Readiness evaluation: Case1

Ms A wants to let her daughter to check hemophilia test and wants to know hemophilia.



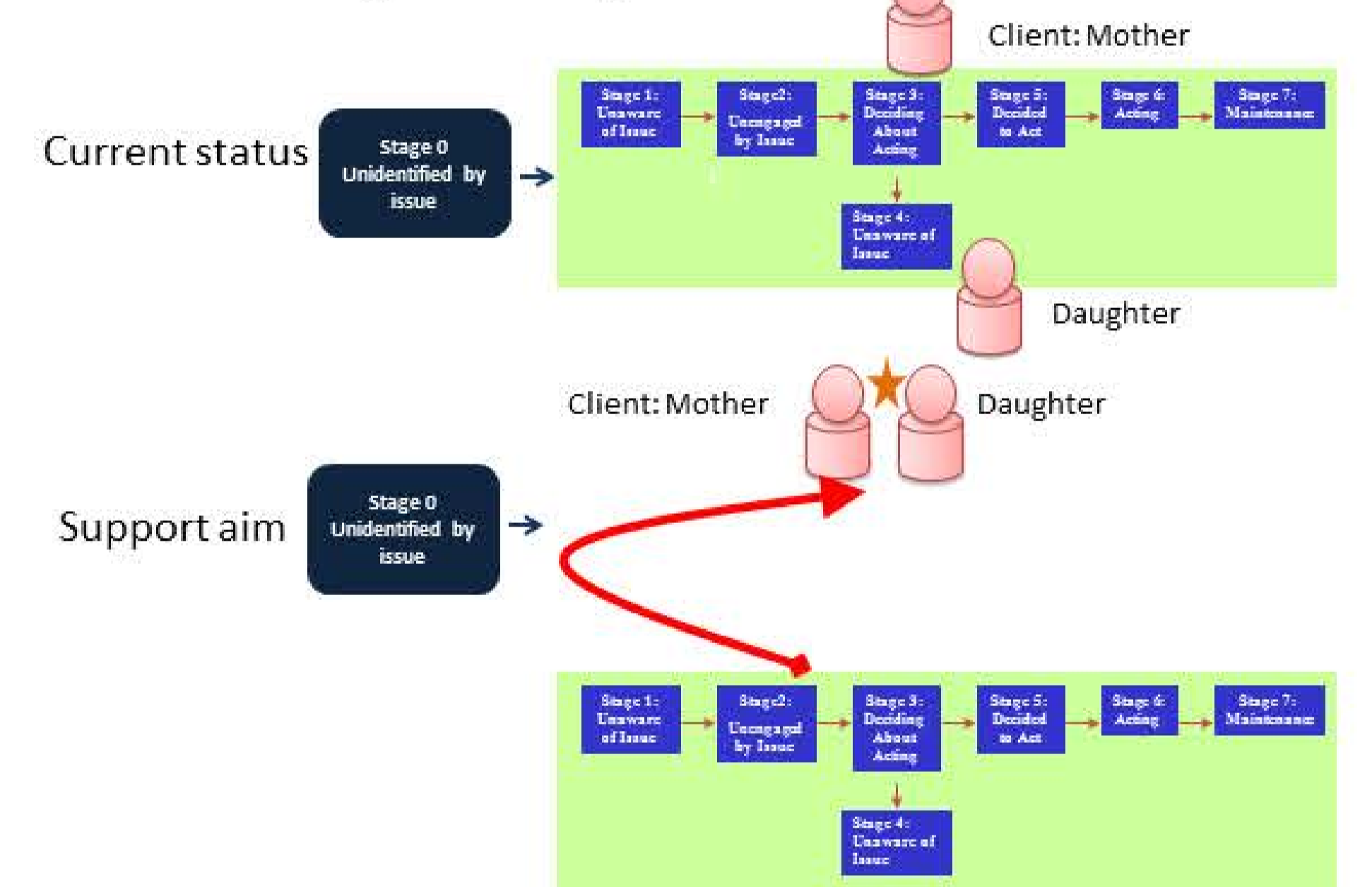
Readiness evaluation: Case2

Client: Ms. C (Mother). She is concerned about how she notifies her daughter of possible carrier status and knowledge of hemophilia.



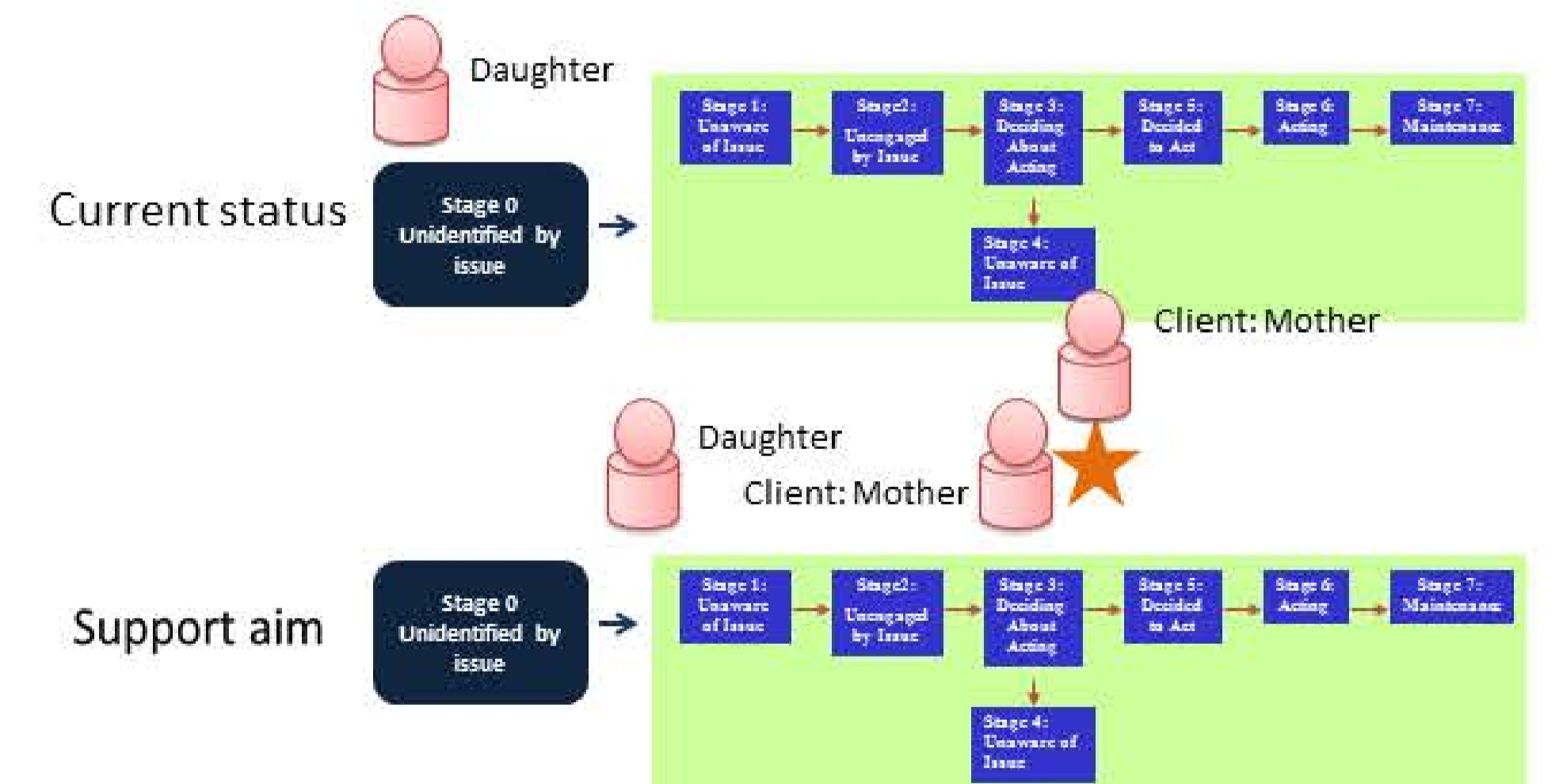
Readiness evaluation: Case3

Client: Mother. We often used to tell her that she could have child with hemophilia. As a result, she has not married yet. We are wondering she has been watching difficulties of her brother though her brother gets married now.



Readiness evaluation: Case4

Client: Ms. D (Mother). Ms. D has no intention of recommending hemophilia test though. It is not my business but hers whether her daughter will receive hemophilia test.



Readiness evaluation: Case5

Client: Ms. E (Mother). Ms. E has no relatives with hemophilia. Thus, she would like to let her daughter know a precise information and knowledge of hemophilia due to her status of possible carrier.

