

Discussion Paper

Improving Outcomes and Quality of Life for People Living with Blood Disorders

Introduction

Chronic and non-communicable diseases (NCDs) have increased in recent years, against a backdrop of changing lifestyles and an aging population. Meanwhile, innovations such as the development of new drugs are resolving unmet needs in a variety of diseases, including rare diseases and blood disorders, and the healthcare delivery system in Japan is expanding. However, despite advances in treatment, patients and people with lived experience face a variety of issues in their daily lives, including reducing invasiveness, frequency of hospital visits, coordination between healthcare providers, and promoting shared decision-making (SDM). Against this background, the Health and Global Policy Institute (HGPI) launched the Blood Disorders Control Promotion Project in 2024, with the aim of focusing on the needs from the perspective of patients and people with lived experience and establishing a model case applicable to other disease areas. As a first step, through discussions with industry-academia-civil society advisory boards and individual hearings, the current issues were organized into four perspectives and were summarized in discussion points, with the aim of improving outcomes and quality of life in the field of blood disorders.

Four Perspectives in Blood Disorder Care

Perspective

I

Structural Issues in the Healthcare Delivery System

- The medical care of blood disorders requires a high level of specialization, which concentrates patients in specialized healthcare institutions.
- Mechanisms for coordination and role-sharing with general healthcare institutions are underdeveloped, leading to excessive workloads for specialist physicians and disparities in access for patients.
- Regional disparities in medical resource distribution, inflexible treatment systems, and heavy workloads for specialized personnel are issues.

Perspective

II

Issues in Community Transition and Healthcare Coordination

- In blood disorders, which require long-term management as chronic disorders, a smooth transition from specialized to community healthcare is ideal.
- However, there are numerous structural issues that hinder the community transition, such as a shortage of receiving institutions, inadequate coordination systems, and the state of specialist involvement.
- There has been a delay in the development of cooperation tools specific to blood disorders, as exemplified by the community-based cooperative care pathways for cancer, which exclude blood cancer.

Perspective

III

Structural Barriers to Delivering Patient-centered Care and Enhancing Quality of Life

- Patients with blood disorders must balance daily living with ongoing treatment, and often experience emotional challenges such as anxiety and isolation.
- Given factors such as insufficient information and decision-making support, lack of support for daily living, and regional disparities in insurance coverage and reimbursement, the current infrastructure is insufficient for improving quality of life (QOL).
- As the shift from “treatments that cure” to “treatments that support throughout life” is called for, the perspective of supporting patients’ ‘life choices’ and ‘daily life’ is even more important.

Perspective

IV

Issues in R&D and Institutional Support

- Due to constraints on human resources and miscellaneous other resources, and lack of institutional support, current systems are insufficient to support continuous clinical trials and research activities.
- Coordination and data infrastructure connecting industry, government, academia, and civil society are underdeveloped, raising concerns about declining international competitiveness and loss of momentum in blood disorder research.
- Most new drug development is conducted under international guidance, and the role of Japanese medical institutions is diminishing.

For the Future

The blood disorder field requires a multi-layered approach due to its rarity, high degree of specialization, and increasingly prolonged and complex treatments. At the same time, the field has seen significant progress, thanks to the steady promotion of advances in medical technology, innovations incorporating patient perspectives, and coordination between health professionals and patients and people with lived experience. In clinical contexts, stakeholders such as academic associations are deploying advanced initiatives. Thanks to these efforts, the field of blood disorders has become model example of patient-centered healthcare in Japan, with potential applications in other disease areas. These successes are resulting in a gradual shift from “treatments that cure” to “treatments that support throughout life,” and in new efforts to facilitate community transition and provide support for daily life. However, the following issues have been identified in order to respond to new values and further needs.

Main Current Issues

- **Divergence between specialized healthcare and community transition:** Although patients are becoming increasingly concentrated at advanced medical facilities, community healthcare receiving points and coordination frameworks remain undeveloped, constraining the sustainability of healthcare delivery.
- **Delayed shift toward patient-centered care:** Support for QOL and psychological/social needs remains inadequate, making it difficult for patients to choose and undergo medical care based on their own values.
- **Weak research and institutional infrastructure:** Efforts to secure research personnel, establish a suitable environment for conducting clinical trials, and participate in joint international research remain limited, and there is no adequate platform for linking research and clinical efforts.

To address these issues, we hope to see multilayered, strategic responses that build on existing efforts, such as the following.

Future Prospects

- **Building an optimal care coordination system:** Clarify the allocation of roles between specialized and community healthcare, and develop a flexible healthcare system adapted to patient condition, to reduce burden and optimize use of medical resources.
- **Developing optimal support environments based on the needs of patients and families:** Facilitate the expansion of information sharing, psychological support, and financial support to create an environment where patients can balance treatment and daily life with confidence while making autonomous decisions.
- **Promoting optimal information coordination and medical DX:** Institutionally support the use of ICT and digital technology to enable bidirectional information sharing among healthcare professionals and between healthcare professionals and patients.
- **Rebuilding a sustainable R&D environment:** Make blood disorder research sustainable by structuring the work of health professionals so that they can balance research with clinical duties, investing in rare diseases on an ongoing basis, promoting international coordination.
- **Ensuring consistency and transparency in system implementation:** Rectify the regionally inconsistent operational rules for medical care reimbursement and insurance coverage, and build a mechanism to ensure that the institutional principle of “uniform access to healthcare nationwide” is upheld in practice.

The full text of the Discussion Paper can be found on our website (<https://www.hgpi.org>).

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