Health and Global Policy Institute (HGPI)
Blood Disorders Control Promotion Project
Phase 1

"Redesigning Disease Control from the Perspectives of Patients and People with Lived Experience" Series:

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

Discussion Paper

Current Challenges and Prospects in Promoting Control of Blood Disorders

HGPI Health and Global Policy Institute

Background of these Discussion Points

Against a backdrop of multiple factors, including lifestyle changes and population aging, chronic diseases or non-communicable diseases (NCDs) are increasing not only in industrialized countries, but also in low- and middle-income countries. Some observers note that much time has passed since NCDs were described as a “silent pandemic.” Meanwhile, innovation is progressing on many fronts such as new drug development, opening paths to remission for intractable diseases, and unmet needs are gradually being met in a wide variety of disorders including rare disorders and blood disorders (a collective term for abnormalities in blood components or function). In Japan, the efforts of industry, government, academia, and civil society have expanded the scope of the healthcare delivery system for chronic diseases. Notable milestones include the promotion of the Health Frontier Strategy, the 2006 enactment of the Cancer Control Act, and the 2018 enactment of the Basic Act on Cardiovascular Disease Measures.

However, as pointed out in the above basic acts and subsequent basic plans, while disease treatment is a matter of great concern for patients and people with lived experience of disease, when considered in the context of their patient journeys and the far-reaching decisions they face, there are many challenges in daily life that remain to be solved. Long-standing requests from patients and people with lived experience include reducing the invasiveness of treatment, minimizing the frequency of hospital visits, ensuring smooth communication between specialist and primary care physicians, and promoting shared decision-making (SDM).

The Japanese Society of Hematology and other groups involved with blood disorders were some of the first in Japan to begin focusing on the needs of patients and people with lived experience. Given that blood disorders have historically been difficult to achieve remission for, the emergence of innovative treatments has raised expectations for a new healthcare delivery system that reflects the needs of patients and people with lived experience. Among other things, this entails ensuring coordination between specialist and primary care physicians, and reducing the invasiveness of treatment and frequency of hospital visits. Academic associations and other healthcare providers are responding with initiatives that accommodate this perspective. To support new efforts in the field of blood disorders and share best practices in other therapeutic areas, the present project was launched in 2024 at Health and Global Policy Institute (HGPI) in line with its mission of achieving citizen-centered health policy.

In the first phase of this project, an advisory board was established comprising representatives from industry, government, academia, and civil society, including patient and patient advocate leaders, as well as academic association representatives. This board conducted round-table discussions, followed by in-depth individual interviews. Based on the insights gained, we identified key discussion points and best practices regarding current challenges and policy directions to solve them. These findings have been compiled into this discussion paper.

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Summary of Key Discussion Points

This paper aims to explore systemic and structural issues in blood disorder care from the perspectives of patients, health professionals, and system implementation, and identify actionable directions for policy and practice reform. With advances in treatment technology enabling remission and long-term survival, there is an increasing need for a shift from "treatments that cure" to "treatments that support throughout life." This shift gives rise to several intersecting discussion points, such as redesigning the healthcare delivery system, rethinking relationships with patients, and securing sustainable support for research and systems. In this paper, these discussion points and their related issues are organized into the following four perspectives.

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.

Perspective II: Issues in Community Transition and Healthcare Coordination

Ideally, patients with blood disorders that require long-term management as chronic disorders should be smoothly transitioned from specialist to community healthcare. In practice, however, there are numerous structural issues hindering community transition such as a shortage of receiving institutions, inadequate coordination systems, and the state of specialist involvement.

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).

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. In addition, 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.

Examination of Discussion Points

Perspective I: Structural Issues in the Healthcare Delivery System

Because blood disorders are rare and highly specialized, they require a high-level, centralized healthcare model. There is actually only a limited number of certified hematology specialists ("specialists"), who diagnose and treat blood disorders, which causes treatment to be concentrated around central healthcare institutions. However, this structure tends to create regional disparities in medical resource distribution, inflexible treatment systems, and heavy workloads for specialized personnel, all of which impact sustainability in frontline healthcare delivery. Moreover, systems for assigning roles to general healthcare institutions and coordinating with community healthcare remain underdeveloped, highlighting the need for further efforts to build a healthcare delivery system that supports patients' long-term management and daily lives. This section analyzes structural issues in blood disorder care from multiple angles, including structural reliance on specialist treatment, functional differentiation in community healthcare, and lastly, placement, training, and support of healthcare personnel. It identifies key challenges for developing a sustainable healthcare delivery system.

Issue 1. Limited involvement by general healthcare institutions due to the high specialization and rarity of blood disorders

The medical care of blood disorders is an extremely highly specialized endeavor due to the many types of disease, complexity of pathology, specialized tests required for examination and treatment, and use of high-level medicines. For example, in blood disorders such as chronic myeloid leukemia (CML) and multiple myeloma (MM), the introduction of new drugs such as molecularly targeted drugs has expanded treatment options. However, optimally individualized treatment requires comprehensive and sustained management, including genetic testing, drug response monitoring, and management of severe side effects.

Effective treatment requires substantial clinical experience and up-to-date knowledge, which are difficult to attain for general practitioners and typical community healthcare institutions. Consequently, community healthcare providers often avoid providing care for blood disorders and refer patients to specialized institutions even before a full assessment is completed. In some cases, general practitioners who suspect a blood disorder lack the diagnostic equipment needed to confirm it, delaying both diagnosis and treatment.

Due to these circumstances, most initial diagnoses and follow-up visits take place at advanced medical facilities such as university hospitals or designated cancer hospitals. This increases patient travel burdens and specialist workloads. Furthermore, the lack of capacity-building at community facilities hinders the advancement of function allocation with specialist centers, perpetuating the structural issue of the healthcare system's inflexibility.

To increase the number of community healthcare institutions capable of managing blood disorders, ongoing educational coordination with specialists is needed, along with information-sharing tools for second-opinion consultations. Building capacity for initial consultation and chronic follow-up would reduce regional disparities in access to care and benefit patients' daily lives.

Issue 2. Uneven distribution of medical resources due to excessive concentration of patients at specialized institutions

Most care for blood disorders, from diagnosis to treatment and long-term follow-up, is provided entirely within specialized healthcare institutions. For example, in diseases such as CML, molecular response must be monitored, so follow-up typically continues with specialists even after remission. This keeps stable patients tied to specialized institutions for long periods, over-concentrating medical resources and hindering their redistribution.

Ideally, once a patient's condition is stable, regular blood tests and monitoring for side effects should be managed by general community healthcare institutions, allowing specialists to concentrate their resources on more severe cases and cases that require a review of their treatment plans. Dividing roles through such counter-referrals could improve the efficiency of medical care and reduce patients' travel burdens.

However, current systems lack effective structures for counter-referral, forcing patients to continue long-term visits to specialized institutions. Transition from specialized to community healthcare institutions can be hindered by the latter's lack of experience treating blood disorders, anxiety over the services to be provided, and uncertainty about treatment responsibilities in emergencies. In some cases, patients themselves may harbor doubts over transition,

preferring to stay under specialist supervision or fearing a drop in treatment standards if they are handed off to a general practitioner.

Meanwhile, specialists can be reluctant to coordinate with community healthcare institutions due to concerns about follow-up responsibility and inadequate communication systems after patient transfer. This has resulted in a vicious cycle where specialist outpatient volumes remain high, restricting their capacity to accept new patients or conduct clinical research.

Improving this rigid structure caused by over-concentration at specialized institutions requires sustained dialogue and trust-building between specialists and general practitioners, as well as clear role allocation, systems for smooth referral and counter-referral, and careful explanations and reassurance for patients. Another critical issue is institutional support, such as establishing reimbursement schemes or incentive systems to encourage coordination between healthcare providers.

Issue 3. Structural mismatch between specialist and patient numbers

Advances in treatment have extended patient survival, meaning that an increasing number of cases require long-term follow-up, yet the number of blood disorder specialists remains limited. As the follow-up period is particularly long in chronic cases, the number of patients assigned to each specialist continues to increase every year, limiting their ability to take on new cases.

Furthermore, restrictions on working hours under labor reform policies have increased the burden on specialists by concentrating their outpatient, inpatient, and administrative workloads. In addition, patients are sometimes referred to hospitals merely for the sake of efficiency, which further hinders counter-referral. In this way, roles and responsibilities are not being adequately allocated among healthcare institutions.

Amid this context, general internists and community general healthcare professionals do not share an adequate understanding of blood disorders or sufficient awareness of cases that can be managed in primary care. Even cases that could be managed at the primary care level, such as mild anemia or thrombocytopenia, are often referred to specialists out of caution, further increasing their workload. This is another factor keeping referral numbers high and adding to specialists' workload.

Although the number of specialized hematologists is edging upward, supply is lagging behind rising demand, and the issue of securing and training personnel in the medium to long term is becoming more pronounced. At present, recruitment and career support for young physicians aspiring to specializations such as hematology is generally inadequate. Institutional mechanisms and educational environments are needed that can sustain interest in these specialized fields. Fostering blood disorder specialists requires not only academic association-led efforts, but also systems built through coordination among industry, government, academia, and civil society.

In this way, rising patient numbers are being met with constrained specialist capacity, making the construction of a sustainable care model a major issue. Going forward, in order to provide high-quality healthcare sustainably while alleviating specialists' workloads, we hope to see task-sharing among healthcare support staff, better role-sharing with community providers, medium- to long-term strategies for specialist training and deployment, and stronger institutional support systems.

Issue 4. Gaps in patient support due to limited involvement of non-physician health professionals

Due to the highly specialized nature of the field, physicians tend to play a central role in the medical care of blood disorders. This leaves limited room for participation by pharmacists, nurses, medical technologists, physical therapists, medical social workers, and other non-physician health professionals, which hinders the introduction of team-based care. This is resulting in inadequate medical, psychological, and other support for patients.

For example, blood cancer should be managed with a multidisciplinary approach involving side effect management, medication counseling, advice for daily life, and psychological care. Despite the need for multidisciplinary approaches, in practice, physicians are often left to handle all aspects of care alone. Moreover, few facilities post or train non-physician healthcare personnel with specialized knowledge or skills relating to blood disorders; this means that providing opportunities and infrastructure for continued education remains another important issue.

In particular, there is a lack of support systems for ascertaining the condition and anxieties of chronic disease outpatients between hospital visits and providing support when required. As some patients experience a sense of isolation when contact with health professionals is limited, there have been calls for a system that can provide comprehensive support during recuperation. Although coordination is possible not only with general community healthcare institutions but also with pharmacies, home nursing services, and care managers, challenges remain in establishing the institutional support and information-sharing mechanisms needed to make such cooperation effective.

Going forward, it will be important to redesign role-sharing and establish a multidisciplinary collaboration system in line with the characteristics of blood disorders. To achieve this, we expect to see institutional infrastructure strengthened through efforts such as supporting the training of non-physician health professionals, providing practice settings, and reviewing the reimbursement systems for medical fees.

Issue 5. Regional disparities and healthcare system inflexibility arising from selection and concentration of medical resources

The medical care of blood disorders often requires advanced technology, equipment, and expertise. For blood disorders, especially leukemia and other blood cancers, policy discussions have favored concentrating resources at designated advanced medical facilities such as advanced treatment hospitals and designated cancer hospitals. Advanced treatments such as CAR T-cell therapy, hematopoietic stem cell transplantation, and cancer genome testing can only be provided at a limited number of core hospitals, and this concentration is more or less considered to be a rational use of limited medical resources.

Still, this concentration is revealing disparities in healthcare access between regions. For example, in one prefecture, there is only a single specialized healthcare institution specializing in complicated, high-level therapies such as hematopoietic stem cell transplantation, requiring some patients to complete a round trip of 2–3 hours just to receive necessary treatment. For patients with diseases that require extended follow-up, spending an entire day on every visit imposes a heavy burden on daily life.

Even differential diagnosis of mild disorders such as anemia or leukopenia sometimes falls to specialists. In some cases, it is difficult to concentrate high-level treatment resources on severe disease because specialists accept consultations that could be handled by general community healthcare institutions. This indicates that the model for role-sharing and functional differentiation between specialists and community healthcare is inadequately designed.

Even in metropolitan areas, there are instances where patients are concentrated in certain healthcare institutions, prolonging waiting times and limiting access for new patients. In this way, healthcare system inflexibility is a concern not only in regional communities, but also in urban centers.

To build a system that is optimal for all regions, the select-and-concentrate approach must be balanced by a layered healthcare system in which specialists, generalists, and regional and urban providers collaborate to complement each other. This requires a reorganization of healthcare service functions, clear role allocation, and a mechanism to support patient transition.

Perspective II: Issues in Community Transition and Healthcare Coordination

Longer treatment courses and better prognoses in blood disorders increased the need for not only specialized but also community healthcare institutions to provide ongoing follow-up and support for daily life. In spite of this, community transition is not progressing smoothly, hindered by limited availability of human, material, and financial resources in regional communities, as well as inadequate systems for role-sharing and collaboration between specialists and community healthcare institutions.

In particular, the healthcare delivery system in communities is inadequately prepared to provide receiving points, creating a structural issue where specialized institutions are heavily burdened while community healthcare systems remain underdeveloped. Moreover, infrastructure for sharing information on blood disorders between physicians is still insufficiently developed. One example of this is the nationwide use of community-based cooperative care pathways for cancer, which support information-sharing among healthcare providers. While the framework still needs to be improved, as it stands, blood cancers are excluded from paths altogether, and there is still no progress on specialized cooperation tools for blood disorders. Amid these conditions, patients are often passed between multiple healthcare institutions, which runs the risk of disrupting the continuity and consistency of examination and treatment. As a result, patients themselves have no choice but to choose a hospital based on healthcare institution structure or general conventions, without a clear idea of where or who to consult for examination and treatment.

Perspective II highlights the specific bottlenecks that hinder linkage with community healthcare, including institutional and operational issues surrounding community transition, handover of medical information and responsibility, and coordination mechanisms.

Issue 1. Lack of receiving institutions due to human, material, and financial resource shortages in regional communities

For patients with blood disorders to transition from specialized to community healthcare, the receiving side must have the necessary medical resources. Yet in reality, many regional communities lack sufficient human, material, and financial resources to be viable as receiving points for patients.

The primary bottleneck for community healthcare is a lack of personnel who can provide care for blood disorders. Many regional communities lack physicians and nurses with experience in treating blood disorders, which presents a significant barrier to continuing care and providing patient support. There is a need to secure health professionals who understand and have experience in managing blood disorders, even if they are not certified hematology specialists.

In order for a community to provide regular outpatient testing and follow-up, coordination is required with not only the primary care physician but also nurses, the medical technologist, and the pharmacist, but many regions lack adequate systems for coordination. An even higher level of specialization and teamwork is required to provide procedures at home such as transfusion and chemotherapy. These services are provided in coordination with physicians and nurses, but skilled personnel are in short supply in regional communities, which imposes a heavy burden on community healthcare institutions.

Furthermore, there is a lack of physical infrastructure. Challenges persist among healthcare providers about the management of necessary testing equipment and medicines.

In addition, the inadequate design of the reimbursement system is hindering community transitions. Community healthcare institutions are not sustainably reimbursed for home transfusions or long-term observation, which means that they cannot take on the role even if they want to.

Consequently, patients must travel long distances to specialized institutions for each visit, increasing their burden and disruption to daily life. Even patients with chronic diseases are locked into this hospital-centric lifestyle, which can reduce QOL. Going forward, it will be essential to develop policy measures to support community healthcare systems and design incentives to help community healthcare institutions to accept patients with blood disorders. Mechanisms need to be designed that leverage regional strengths while considering role-sharing and medical resource distribution.

Issue 2. Lack of shared understanding among blood disorder specialists on the role of community healthcare

To promote transition to community healthcare, it is important for specialists themselves to share an understanding of role-sharing and coordination. However, specialists differ widely in their approach to community healthcare involvement, and there is no common standard for determining which patients can be managed in the community or when counter-referral is appropriate.

Each institution has its own policy for deciding whether and to what extent communities should be delegated with treatments such as transfusion or outpatient chemotherapy that require special management or arrangements. The need for a clear coordination framework is particularly crucial for home transfusion, which is beginning to grow more common. Chemotherapy likewise requires coordination framework among spcialists, including pharmacists, particularly for managing toxic drugs and standardizing treatment regimens. In addition, there is no common policy for community transition to determine the duration and content of follow-up and assign responsibility in emergencies.

As a result, community healthcare institutions may feel anxious or at a loss when receiving counter-referred patients, and the patients themselves may feel that specialist care is more reassuring and request re-referral. These conditions hinder the establishment of community transition as standard practice.

In some cases, specialists do not have a clear idea what community-based care should involve, making it difficult for personnel such as young physicians to get involved in community healthcare. On the institutional side, there is a lack of clear rules to determine how community-based activity impacts career advancement and evaluation, which leaves few structural incentives for specialists who want to work in regional communities.

Building a sustainable healthcare delivery system for blood disorders will require fostering a shared understanding among specialists, establishing a system to underpin it, and promoting face-to-face relationships among the health professionals involved.

Issue 3. Lack of coordination in regional communities between blood disorder specialists and general practitioners

In the medical care of blood disorders, role-sharing and coordination between specialists and general practitioners is important throughout the entire care process, from initial consultation to long-term follow-up. However, frameworks for intra-regional coordination between specialists and general practitioners remain underdeveloped, hindering the establishment of counter-referral and inter-clinic coordination.

When a specialist completes a diagnosis or initial treatment and refers a patient to community general practitioner for follow-up, it is essential for the specialist to provide appropriate information such as referral letters and test data. In practice, however, the quantity and content of this information varies widely, and community healthcare institutions commonly receive inadequate information, which makes them uneasy about providing medical care. Uncertainties tend to remain not only regarding the specifics of specialized treatments, but also around recurrence management policies and decision-making criteria for emergencies. Consequently, patients tend to remain at specialized institutions.

Non-medical information such as a patient's lifestyle circumstances, personal preferences, and family support situation is hard to share in patient referral documents or referral letters, which can hinder advance care planning (ACP) or transition to home medical care. This makes it difficult for patients to receive continuous, consistent healthcare, potentially causing feelings of anxiety or distrust.

System issues are also impacting coordination. System issues are also impacting coordination. The systems by which specialists and general practitioners can exchange information periodically or consult with one another on an ad hoc basis are limited or underdeveloped. Although certain regions have begun using ICT to share medical information, these systems have yet to be scaled up to the national level.

Given these circumstances, strengthening inter-clinic collaboration will require the introduction of standards for mutual information exchange, as well as institutional infrastructure that enables specialists and general practitioners to collaborate and provide support on an equal footing.

Issue 4. Lack of mechanisms for sharing information between physicians

Blood disorders require long-term medical care, spanning acute and chronic phases, with multiple cycles of recurrence and remission. Throughout this process, changes such as the replacement of the primary care physician or a transfer to another healthcare institutions (admission/discharge, counter-referral, community transition, etc.) are unavoidable. To maintain continuity of care, smooth information sharing among physicians is essential. However, the systems and technologies currently in use are not regularly updated or modernized, which raises concerns about the consistency of care.

Notably, reliance on analog means of transmitting medical information, such as paper referral letters or fax, can hinder proper sharing of treatment details, clinical course, and care plans. Meanwhile, electronic medical records suffer from low compatibility between service vendors, making it difficult to browse or share information across different healthcare institutions. As a result, there are cases where the receiving physician begins examination and treatment without full knowledge of the patient's medical history and test results. In such situations, the patient may have no choice but to verbally explain their treatment history and test results, which can easily lead to misunderstanding and miscommunication, delayed treatment, and psychological distress. It also forces physicians to make decisions based on limited information, leading to repeat testing, redundant examinations, and other inefficient uses of medical resources.

Furthermore, when patients are transitioned to community or home care, the inadequate inter-clinic sharing of information can hinder smooth coordination and cause gaps in care for patients. For example, cases have been reported where ACP or family agreement documentation was not handed over to the receiving institution, resulting in inconsistencies in care.

Another issue is the lack of reimbursement or institutional incentives that promote information sharing. In practice, communication on the ground depends on the efforts of individual healthcare institutions and the goodwill of individual physicians, so continuity and fairness remain an issue. Policies are needed to build common platforms, visualize the state of coordination, support the introduction and use of information-sharing tools, and implement mechanisms for evaluating these efforts.

To address these issues, it will be necessary to provide institutional support for the clinical introduction and sustained use of medical chat tools and shared electronic medical records that leverage ICT, as well diverse coordination models such as "D to D with P" (doctor-to-doctor with patient participation) and "D to P with D" (specialist doctor-to-patient consultation with non-specialist doctor participation) online consultation.

Issue 5. Lack of institutional mechanisms for decision-making support in community healthcare

In treating blood disorders, there are many turning points where a patient's treatment plans should be reassessed in light of prolongation of treatment, risk of recurrence, transition to home medical care, or other factors relating to changes in the patient's condition or living environment. An important role is played at such times by structured decision-making support that centers the patient's values and facilitates shared discussions with families and care providers. However, current institutional mechanisms are inadequate for providing this support in regional communities.

During key transition periods such as admission, discharge, change in outpatient care provider, and community transition, decisions are required that take patients' wishes and values into account. In spite of this, opportunities for discussing these things are not being adequately secured. In addition, as patients' preferences and the content of prior discussions are not recorded and shared, patients and their families must bear an increasingly heavy psychological burden of explaining everything from the beginning every time they change healthcare institutions and health professionals. Furthermore, although physicians, nurses, and community care managers who provide decision-making support must have both clinical judgement and communication support skills, training and institutional support for acquiring these skills are scarce, which means that the quality of decision-making support depends on the provider's own enthusiasm and experience. Moreover, since the process of patients' decision-making support itself is not subsidized under the current Japanese medical fee incentive system, there are some critiques suggesting that it is difficult to incorporate it as part of regular duties.

Decision-making support should assist patients in making medical decisions based on their own worldviews and values. The quality and continuity of this support is a major factor in ensuring each patient's own worldview and values, and the quality and continuity of this support is a major factor in ensuring the patient's sense of reassurance and faith in treatment. Going forward, it will be necessary to strengthen institutional backing and promote the training of personnel so that regional communities can provide an equivalent level of support for decisions concerning not only treatment but also life choices.

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

Blood disorders often require prolonged treatment and carry a risk of recurrence, exerting a persistent impact on patients' lives. Survival rates have improved in recent years due to advances in treatment, but patients are compelled to balance treatment with daily life while coping with side effects and uncertainties about the future. Many continue to work while living with cancer, and face new challenges balancing treatment, employment, and daily life.

In such circumstances, it is important for treatment to go beyond mere disease management and provide support for life choices and daily life. However, current medical care frameworks tend to emphasize improving symptoms and treatment efficacy, and consideration and support for patients' QOL is often overlooked or treated as a lower priority. It is not uncommon for examination and treatment to proceed without the patient's own condition and preferences being clearly expressed, causing feelings of isolation and anxiety during recuperation amid inadequate information and support.

In addition, issues relating to the design and operation of the healthcare system also affect patients' QOL. These include the absence of life-course perspectives such as consideration for fertility, lack of support during transition, disparities in access to information about diseases and treatments, financial burdens such as medical expenses, and system incoherencies. All these issues compound, making it hard for patients to face treatment with hope for their future and daily lives.

Perspective III takes a multifaceted look at factors impacting the QOL of patients with blood disorders, and presents discussion points outlining the institutional reforms, support systems, and changes in clinical attitudes required to achieve patient-centered care.

Issue 1. Ongoing psychological stress due to anxiety over side effects and disease recurrence

Although recent advances in treatment have made remission and long-term control possible in many blood disorders, patients still live with the risk of side effects and relapse. This means that psychological tension and anxiety can easily persist not only during treatment but also after remission. In chronic diseases such as CML and chronic lymphocytic leukemia (CLL), patients' lives are continually burdened by psychological pressures from a wide range of future uncertainties, including prolongation of treatment, continued medication, risk of secondary cancer or impaired fertility due to treatment, and financial burdens.

Additionally, when information about side effects is insufficient, or systems for consultation on physical changes are lacking, patients may fail to adequately communicate symptoms (such as malaise, nausea, insomnia, etc.) to healthcare providers and continue to receive treatment while harboring anxieties. Some observers point out that this issue is especially pronounced among elderly patients and patients living alone, who face many opportunities for anxiety but may have limited opportunities to share them, potentially heightening their sense of isolation. Moreover, anxieties over uncertainty associated with recurrence or changes in disease progression tends to flare up around regular check-ups. This psychological pressure surrounding testing is sometimes dubbed "scanxiety." Such sustained anxiety or tension affects daily life, work, and personal relationships, and can significantly impact a patient's quality of life.

To alleviate this psychological burden, it is important not only for health professionals to respond empathetically to symptoms and emotions, but also to expand support systems and introduce psychological support. A coordinated system involving physicians, nurses, clinical psychologists, and other disciplines is needed to provide continuous support for unspoken anxieties and everyday difficulties.

Issue 2. Heightened isolation and anxiety due to inadequate systems for providing information and consultation

In everyday life, recuperating blood disorder patients must navigate a wide range of anxieties beyond treatment and side effects. These anxieties include balancing treatment with work, study, or family life, planning for future events such as one's own or one's partner's pregnancy and childbirth, and coping with financial burdens. However, there is currently no framework for providing information or counseling to meet these patients' individual needs. Consequently, there are cases where patients are forced to make decisions without understanding their treatment plan, or become isolated without receiving advice suited to their own life circumstances.

Patients are often at a loss as to what questions to ask at important junctures such as when the disease initially occurs or the treatment plan is changed. At such junctures, it is easy for informational asymmetry to occur between patients and health professionals. In some cases, patients are not provided adequate explanatory material about

their disease or treatment, or do not have access to a unified source of information about medical expense subsidies or support programs. This lack of information can cause further confusion and anxiety.

Although some healthcare facilities offer cancer counseling support centers and medical social workers, their availability and functions vary by region and institution, and institutional backing is limited. Consequently, patients are required to find information themselves, and may be forced to rely on untrustworthy internet sources due to a lack of access to accurate information.

This deficit in information and consultation can not only intensify patients' feelings of isolation, but also affect their desire to continue treatment and take care of themselves properly. Going forward, we hope to see improvements in the quality and quantity of information provided in clinical settings, environments that enable patients to easily and comfortably seek advice, and systems that provide access to trustworthy information.

Issue 3. Lack of consideration for QOL due to a treatment-centered healthcare delivery system

Care for blood disorders is generally centered around treatment that prioritizes saving lives. This structure has made it difficult to assess the effect of care on patients' QOL and daily life. Prolonged outpatient care and anxieties over side effects and recurrence associated with treatment all take a toll on patients' daily lives, and in many cases make it difficult to balance treatment with employment, family life, or study.

For example, certain treatments such as CAR T-cell therapy require frequent hospital visits, hospitalization, and extended monitoring. The associated traveling, waiting, and medical care occupies patients' time, forcing them to plan their daily lives around the hospital. Furthermore, lingering subjective side effects such as fatigue and lack of appetite can cause patients to perceive treatment not as something that supports their life, but something that restricts it.

Meanwhile, time limitations often force healthcare providers prioritize symptom management, leaving little margin for considering patients' overall life. Consequently, patients may feel that their quality of life has deteriorated even when treatment is medically successful.

Going forward, it will be necessary to not only improve treatment outcomes, but also incorporate QOL in medical evaluation and deliver personalized medicine that takes into account each patient's own values and life circumstances.

Issue 4. Inadequate mechanisms for bidirectional information sharing between physicians and patients

In order to provide high-quality medical care for blood disorders, it is essential for patients to accurately grasp their own condition and appropriately communicate their everyday symptoms and side effects to health professionals. However, under the current healthcare system, information is typically shared by physicians to patients in a unidirectional manner, with only limited opportunities for feedback and consultation from patients to physicians.

For example, due to limited consultation time, it is not uncommon for medical consultations to end without taking sufficient note of what patients want to say. Furthermore, as there are few established means for communicating subjective information (side effect severity, everyday changes in physical condition, etc.) during consultation, physicians have no choice but to make clinical decisions based on limited information. Meanwhile, patients may feel rising helplessness and anxiety when their personal experiences are not reflected in their medical care.

These information gaps between physicians and patients may impact clinical satisfaction and the appropriate timing of treatment. In recent years, some efforts have emerged that make use of smartphone apps, simple questionnaires, and patient-reported outcomes (PROs), but these efforts tend to be limited to research frameworks or certain facilities, and have not yet been incorporated into institutional systems.

Creating a system for smooth bidirectional information sharing would allow patient feedback to be reflected in treatment and enable health professionals to grasp situations in a timely manner. The introduction of such systems would also contribute to early intervention and more reassuring continuous treatment.

Issue 5. Confusion due to information overload and lack of health literacy among patients and people with lived experience

A high level of specialization is required to provide medical care for blood disorders. For this reason, it is not easy for patients to gain an accurate understanding of their own condition and treatment, side effects, and the necessity of ongoing monitoring, or to correctly choose a treatment and manage themselves. In fact, cases have been reported where patients discontinued hospital visits or medication due to insufficient explanation, highlighting the need to improve patient health literacy.

Patients are inundated with information on the internet and social media, and exposure to incomplete or inaccurate information sometimes leads to greater anxiety or misguided judgement. As trustworthy information on rare diseases is scarce, patients tend to be excessively influenced by individual case reports and stories by outliers.

In this information environment, it is important to establish mechanisms that enable patients to confidently gain the knowledge they need. It will be important to clearly specify trustworthy sources and help patients to evaluate and use medical information appropriately.

Going forward, we hope to see coordinated efforts between healthcare institutions, academic associations, and public organizations to increase societal health literacy in collaboration with patient groups through a variety of means including peer support, consultation support, and the development and distribution of patient-oriented educational and explanatory material.

Issue 6. Lack of transitional support and growing financial burdens due to extended life expectancy and prolonged treatment

Advancements in treatment have greatly improved the life expectancy of patients with blood disorders, making it increasingly possible to achieve "daily life with ongoing treatment" based on long-term outpatient care and follow-up. However, the current healthcare system and support frameworks do not adequately reflect this change. Consequently, financial burdens and support gaps during transition periods are impacting patients' lives during recuperation.

One area where issues are emerging is in transitional care, which bridges the gap between pediatric and adult care. Although patients in pediatric care receive comprehensive support for daily life, cases have been reported where they lose access to the same level of medical explanations and psychological care upon transition to adult healthcare, making it difficult for them to continue outpatient visits. In addition, medical expense subsidy coverage is inconsistent between the specific chronic pediatric disease and specific medical expense (designated intractable disease) programs, and sometimes support is cut off when patients reach a certain age or fall into gaps between systems. Moreover, as treatments grow longer, financial burdens grow heavier. While public programs such as the High-Cost Medical Care Benefit System offer some support, the cumulative burden of out-of-pocket expenses, as well as direct and indirect expense (transportation, caregiver costs, difficulty continuing employment) weighs heavily on patients and their families. Recent discussions on system reform have touched on raising copayment caps and changing eligibility criteria, increasing the risk of treatment being suspended for financial reasons.

Furthermore, the complexity of support programs makes them difficult for patients to use. In some cases, even health professionals are unable to explain them to patients accurately, highlighting the importance of not only supporting patients directly, but also providing information to health professionals and developing consultation support systems.

In response to this, to help patients balance treatment and daily life, it will be necessary to strengthen transition support systems that ensure continuity of care, ensure compatibility between medical subsidy programs, and develop mechanisms that comprehensively support patients, families, and health professionals.

Issue 7. Regional variation in insurance coverage and reimbursement practices are affecting the lives of patients and people with lived experience

Japan's National Health Insurance system is designed to operate uniformly nationwide, but in practice, interpretations of coverage and reimbursement policies can vary depending on "local rules" observed by individual regions and review organizations. This is especially true for a highly specialized field like blood disorders, where the wide range of tests and treatments makes it easy for regional disparities in insurance coverage to arise, causing confusion in practice for both healthcare providers and patients.

For example, it has been reported that International Scale-PCR tests, used for monitoring CML, are covered by insurance at clinics in some regions but not others. Regional differences are also seen in the handling of specimen test interpretation fees, hindering inter-clinic collaboration on testing.

It has also been reported that while some regions have a two-month upper limit on the duration of regular prescriptions, this limit is three months in other regions. In this way, regional differences directly affect patients' outpatient visit frequencies and recuperation plans. In some cases, patients even consider changing their place of residence due to the impact of these differences on their life plans.

These inconsistencies in system implementation raise the risk of the treatments being determined by the patient's place of residence. At the same time, they not only compromise the system's fairness and transparency, but also increase the burdens borne by patients, people with lived experience, and physicians on the ground. It will be necessary, particularly for specialized fields such as blood disorders, to increase the dependability and transparency of the system by working at a national level to develop a reimbursement mechanism and nationally consistent guidelines.

Perspective IV: Issues in R&D and Institutional Support

As blood disorders include many rare and intractable diseases, research in this field can directly improve patient QOL and increase the range of available treatment options. However, current constraints on human, physical, and financial resources make it difficult to promote everyday medical care and research activities concurrently. In addition, Japan lacks a common platform for promoting coordination between industry, government, academia, and civil society, as well as data infrastructure such as registries. As a result, Japan still faces issues hindering the establishment of a system that enables stable participation in domestic and foreign clinical research and trials, or joint international research. Perspective IV outlines issues affecting the promotion and continuation of research and development in the blood disorders field from the perspectives of "personnel and resource constraints" and "lack of institutional and structural platforms for coordination."

Issue 1. Inadequate sustainable implementation frameworks for supporting research due to constraints on personnel and resources

In the field of blood disorders, most new drug development is conducted under international guidance, and the role of Japanese medical institutions in clinical trials and clinical research is diminishing. Some observers point out that it has become difficult to balance research with clinical duties, especially for young physicians, who may struggle to maintain interest and motivation to participate in research activities.

Furthermore, as clinical research is conducted outside the scope of reimbursement systems, administrative tasks such as document preparation and ethical reviews fall to physicians themselves, who lack the spare capacity to deal with research within their restricted clinical schedules. Meanwhile, at university hospitals and similar institutions, where multiple clinical trials may be conducted concurrently, there is the tendency for rare diseases to be deprioritized due to limited personnel.

Furthermore, despite the high costs of basic research and new drug development in Japan, funding often has to be provided by the researchers themselves, and in the case of rare diseases such as blood disorders, corporations are reluctant to invest due to the limited number of potential patients. Due to these circumstances, there have even been reports questioning the viability of supplying certain existing drugs due to drug price cuts and other factors.

In order to maintain and strengthen research capacity amid all this, it will be necessary to strengthen research infrastructure as a whole. Among other things, this may entail standardizing an ethics review framework for multicenter research, expanding research support staff, designing appropriate incentives for healthcare institutions, providing career support for young physicians, and reviewing both public and private funding schemes.

Issue 2. Immature frameworks for innovation and coordination among industry, government, academia, and civil society

Although medical technology and therapies for blood disorders have made significant progress, the R&D platforms and coordination ecosystems that sustain this progress remain underdeveloped. For example, some healthcare providers have introduced a mechanism for patients with CML to record side effects and QOL via a smartphone app—but this initiative has yet to be generalized across other regions or diseases.

Meanwhile, diverse stakeholders such as pharmaceutical companies, research institutions, government bodies, and patient groups are each pursuing their own activities. But there is a lack of collaborative platforms to organically connect their efforts, and governance structures for producing results are underdeveloped. As a result of this, building a strategic coordination system with a long-term perspective remains an issue.

Furthermore, limited Japanese participation in joint international research and insufficiently developed registries and databases have been cited as contributing to "drug loss," in which pharmaceutical companies shun the Japanese market. This is limiting the domestic selection of new drugs, disadvantaging healthcare providers.

Going forward, in order to accelerate coordination between blood disorder research and policymaking via collaboration between industry, government, academia, and civil society, it will be necessary to develop common data infrastructure and registries, strengthen intermediary support organizations, and provide institutional support to promote coordination.

International Case Study: Management of CML in Canada

This case study offers a complementary perspective that helps frame key issues in the care of blood disorders in Japan, based on an examination of current CML care in Canada. In Canada, CML is regarded as a "manageable chronic illness," and a multifaceted approach is used, including transitioning from specialized to community-based care, as well as developing patient education and support systems. In this context, various challenges and limitations have emerged, some of which mirror issues similarly seen in Japan, as outlined below.

Seven Aspects

1. **Misalignment between the needs of health professionals and patients** (related: Perspective III, Issues 1 and 3)

   In Canada, like in Japan, health professionals typically prioritize care based on clinical severity while giving less consideration to patients' lifestyle difficulties such as fatigue, malaise, or difficulties commuting and working. Patients are often reluctant to express their true concerns to physicians, fearing that they might inconvenience them or lose their primary care physician. On the other hand, physicians often struggle to adequately address lifestyle impacts due to time constraints.

2. **Progress and limitations in transitioning to community-based care** (related: Perspective II, Issues 1 and 3)

   CML is considered a chronic illness in Canada, and efforts are being made to transition patient follow-up from cancer centers to general community healthcare institutions. However, many community healthcare institutions are not fully equipped with the specialized knowledge or rapid diagnostic capacity required for CML management, resulting in cases where patients may feel uncertain or hesitant about continuing their treatment.

3. **Patient education and empowerment** (related: Perspective III, Issues 2 and 4)

   The Canadian CML Network, an advocacy group for CML patients in Canada, distributes handbooks for patients and holds national conferences to provide opportunities for interaction and learning among patients. These efforts provide valuable opportunities for patients, especially in rural areas, to learn about treatment practices in other regions and realize that they have multiple treatment options.

4. **Roles and limitations of support personnel and systems** (related: Perspective I, Issue 4; Perspective III, Issues 1 and 3)

   In the past, Canada assigned specialist nurses to manage side effects, but this arrangement has been scaled back due to resource shortages. Although the use of patient volunteers was explored as an alternative, the effort stalled over accountability and privacy concerns.

5. **Balance between treatment costs and system design** (related: Perspective III, Issue 7)

   Public insurance systems in Canada vary by province and territory, which can result in regional disparities in access to CML medications. The majority of patients rely on a combination of public programs, private insurance, and pharmaceutical company support programs to cover drug costs. Although treatment interruptions are rare, challenges remain in achieving consistent and reliable system-level coverage. Meanwhile, in Japan, a consistent national healthcare system exists in principle. However, there are regional disparities in implementation ("local rules"), with differences arising in terms of specific tests and insurance coverage.

6. **Delayed institutional response for TFR cases** (related: Perspective V, Issues 1 and 3)

   Medication for CML may be discontinued under a treatment-free remission (TFR) approach if certain criteria are met. In such cases, frequent checkups are necessary. In some parts of Canada, the associated tests are not covered by insurance, indicating a delay in system-level support.

7. **Psychological burdens specific to chronic disease** (related: Perspective III, Issues 1 and 6)

   Chronic diseases such as CML that are managed rather than cured may impose a prolonged psychological burden due to concerns about relapse and adverse effects. In both Japan and Canada, conventional healthcare systems remain primarily focused on actual medical care, and they lack the structural capacity to address long-term psychological challenges. Establishing a comprehensive support system that integrates medical care, welfare services, and psychological support remains a key challenge for the future.

Policy directions inferred from the Canadian case

While Canada's approach to CML care shares some structural similarities and common challenges with Japan's, it does feature some noteworthy initiatives and arrangements. These are grounded in the actual needs of chronic disease patients who continue with their daily lives while receiving treatments, and offer useful insights for both system design and practical support in Japan. Blood disorders in particular require specialized expertise and have an uncertain long-term prognosis. With such diseases, quality and sustainability in treatment hinge on integrating and implementing medical management and livelihood support through institutional systems. The following section outlines four practical directions distilled from the Canadian example.

1. Improving communication between patients and health professionals

It is essential for physical and psychological hurdles between patients and health professionals to be lowered so that patients feel safe discussing their symptoms and concerns. We consider the following initiatives to be effective options:

- Introducing preliminary examinations or interviews with nurses or medical social workers to identify issues that might not be adequately addressed during limited medical consultation time
- Periodically using checklists to monitor patients' living conditions and difficulties visiting hospitals or taking medication
- Providing physicians with opportunities to learn communication skills and listening techniques that take patients' social and personal contexts into account

These initiatives create conditions where "medically minor concerns" are not overlooked, which helps to ensure continuation of treatment and QOL.

2. Promoting patient education and peer support

Japan can learn from initiatives such as the Canadian CML Network, which helps patients to understand their condition, seek appropriate treatment, and engage with healthcare providers. Specific aspects include the following:

- Developing clear, updatable educational materials on patients' diseases and treatment options (pamphlets, videos, etc. for patients)
- Providing opportunities for peer consultation and interaction at the hospital and community level
- Establishing online patient groups to prevent information gaps among rural residents

Such approaches can not only prevent isolation, but also empower patients to ask questions and make proactive treatment choices.

3. Balancing institutional arrangements with financial support

In designing healthcare systems, it is important to not only reduce financial burden of medications through mechanisms such as the High-Cost Medical Care Benefit System, but also to prepare institutional support for emerging treatment options such as TFR. Specific measures could include the following:

- Introduction of subsidies or bundled payment systems like Diagnosis Procedure Combination, as TFR requires frequent monitoring
- Provision of public funding to develop ICT infrastructure to facilitate monitoring and coordination among healthcare providers
- Promotion of transparency and national standardization in insurance coverage criteria for high-cost tests and procedures at community healthcare institutions

Policies are required that bridge the gap between system design principles and real-world situations to prevent disadvantages for patients.

4. Constructing psychological and social support systems for chronic disease

Chronic diseases are typically accompanied by chronic psychological strain and persistent anxiety about relapse or side effects. Addressing these requires measures such as the following:

- Increasing the involvement of mental health professionals (certified public psychologists, clinical psychologists, psychiatric nurses, etc.)
- Standardizing consultation support related to employment, family relationships, and life planning
- Establishing spaces for dialogue (peer group work etc.) so that patients can express their uncertainties surrounding the duration of treatment

In areas where healthcare providers may have limited capacity to respond, there is a need to develop systems and personnel that serve as bridges between patients and available social resources such as patient groups.

Review and Conclusions

This discussion paper was produced with the aim of analyzing issues in the structure and operation of the healthcare delivery system in the blood disorders field, and identifying discussion points that contribute to improving system designs and realities on the ground.

Blood disorders are characterized by their rarity, high degree of specialization, and increasingly prolonged and complex treatments. Accordingly, they require flexible, multilayered management that transcends conventional healthcare frameworks in every aspect, including healthcare model, system implementation, and patient support. At the same time, the field has seen significant progress, even in conditions once thought to be difficult to bring to remission, 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 actively deploying advanced initiatives that incorporate the perspectives of patients and people with lived experience. 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.

The accumulation of these successes is 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. It is becoming clear what issues must be addressed to accommodate the values and needs that are emerging.

- **Divergence between specialized healthcare and community transition**: Although patients are becoming increasingly concentrated at advanced medical facilities, community healthcare receiving points, personnel, and coordination frameworks remain undeveloped, constraining the sustainability of healthcare delivery.
- **Delayed shift toward patient-centered care**: Institutional and clinical 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 and life circumstances.
- **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 organically linking research and clinical efforts.

These issues are difficult to solve by reforming individual systems and care frameworks alone—it is necessary to reexamine the healthcare delivery structure itself on all levels. Going forward, we hope to see multilayered, strategic responses that build on existing efforts, such as the following.

- **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 and treatment stage, to reduce patient 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 work to enable research to be balanced 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.

Going forward, it will be necessary for stakeholders from diverse contexts to continue cooperating to restore discourse between policymakers and voices in the field, while proceeding with concrete initiatives aimed at building a sustainable healthcare delivery system under which patients can balance treatment and daily life with confidence. We look forward to seeing further developments in the field of blood disorders, where coordination based on the perspectives of patients and people with lived experience has already been making progress.

Acknowledgement

When formulating this overview of discussion points, we received opinions from the experts listed below who participated on our Advisory Board. We express our deepest gratitude for their input. This overview of discussion points was compiled by HGPI in its capacity as an independent health policy think tank, and should not be taken to represent the opinions of any individual Advisory Board member, related party, or organization or group to which they are affiliated.

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