Global Coalition on Aging

How to Better Support Older Adults and Their Families for Shared Decision-Making About Cancer Care

ROUNDTABLE REPORT FROM THE GLOBAL COALITION ON AGING (GCOA)

February 2024

Executive Summary

On October 12, 2023, Global Coalition on Aging brought together healthcare providers, patient representatives, and academic experts from Japan, the United States, Canada, Ireland, and the United Kingdom for a roundtable on cancer care for older adults, and how the advancement of shared decision-making (SDM) practices could help to improve it. This roundtable was convened to create an opportunity for experts in the field of cancer care for older adults to discuss ideas and challenges related to shared decision-making. It was held in response to policy changes in Japan around cancer, but its topic is relevant to care practices worldwide. This paper summarizes the discussion at the roundtable with the goal of sharing information on how to better support decision-making around cancer treatment for elderly patients and their families. It includes a summary of stakeholder opinion about lessons learned thus far, and recommendations toward the achievement of better care outcomes. The roundtable and this whitepaper were sponsored by Pfizer Japan Inc.

The single greatest risk factor for cancer is aging.[1] Approximately half of all cancer patients globally are age 65 or older. Cancer among older patients can present unique challenges for care which can greatly affect quality of life and the ability to age healthily. As lifespans increase, medical systems are increasingly being asked to cater to the needs of older cancer patients and their families. Already, approximately 75% of Japan's one million cancer patients are older adults. For Japan, cancer treatment means treatment for older adults, and improving care for this group is increasingly important.

In part to respond to the needs of its older population, guidelines for Japanese medical facilities involved in cancer care were revised in 2022 to include requirements on the creation of systems to support decision making by older cancer patients and the development of collaborations among regional medical institutions and care facilities. Additionally, the 4th Basic Plan for the Promotion of Cancer Control Programs initiated in FY2023 put forth the goal of 'enhancing collaborations across medical disciplines and among regional medical facilities, aiming to provide appropriate medical care to patients at the places that they wish to receive it.' As a means of achieving that goal, the Plan states that 'the Government will promote initiatives to support older cancer patients and their families in shared decision-making, such that older patients can receive appropriate care based on their own decisions.' There is a need now for deliberations on how to advance SDM in line with these goals.

At the October roundtable, experts discussed challenges and opportunities for advancing SDM practices with older cancer patients and their families from the patient and family perspective, the healthcare provider perspective, the age-friendly communities perspective, and from the perspective of healthcare innovation. Information was shared about SDM in each country, and shared issues and insights emerged from the discussion.

Issues and Insights

ISSUE	INSIGHT
Older cancer patients are diverse and face varying comorbidities, including dementia. Decision making processes should respect that diversity.	The use of geriatric assessment and other tools that can help assess decision-making capacity can aid both medical practitioners and patients to help weigh the benefits and harms of treatment.
There are a limited number of doctors with training in both geriatrics and oncology—expertise about older cancer patient issues is often split among teams of healthcare professionals. While this can be good for patient care, it can also leave patients unsure of their main point of contact for care decisions.	More could be done to promote the training of additional geriatric oncologists. Having a medical professional specified to coordinate a patient's care can help streamline communication with the patient and their family. Tools that can help non-geriatricians conduct geriatric assessments are needed.
	Advancing the integration of care managers, care workers, pharmacists, nurses and other patient liaisons into decision-making processes and the further digitize healthcare systems and medical consultations.
Ageism among both medical providers and patients can hinder shared decision making.	Continuing cultural change and education around shared decision making with older patients would help; efforts to foster champions for this issue are needed, including those who are patients or patient advocates themselves.
Healthcare systems may not be able to offer patients and doctors the right choices for them because of system design or reimbursement issues.	If we want to succeed with SDM, systems healthcare and reimbursement systems may ultimately need to be adapted to allow for better freedom of choice to patients.

Recommendations

Based on the above insights, the following actions could help expand SDM and improve cancer care for older adults:

1. Health systems should explore ways in which geriatric assessment and decision aids can be 1) made more widely available, 2) provide education and training to healthcare providers on how to use them, and 3) support the uptake of such tools within the care system. Stakeholders in the private sector like Pfizer are working to develop decision aids and promote continuing educational opportunities for healthcare professionals. These activities help to improve patient care, and Governments should encourage and support them.

2. Cross-training and specialization within the medical education system should be encouraged and supported. There is a noted insufficiency of geriatric oncologists, an important gap to fill in light of the increasingly older ages of patients diagnosed with cancer.

3. Advance and incentivize the improved integration, as well as the further use of digitized medical records, which all together could provide a more seamless healthcare experience for both patients and providers.

4. While it can be challenging to address a subjective notion such as ageism, implementation of tools like decision aids, geriatric assessment, and integration of care managers and patient advocates into medical interactions can help to support more objective decision-making. Increased efforts for cancer prevention and awareness could also help on this issue by bolstering trust among communities and their healthcare systems. Patients that already feel high trust in their healthcare providers may have an easier time in participating in shared decision making.

5. Where not implemented, reconfigure reimbursement and healthcare systems to support the implementation of SDM and offer broader access to cancer treatments such that patients can choose the best options for themselves.

The following report summarizes the discussion at the roundtable on these points.

"Japan is unique among developed countries—until 30 years ago, doctors did not let patients know that people had cancer. In the past five years, people have been starting to speak about terminal care and cancer care more with patients and their families, but there have been some challenges to uptake."

– Satoshi Umemura

"'Nothing for us without us'—patients need to be involved in the decisions that medical staff are making and that substitute decision-makers are making. In the case of dementia or people who cannot understand, it is really important to ensure that the healthcare system has resources to support this."

– Dorothy Senior

"The number of older adults requiring medical care is increasing in Japan, as is the prevalence of dementia. At about 85% of facilities, less than half of patients are thought to be receiving adequate support. Shared decision-making aids and comprehensive geriatric assessment can help improve this."

– Asao Ogawa

Shared Decision Making—How it Can Help, Why it's Important

Shared Decision Making (SDM) is a collaborative process by which patients, their families, and medical professionals collaborate on decisions about diagnosis, tests, treatments, and care plans. It was developed in the United States in the 1980s out of a push in the health policy field to achieve ethically valid consent in medical decisions.[2] There is no standard process for SDM. 'Decision aids' may be used to help facilitate communication between healthcare providers and patients and deepen patient understanding about medical decisions. Decision aids may be pamphlets, videos, web-based tools or other media. Over 100 randomized control trials have found that decision aids used for SDM improve patient involvement, satisfaction, and understanding of their care and care decisions.[3] Decision aids are tools not just for cancer care or older adults, but can be used for any medical decision that any patient might face.

SDM can help to align treatment plans with patient values and adapt care to the individual requirements of each patient. Research shows that cancer in older patients is different that cancer in the young.[4] Dementia and other comorbidities can complicate decision making among older patients—research suggests that as much as one-fourth of older adults with cancer may have reduced decision making capacity.[5] It is crucial that the healthcare community consider how to overcome these complications. Older adults constitute the majority of new cancer cases.[4] In super-aging Japan, where a third of the population is already over the age of 65, three-fourths of new cancer patients are older adults.[6] The number of people over age 60 is expected to double globally by 2050.[7] Cancer will continue to be a disease primarily of older adults, and with growth in this population, we can expect the number of cancer patients to increase in the future. It is vital that best practices be developed and shared to achieve better cancer care that is more aligned with older patient wants and needs.

Understanding Older Cancer Patients

ISSUE **Older cancer patients are diverse and face varying comorbidities, including dementia. Decision making processes should respect that diversity.**

No two cancers are the same, and there is no common definition of an older adult. Older adults are more diverse than they are alike. At an ecological level, there is data to warrant certain generalizations, but these trends are not necessarily applicable for every individual patient. For instance, research shows that older adults tend to undergo less aggressive treatment plans. Older adults may sometimes be reluctant to face minor adverse events or decline in physical function. Two-thirds of older adults say that their life experiences have helped them to come to terms with cancer.[8] Comorbidities more common among older adults, like dementia, can make decision making more difficult. However, the presence of dementia does not absolutely equal a lack of decision making capacity. The diversity of older patients is why SDM is so important—it can help medical professionals, patients, and patient families overcome communication and information barriers to arrive at the best decisions for each individual.

Health communication is inherently difficult. Baseline health literacy is known to be low across the world, with research from different countries reporting between one-third and two-thirds of any general population to have difficulty in understanding health information. Even among those with perfect health literacy,[9] later recall of medical information and instructions among patients can be poor.[10] Learning of a cancer diagnosis and dealing with it can be terrifying, and the emotional toll of the information alone can impede comprehension. Yet patient understanding of treatment plans is important. Research suggests that those with worse comprehension of their care achieve poorer outcomes.[11]

I want to emphasize that older people are not monolithic. As people age, heterogeneity increases. Older people are way more different from each other than they are alike. In medicine, the goal is to approach people individually."

– Harvey Cohen

In my case of cancer treatment, I was able to refer to guidelines to see what treatment options I could undergo. But in the case of elderly patients, including my father there was not the same evidence. My father had cancer and some symptoms of dementia, which complicated things."

– Naomi Sakurai

INSIGHT **The use of geriatric assessment and other tools that can help assess decision-making capacity can aid both medical practitioners and patients to understand the degree to which SDM should be included in the patient's care plan.**

Geriatric assessment is a process by which medical professionals evaluate patients holistically on their abilities to perform the activities of daily living, cognitive function, mood, communication ability, problem behavior, special needs, and home environment. Its use can help doctors to understand their patients better, and help connect patients and their families with suitable information. Yet surveys in Japan suggest that geriatric assessment is not conducted for the majority of older cancer patients.[12] The expanded use of geriatric assessment could do much to improve care for older cancer patients. It would also help to improve access to decision aids and provide further education for healthcare professionals about geriatric assessment and shared decision-making.

Challenges and Support for Medical Practitioners

ISSUE **There are a limited number of doctors with training in both geriatrics and oncology—expertise about older cancer patient issues is often split among teams of healthcare professionals. While this can be good for patient care, it can also leave patients unsure of their main point of contact for care decisions.**

Shared decision making is not only a challenge of patient and patient family comprehension. It also relies on the ability of doctors to effectively communicate around the merits of different treatments and potential outcomes. This is hindered by the low number of medical professionals across the world with training in both oncology and geriatrics. There are few if any opportunities for education in geriatric oncology in many countries.[13,14] In Japan, there are few geriatric oncologists, with only approximately 1,200 doctors specializing in the broader area of geriatrics out of the approximately 320,000 doctors working across the entire country.[15] Beyond the lack of training, there is also a paucity of medical evidence available to doctors related to older cancer patients.

Although older adults make up the majority of cancer patients, they are greatly under-represented in oncology clinical trial populations.[16] With a lack of training and a lack of medical information specific to their older cancer patients, individual healthcare professionals are often ill equipped to effectively tailor communication to their older patients. This is compounded by a lack of expertise in pedagogy among many health-care providers.

There are healthcare tools and practices that can help connect patients and their families to the information they need for shared decision making and assist healthcare providers in better understanding their older patients—among them, geriatric assessment, team-based care and task sharing, and digitization.

Education of clinicians is important. Most of the doctors who have a specialty for oncology are very familiar with cancer, but not in geriatrics, and how this intersects with cancer. We need to increase the number of geriatric oncologists, or the collaboration between oncologists and geriatricians. However, the number of geriatricians is low in Japan, so such collaboration between oncologists and geriatricians is very limited."

– Hidenori Arai

Every time you engage with a medical practitioner, they are trying to teach you something that you don't know, and that means pedagogy is really important. There needs to be more emphasis on pedagogy in medical training because these front-line practitioners are teachers."

– Don Desserud

INSIGHT

More could be done to promote the training of additional geriatric oncologists. Team-based care can fill knowledge gaps and help get the right information to patients and their families.

Team-based healthcare and task sharing can be helpful for healthcare providers by allowing those with specializations in geriatrics and oncology to work together. It can also help to reduce overwork for any single healthcare provider, an issue which can lead to a decline in care quality. That said, for patients and their families, team-based care can also lead to a situation in which they do not feel they have the opportunity to

build a relationship of trust with any single healthcare provider, which can hinder effective communication around treatment decisions. All cancer centers in Japan report to the Ministry of Health, Labour and Welfare that they are utilizing team-based care, yet only half of patients at these centers said that they felt there was a healthcare provider on hand that they felt was easy to talk to.[17] Team-based care is critically important, but needs to be implemented with consideration for the patient experience.

INSIGHT

Advancing the integration of care managers, care workers, pharmacists, nurses and other patient liaisons into decision-making processes and the further digitize healthcare systems and medical consultations.

In Japan and elsewhere, care managers, pharmacists, and nurses can be very helpful in serving as that point of content. These healthcare professionals can work with patients to ascertain their wants and needs when it is difficult for the patient to communicate, coordinate multidisciplinary care, help patients to resolve environmental factors that are impacting their decisions, support patients to enter and be discharged from hospitals, and provide consultation about shifts to long-term care facilities.

Digitization is another key tool for improving communication between healthcare providers and patients. Evidence suggests that patient health portals, by which patients have the ability to contact healthcare providers digitally at any time with questions about their care, generally improve patient satisfaction with treatment and care adherence.[18] Online consultations too can help connect patients and their families with medical providers in a way that is more convenient for all, particularly for patients with difficulty in travelling to healthcare facilities. Evidence suggests that digital tool utilization may be underutilized in Japan—while the US Department of Health and Human Services reports that approximately one-fifth of US adults use telehealth services each month,[19] in Japan, only approximately 15% of hospitals are able to perform telehealth consultations.[20]

Creating Support Structures for Care

ISSUE

Ageism among both medical providers and patients can hinder shared decision making.

The aforementioned issues are compounded by ageist assumptions about patients' capabilities and capacity to make decisions pertinent to their own treatment, held by both patients and medical providers alike, which often color patients' experiences with cancer treatment. Ultimately, this can lead to reluctance from both parties to partake in SDM. Patients may feel that their problems are just 'issues of growing old' and be reticent to communicate or feel that doctors should make all the decisions about care, notwithstanding their own preferences. Meanwhile, healthcare providers may feel that functional capacity issues or cognitive conditions like dementia mean that a patient cannot make decisions themselves.

INSIGHT

Continuing cultural change and education around shared decision making with older patients would help; efforts to foster champions for this issue are needed, including those who are patients or patient advocates themselves.

Healthcare systems should be supportive of practitioners in assessing a patient's capacity to make decisions. Such support might take the shape of guidelines, geriatric assessment tools, or decision aids. Systems should encourage a forward-looking view of SDM by collecting data and evaluating the outcomes specific to SDM for older adults, which can help to fill the current data gap in this area. Embracing tools and practices that enable SDM will then allow patients to feel more comfortable and empowered to participate in their care decisions.

General distrust of the healthcare system is a background cause of the challenges faced with cultural change and ageism related to shared decision making. Better communication and more active engagement around health and prevention before a cancer diagnosis occurs could help grow confidence in the healthcare system among patients ahead of any cancer diagnosis. This could make shared decision-making for cancer care easier for both patients and healthcare professionals when it is needed.

Older people tend to internalize societal expectations and what it means to be old – they internalize ageism and this can work against them when it comes to treatment decisions and their medical care."

– John Beard

Hospitals [in Japan] are so overwhelmed with providing cancer treatment that they are not necessarily able to focus on other things. The system is now being built under the 4th Basic Plan for the Promotion of Cancer Control Programs. Patients, especially elder patients, need to be at the core of this. We need to support the patients as a whole and provide treatment. There are social aspects as well – elderly patients need to have a plan that is centered on care and support in their lives."

– Kazuo Tamura

ISSUE

Healthcare systems may not be able to offer patients and doctors the right choices for them because of system design or reimbursement issues.

Systems must be set up in a way that allows for patients and providers to participate in SDM, and for other facets of healthcare like social services, pharmacies, and non-cancer healthcare services to operate in a coordinated manner and facilitate whole-person care. This comes down to improving the design so that different care systems are not siloed—for example, investing in digital patient records that can be accessed at different hospitals, or increasing the number of cross-trained specialists, like geriatric oncologists. It also means working to ensure that patients have access to the most appropriate treatments for their individual case.

INSIGHT

If we want to succeed with SDM, systems healthcare and reimbursement systems may ultimately need to be adapted to allow for better freedom of choice to patients.

Choice is crucial for making sure that cancer treatment plans mee the needs of older patients. With little data from clinical trials and otherwise, cancer treatments are not always being developed with consideration for older patients, and health systems may not always have the data to appropriately reimburse treatments that could help this group. Even with perfect communication and decision making, if patients don't have

access to treatments that suit their values—either for reimbursement or innovation reasons—they may not be able to achieve their cancer care goals. It is important that pharmaceutical innovators give added consideration to the diversity of older adults when developing products to avoid this problem.

Beyond innovation, reimbursement policies that allow for wider implementation of SDM and a greater variety of treatment options should also be considered. This can mean the creation of billing codes for the application of geriatric assessment, consultations using decision aids, or SDM itself. Through this kind of policy, physicians will be better equipped to devote time to SDM, which will facilitate its implementation.

Conclusion—Actions and Recommendations

SDM is a multi-faceted and collaborative process, which means that supporting its successful implementation will require a similarly involved strategy. Medical practitioners, health services providers like care managers and pharmacists, the healthcare system, policymakers, and patients and their family members all have critical input and an important role to play. Moreover, these entities must work in conjunction to ensure that any solution is patient-centered, but also realistic and feasible.

This roundtable discussion brought together experts representing all these viewpoints to discuss effective ways to approach SDM for cancer patients, with a focus on older adults. The discussion resulted in the following key thematic insights, all of which can be tied to concrete recommendations relevant to the Japanese policy context.

1.

Use of geriatric assessment and other tools that can help assess decision-making capacity can aid both medical practitioners and patients help weigh the benefits and harms of treatment.

RECOMMENDATION Health systems should explore ways in which geriatric assessment and decision aids can be 1) made more widely available, 2) provide education and training to healthcare providers on how to use decision aids and engage older adults in shared decision-making, and 3) support the uptake of such tools within the care system.

Stakeholders in the private sector like Pfizer are working to develop decision aids and promote continuing educational opportunities for healthcare professionals. These activities help to improve patient care, and Governments should encourage and support them.

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2. More could be done to promote the training of additional geriatric oncologists. Having a doctor or care manager coordinate care can help streamline communication with patients and their families. Tools that can help non-geriatricians conduct geriatric assessments are needed.

RECOMMENDATION Cross-training and specialization within the medical education system should be encouraged and supported. There is a noted insufficiency of geriatric oncologists, an important gap to fill in light of the increasingly older ages of patients diagnosed with cancer.

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3. Advancing the integration of care managers, care workers, pharmacists, nurses and other patient liaisons into decision-making processes and the further digitize health-care systems and medical consultations.

RECOMMENDATION Advance and incentivize the improved integration, as well as the further use of digitized medical records, which all together could provide a more seamless healthcare experience for both patients and providers.

4. Continuing cultural change and education around ageism and shared decision making with older patients would help; efforts to foster champions for this issue are needed, including those who are patients or patient advocates themselves.

RECOMMENDATION While it can be challenging to address a subjective notion such as ageism, implementation of tools like decision aids, geriatric assessment, and integration of care managers and patient advocates into medical interactions can help to support more objective decision-making. Increased efforts for cancer prevention and awareness could also help on this issue by bolstering trust among communities and their healthcare systems. Patients that already feel high trust in their healthcare providers may have an easier time in participating in shared decision making.

5. If we want to succeed with SDM, systems healthcare and reimbursement systems may ultimately need to be adapted to allow for better freedom of choice to patients.

RECOMMENDATION Where not implemented, reconfigure reimbursement and healthcare systems to support the implementation of SDM and offer broader access to cancer treatments such that patients can choose the best options for themselves.

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Global Coalition on Aging

GCOA represents a cross-section of global business including technology, pharmaceuticals, healthcare, home care, financial, transportation, and consumer sectors. We engage global institutions, policymakers, and the public to drive debate on, create, and promote innovative policies and actions to transform challenges associated with the aging of the global population into opportunities for social engagement, productivity and fiscal sustainability.

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