Awareness, Knowledge, Perceived Benefits, and Barriers Regarding Precision Medicine and Willingness to Participate in a National Registry: Comparison of Cancer Patients and the General Population

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Abstract

Background

Precision medicine (PM) is a growing area of interest in cancer care. However, relatively little is known about the public attitudes toward PM and the factors associated with the willingness to participate in the construction of national registries for PM.

Methods

A cross-sectional survey was conducted with 1,500 cancer patients and 1,496 general population in South Korea from November 2016 to February 2017. We evaluated cancer patients' awareness, knowledge, as well as perceived benefits and barriers regarding precision medicine (PM), and their willingness to participate in a national registry for PM, compared to the general population. Logistic regression analysis was performed to identify the factors associated with the willingness to participate in a national registry for PM.

Results

1,500 cancer patients and 1,496 general population were recruited for the study. Cancer patients were less likely to have heard of PM than the general population (20.0% and 33.1%, $P < .001$), 34.2% of the participants knew the correct definition of PM. Cancer patients were more likely to However, fewer study participants in both groups said they would like to share their personal health data for PM, compared to the number of people who are willing to participate. Cancer patients (aOR 2.98, 95% CI, 2.47–3.61), participants who had heard of PM before (aOR 1.40, 95% CI, 1.00–1.95), had greater perceived benefits (aOR, 2.48, 95% CI, 1.88–3.27) and fewer perceived barriers (aOR 1.57, 95% CI, 1.18–2.08) regarding PM were more likely to have the willingness to participate in the registry compared to those who did not.

Conclusions

Cancer patients were more likely to have greater perceived benefits of PM and higher willingness to participate in the related study than the general population. However, both two groups were still informed about PM well. This study suggests considering the provision of information and education about PM such as expected values and required roles both to the general population and cancer patients.

1. Introduction

Precision medicine (PM) is a growing area of interest in cancer care. In 2015, the *Precision Medicine Initiative* (currently known as *All of Us*), with \$215 million in funding, initiated research to accelerate biomedical discoveries [1]; \$70 million of this fund was allocated to the National Cancer Institute for

increased efforts in identifying the genomic drivers of cancer and the application of new knowledge in developing more effective treatments [1]. The obtained knowledge on the oncogenic mechanisms has enabled the provision of tailored medical care depending on individual variability, with advances in diagnosis and treatment [2, 3]. The Cancer Genome Atlas has been helpful in defining the genomic features unique to different cancers and developing specific therapies targeted at those features [4]. Other cancer-related studies have also developed many targeted therapies resulting in increased clinical benefit [5–7]. However, PM in cancer care is not yet a part of routine care for most patients.

As part of PM, it is important to collect a variety of biomedical data including those pertaining to genomic, behavioral, physiological, and environmental parameters [8]. Many countries, including the United States (US) and the United Kingdom, are constructing national registries or large cohorts for PM [9–12]. Additionally, major efforts are being driven in a bid to increase the level of awareness on PM in the general population, as voluntary participation is essential for the success of national registries [10, 13, 14]. Yet, the participation rates in national registries vary from 5–90% [15, 16], and relatively little is known of the public attitudes toward PM and the factors associated with participation in the construction of national registries for PM.

Although the terms ‘precision medicine’ and ‘personalized medicine’ are used interchangeably, the former may be new both to cancer patients and the general population [17]. Most previous studies evaluated peoples’ attitudes towards genetic testing as a part of personalized medicine and included a single stakeholder, either patients or the general population. Few studies have evaluated cancer patients’ knowledge and perception of PM with limited sample size. This may provide the just partial information on clearly understanding the holistic reactions of people toward PM that can be founded at the initial stage. Therefore, to help people including patients to accept, utilize and receive adequate benefits from PM, it needs to carry out the integrated evaluation regarding various aspects of PM with the large scale of a sample. This study aimed to evaluate cancer patients’ awareness, knowledge, as well as perceived benefits and barriers regarding PM, and their willingness to participate in a national registry for PM, compared to the general population.

2. Methods

2.1. Participants

This cross-sectional survey involved face-to-face interviews administered by trained researchers. At the Korean National Cancer Center and the Samsung Medical Center in Seoul-Metropolitan area, South Korea, 1,500 consecutive cancer patients were recruited at outpatient clinics or inpatient rooms from November 2016 to February 2017. The patients had to be at least 18 years of age to be eligible for this study, and have histologically confirmed stomach, breast, lung, gynecological, or colon cancer. The participants comprised 300 patients with cancer types that met our criteria. At an outpatient clinic and inpatient room, trained researchers explained the research and its objectives to the participants and obtained informed consent. Participants were then asked to answer the survey questionnaire.

In addition, we recruited a sample that was representative of the Korean population as the control group. Individuals from the general population who were at least 18 years of age and did not have cancer were eligible for inclusion into the control group. To obtain a representative sample of the Korean population, we used the quota sampling method which takes the distribution assembled by sex, age, and area of residence into account. We conducted home visit or street survey and trained researchers explained the study details and administered the interviews when people agreed to participate. All study participants provide written informed consent. We first recruited 1,500 people; however, four participants with a history of cancer were excluded. A total of 1,496 people were finally included.

The study was approved by the institutional review boards of the National Cancer Center Korea (NCC 2016 – 0256) and the Samsung Medical Center (SMC 2016-12-040).

2.2. Measurements

As there was no specific questionnaire to assess PM-related awareness, knowledge, and perceived benefits and barriers, we developed a questionnaire based on a literature review and experts' opinions. Further, we conducted a pilot study to evaluate the length and logic of the questionnaire before the actual survey. In total, 23 questions were developed to assess awareness (n = 2), knowledge (n = 1), perceived benefits (n = 7) and perceived barriers (n = 3), and willingness to participate in a national registry for PM (n = 4).

To assess the level of awareness on PM, we asked participants if they had heard about PM before (dichotomous questions; yes or no); if yes, we asked them where they had heard of it. Participants were provided multiple choices pertaining to the source, such as print materials (books, magazines, and brochures), the Internet, mass media (television and newspaper), healthcare professionals, peers, and family members [18]. The level of PM-related knowledge was evaluated by asking participants to choose the correct definition of PM ("An emerging clinical approach that takes into account individual variability for each person") from four definitions. We developed three incorrect definitions based on common misunderstandings that were determined from the qualitative interviews of the patients: "Use of new tools with more fine-tuned measurement"; "Advanced diagnosis and care using nanorobots that can be implanted in the human body"; "Clinical care that patients could receive regardless of time and place".

A one-page handout that explained the definition and examples of PM (**S1 File**) was provided so participants could answer questions regarding the perceived benefits and barriers, with seven and three questions, respectively. The perceived benefits comprised diagnosis-related items (n = 3) and treatment-related items (n = 4), while the perceived barriers comprised possible factors (cost, applicability of actual practice, and privacy) after the implementation of PM. While composing each item, we considered the issues frequently mentioned in domestic or foreign press, and informational web material on PM; the issues and the material predominantly focused on the clinical promise of PM and the challenge or preparation associated with its implementation in practice [19–21]. Participants were asked to what extent they agreed with the statements on PM, and a 4-point Likert scale was employed (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree).

We then asked the participants about their willingness to participate in a national registry for PM. In addition, we asked study participants about their willingness to share personal health data for PM and type of data they would like to share. Type of personal health data included genetic information, physical characteristics (weight, height, body composition, and etc.), medical records, and lifelog data (nutrition intake, physical activity, sleep pattern, and etc.). Finally, data on participants' sociodemographic characteristics, including sex, age, educational level, household income, and area of residence were collected. For cancer patients, we also collected data on the cancer type, stage at diagnosis, treatment status, and time since diagnosis. Participants in the control group were separately asked about the presence of comorbidities including a history of cancer.

2.3. Statistical analysis

Student's T-test and χ^2 test were used to ascertain differences between the patients and general population. To identify factors associated with the willingness to participate in a national registry for PM, we performed multivariable logistic regression analysis, adjusted for socio-demographics factors (sex, age, education level, and area of residence), awareness (heard of it before; yes or no), knowledge on PM (chose the right PM definition; adequate or limited), and attitudes (benefits and barriers). All statistical analyses were performed using STATA 14.0 (Stata Corp LP, College Station, Texas, USA) and R 3.3.3 (R foundation, Austria), and statistical significance was set at $P < 0.05$.

3. Results

3.1. Characteristics of the study population

The mean ages of the cancer patients and those in the control group were 56.0 and 43.0 years, respectively ($P < 0.001$; Table 1). The cancer patients were more likely to be female ($P < 0.001$), older ($P < 0.001$), have a high school and lower education ($P < 0.001$) and live in a non-metropolitan city ($P < 0.001$) than those in the general population. Of the cancer patients, 44.3% were under active treatment, and the mean time since cancer diagnosis was 2.7 years (standard deviation, 2.9, **S1 Table**).

Table 1
Characteristics of the study population (n = 2,996)

	Cancer patients	General population	
	(n = 1,500)	(n = 1,496)	
	n (%)	n (%)	P value
Age (years), mean (SD)	56.0 (11.1)	43.0 (12.0)	< 0.001
Sex			< 0.001
Male	599 (39.9)	773 (51.7)	
Female	901 (60.1)	723 (48.3)	
Education level			< 0.001
≤ High school	924 (61.6)	797 (53.3)	
≥ College	576 (38.4)	699 (46.7)	
Monthly household income			< 0.001
< \$3,000	668 (44.5)	261 (17.4)	
\$3,000 - \$4,999	592 (39.4)	864 (57.7)	
≥ \$5,000	240 (16.0)	371 (24.8)	
Area of residence^a			< 0.001
Metropolitan city	939 (62.6)	1,051 (70.3)	
Non-metropolitan city	558 (37.2)	445 (29.7)	
^a A metropolitan city is a city with a population of over 500,000			
SD, standard deviation			

3.2. Awareness and knowledge on PM

Cancer patients were less likely to have heard of PM than those in the general population (20.0% and 33.1%, respectively, $P < .001$; Table 2). More than half of the cancer patients had heard of PM from healthcare professionals (54.0%), while most of those in the general population had heard of it through mass media (76.0%). Only 34.2% of the participants knew the correct definition of PM and cancer patients (35.1%) were likelier to know the correct definition than the general population (33.2%, $P = 0.02$). The number of cancer patients and the general population who had heard of PM and knew what it is were 8.47% and 11.9%, respectively (data not shown). About half of the participants incorrectly answered that PM is “a medicine that uses new tools with more fine-tuned measurement.”

Table 2
Awareness and knowledge on precision medicine (n = 2,996)

	Cancer patients	General population		
	(n = 1,500)	(n = 1,496)		
	n (%)	n (%)	P value	Adjusted P value ^d
Heard of it before (yes)^a	300 (20.0)	495 (33.1)	< 0.001	< 0.001
Healthcare professionals	162 (54.0)	58 (11.7)	< 0.001	< 0.001
Mass media ^b	128 (42.7)	376 (76.0)	< 0.001	< 0.001
Internet	102 (34.0)	223 (45.1)	0.002	0.529
Print material ^c	40 (13.3)	63 (12.7)	0.805	0.698
Peers and family	28 (9.3)	130 (26.3)	< 0.001	< 0.001
Definition of precision medicine (single response)				
An emerging clinical approach taking into account individual variability for each person (correct)	526 (35.1)	497 (33.2)	0.287	0.018
Use of new tools with more fine-tuned measurement	738 (49.2)	703 (47.0)	0.226	0.649
Advanced diagnosis and care using nanorobots that can be implanted in human body	209 (13.9)	267 (17.8)	0.003	0.015
A clinical care that patients could receive regardless of time and place.	27 (1.8)	29 (1.9)	0.780	0.980
^a Mutually inclusive (multiple responses), cancer patients (n = 300) and the general population (n = 495)				
^b Mass media: TV and newspapers				
^c Print material: Books, magazines, and educational brochures				
^d Adjusted for age (continuous), sex, education, and living area				

3.3. Perceived benefits and barriers, and willingness to participate in a national registry for PM

Most of the cancer patients answered that PM use would improve the accuracy of disease detection (97.7%) and disease risk assessment (96.9%), improve the strength of therapeutic effects (98.3%), and reduce the risk of side effects or treatment-related complications (92.2%). While there were some differences between the responses of the cancer patients and those in the general population, the general population also perceived the benefits of PM (Table 3). In terms of perceived barriers, both cancer patients (88.1%) and those in the general population (82.9%) reported that they were most worried about the increased healthcare costs associated with PM. The cancer patients (83.7%) were likelier to believe that the actual practice of PM would require some time than the general population (80.2%), and they (64.9%) were also less likely to perceive privacy concerns as barriers to PM than the general population (74.5%, $P < 0.001$). Cancer patients (77.5%) were likelier to participate in a national registry for PM than those in the general population (55.2%, $P < .001$). We found that 70.8% and 39.6% of cancer patients and general population had the intention to share any health data for their own treatment or others which were lower than those of willingness of participate in a national registry for PM. In terms of type of health data, both cancer patients and the general population were most likely to share lifelog data and least likely to share the medical records.

Table 3
Perceived benefits and barriers and willingness to participate in a national registry for precision medicine
(n = 2,996)

	Cancer patients	General population		
	(n = 1,500)	(n = 1,496)		
	n (%)	n (%)	P value	Adjusted P value^a
Perceived Benefits^b				
Improved accuracy of disease detection	1,466 (97.7)	1,349 (90.2)	< 0.001	< 0.001
Better disease risk assessment	1,454 (96.9)	1,368 (91.4)	< 0.001	< 0.001
Reduced performance rate of unnecessary repeated tests	1,280 (85.3)	1,233 (82.4)	< 0.001	0.067
Improved therapeutic effect due to optimal treatment for individuals	1,475 (98.3)	1,350 (90.2)	< 0.001	< 0.001
Reduced treatment-related side effect or complication risk	1,383 (92.2)	1,253 (83.8)	< 0.001	< 0.001
Increased life expectancy	1,336 (89.1)	1,287 (86.0)	< 0.001	0.032
Enhanced quality of life due to tailored health management	1,420 (94.7)	1,399 (93.5)	0.112	0.223
Perceived Barriers^c				
Increased healthcare cost	1,322 (88.1)	1,240 (82.9)	< 0.001	0.007
Takes a while to actually practice precision medicine	1,255 (83.7)	1,200 (80.2)	0.031	0.070
Privacy concern	973 (64.9)	1,115 (74.5)	< 0.001	< 0.001

^a Adjusted for age (continuous), sex, education, and living area

^{b, c} The value was calculated after changing the 4-point Likert scale to a dichotomous variable.

^d Values included the people who responded that they will donate at least one type of health data.

	Cancer patients	General population		
Willingness to participate in a national registry for precision medicine (yes)	1,163 (77.5)	826 (55.2)	< 0.001	< 0.001
Willingness to share personal health data for precision medicine (yes) ^d	1,062 (70.8)	592 (39.6)	< 0.001	< 0.001
Lifelog data	1,053 (70.2)	551 (36.8)	< 0.001	< 0.001
Physical characteristics	1,042 (69.5)	521 (34.8)	< 0.001	< 0.001
Genetic information	1,017 (67.8)	405 (27.1)	< 0.001	< 0.001
Medical records	966 (64.4)	413 (27.6)	< 0.001	< 0.001
^a Adjusted for age (continuous), sex, education, and living area				
^{b, c} The value was calculated after changing the 4-point Likert scale to a dichotomous variable.				
^d Values included the people who responded that they will donate at least one type of health data.				

3.4. Factors associated with participation in a national registry for PM

In the multivariate analysis, the cancer patients were three times likelier to participate in a national registry than the general population (95% confidence interval [CI], 2.47–3.61). Across both groups, participants who had heard of PM (cancer patients: adjusted odds ratio (aOR) = 1.40, 95% CI, 1.00–1.95; general population: aOR = 2.04, 95% CI, 1.62–2.56) and those who perceived more benefits of PM (cancer patients: aOR = 2.48, 95% CI, 1.88–3.27; general population: aOR = 1.34, 95% CI, 1.05–1.71) were likelier to express a willingness to participate in a national registry for PM (Table 4). Similarly, participants who perceived fewer barriers regarding PM were likelier to be willing to participate in a registry (cancer patients: aOR = 1.57, 95% CI, 1.18–2.08 and general population: aOR = 1.05, 95% CI, 0.84–1.31).

Table 4
Factors associated with willingness to participation in a national registry for precision medicine (n = 2,996)

	Overall	Cancer patients	General population
	(n = 2,996)	(n = 1,500)	(n = 1,496)
	Adjusted OR (95% CI)	Adjusted OR (95% CI)	Adjusted OR (95% CI)
Type			
General population	<i>Reference</i>	-	-
Cancer patients	2.98 (2.47, 3.61)	-	-
Age (years)	1.00 (1.00, 1.01)	0.99 (0.98, 1.01)	1.00 (1.00, 1.01)
Sex			
Male	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
Female	0.87 (0.74, 1.02)	0.70 (0.52, 0.92)	1.00 (0.81, 1.23)
Education level			
≤ High school	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
≥ College	0.91 (0.77, 1.08)	0.63 (0.47, 0.83)	1.16 (0.94, 1.45)
Area of residence			
Non-metropolitan	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
Metropolitan	1.22 (1.02, 1.44)	1.41 (1.09, 1.84)	1.14 (0.91, 1.43)
Heard of it before			
No	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
Yes	1.79 (1.48, 2.16)	1.40 (1.00, 1.95)	2.04 (1.62, 2.56)
Knowledge			
Limited	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
Adequate	0.99 (0.84, 1.17)	1.12 (0.86, 1.46)	0.90 (0.72, 1.12)
Perceived benefits^a			
Low	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
High	1.81 (1.51, 2.17)	2.48 (1.88, 3.27)	1.34 (1.05, 1.71)
^{a, b} A value lower than 3 was stratified as “Low” based on the median of values of the whole sample.			
OR, odds ratio; CI, confidence interval			

	Overall	Cancer patients	General population
Perceived barriers^b			
High	<i>Reference</i>	<i>Reference</i>	<i>Reference</i>
Low	1.31 (1.10, 1.55)	1.57 (1.18, 2.08)	1.05 (0.84, 1.31)
a, b A value lower than 3 was stratified as “Low” based on the median of values of the whole sample.			
OR, odds ratio; CI, confidence interval			

4. Discussion And Conclusion

4.1. Discussion

Nearly, one-third of the cancer patients and the general population were heard about PM and knew its concept correctly. The general Nevertheless, most of both two groups agreed that PM may be beneficial in terms of disease risk assessment, disease detection, and therapeutic effect improvement. Specially, cancer patients were more likely to have greater perceived benefits of PM and higher willingness to participate in a national registry for PM than the general population. However, fewer study participants in both groups said they would like to share their personal health data for PM, compared to the number of people who are willing to participate. In multivariable analysis, having heard of PM before, and perceiving a greater number of benefits and fewer barriers were associated with a willingness to participate in a national registry for PM.

In our study, only about one-third of the cancer patients and the general population chose the correct definition of PM; around half of them misunderstood the meaning of ‘precision’ in PM for the use of more fine-tuned medical devices. Other similar studies presented that over two-third of public were not familiar with the term ‘*precision medicine*’ or ‘*personalized medicine*’ [22–24]. And a Korean study conducted in 2018 reported that about one in ten people had heard of PM and what it is [25]. In a systematic review, low familiarity with PM was one of the barriers to public use of PM [26], and another study the familiarity was significant predictor of willingness to participate in PM research [24]. This low familiarity might be due to a paucity of related information. Although, around half of the cancer patients in our study had heard of PM from healthcare professionals, a majority of them had acquired information through either mass media or the Internet. In the general population, these channels were also main sources of PM-related information, and similar studies supported our findings [24, 25]. These sources are generally easy and useful to access rapidly health information they need to find; however, credibility of the online information is controversial [27, 28]. Therefore, it would be important to consider how to communicate accurate and credible information about PM through those channels, or what new channel, such as YouTube or other social media platforms, are effective in delivering the new information to the public.

Most study population agreed with the benefits of PM, greater perceived benefits of PM were significantly associated with participating a national registry for PM. Especially, over 75% of the cancer patients and 55% of those in the general population expressed a willingness to participate in a national registry for PM, consistent with previous studies. In a survey of 2,601 people from the general population in the US, 54% expressed a willingness to participate in the *Precision Medicine Initiative* cohort study [29]. In another survey of 203 patients in the US, 69% expressed a willingness to contribute to a biobank study, a concept similar to PM [30]. A Korean study conducted in 2018 reported 83.5% of adults recruited from online panel said they would participate in PM research, which was higher than our results [25]. This might be due to different sampling method or administration way of survey [25]. Cancer patients may be more willing to participate because they may expect practically effective benefits from PM for better treatment options and outcomes. It may also affect their positive attitudes toward PM that cancer patients have chances experience a certain level of PM during diagnosis and treatment, such as genetic testing or targeted therapy.

However, it may need to be careful because their positive attitudes or reactions toward PM can be due to vague expectations. For instance, less than one-third of the participants had heard of PM and most of them did not know the correct definition. Also, when we asked study participants about willingness to share their personal health data for PM, much less percentage of the study participants in both groups said they would like to share their personal health data for PM compared to the percentage of the study participants who had willingness to participate in a national registry. Although we did not ask specific reasons for not-sharing personal health data, it might have been reflecting their barriers related to privacy; it appears hold true in the general population compared to cancer patients. It might show indirectly the gap between intention and actual behavior. In general, privacy concern is well-known barriers to participating clinical studies [23, 26]. Alternately it might need to mind the gap between individual intention and actual behavior. Generally, the hypothetical willingness rate differs from the actual participation rate [15], clinical research is often viewed with negativity and distrust, with members of the public believing that participants of clinical research are merely guinea pigs [31–33]. A national survey in Australia also mentioned that a high level of trust or strong belief in research was associated with a willingness to participate in biobank research for PM [13]. Another study reported that specifying the purpose of the information was the main factor of the willingness to share individual health data for clinical study [34]. Therefore, before asking participating in PM research, it might need to be prepared to clearly explain what roles would be required and what values could be expected by participating in PM research rather than just explaining what it is.

Our study has several limitations. First, it is a cross-sectional study, and the directions of the associations between willingness, knowledge, and attitude could be interchangeable. Second, most of the data were collected through self-reports, and participants may have overestimated their willingness to participate in a national registry for PM. Third, the participants' knowledge was measured using a single questionnaire with multiple choice, which may not reflect accurately the knowledge levels on PM. Further, it would not be possible to evaluate one's knowledge on PM merely by asking for a definition, as PM is a very broad

concept. Finally, the results of our study may not be generalizable to other countries with different sociocultural perspectives.

4.2. Conclusion

In conclusion, cancer patients as the primary beneficiary group of PM more agreed various benefits associated with PM and showed higher willingness to participate in a national registry for PM compare to the general population. However, both cancer patients and the general population are still not well-informed about it. Additionally, it may need to be careful whether their positive attitudes and hypothetical willingness to participate could be due to vague expectations resulting from a lack of understanding of PM. Considerable work needs to put in to educate the public and advocate participation in studies on PM. Especially, healthcare professionals, researchers, governments, and policymakers need to consider effective ways to inform the public, including cancer patients, what roles can be required and what values can be achieved by participating in PM-related studies.

Abbreviations

PM, precision medicine; CI, confidence interval; aOR, adjusted odds ratio; NR, National Research Council; US, United States

Declarations

Ethics approval and consent to participate: All procedures in the study involving human participants were carried out in accordance with the ethical standards of the international and/ or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable guidelines. The study was reviewed and approved by the institutional review boards of the National Cancer Center Korea (NCC 2016-0256) and the Samsung Medical Center (SMC 2016-12-040). All individual participants included in the study provided written informed consent.

Consent for publication: Not applicable

Availability of data and materials: The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

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