

# The Special Information Needs of Low Health Literate Patients. Exploratory Insights from an Italian Survey

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## Abstract

**Purpose:** *This manuscript provides some exploratory insights on the special information needs of people living with limited health literacy, with the eventual purpose of exploring the role of digital health-related information in bridging the gap between education and health. On the one hand, digital health information are crucial in enhancing the patients' ability to navigate the health service system. On the other hand, the lack of a specific health literacy concern in designing friendly digital health information could pave the way for patients' misunderstanding and disengagement.*

**Methods:** *Drawing from the findings of a survey addressed to a convenience sample of 500 patients who were assisted by a public hospital operating within the Italian National Health Service (INHS), the ability of users to obtain, understand, process, and apply health information was examined. The Italian version of the Newest Vital Sign (NVS) was used to assess the functional ability of the respondents to deal with health-related information. In addition, the respondents were asked to self-report their ability to navigate the health system. A correlation analysis between NVS scores and self-reported patients' ability to obtain, understand, process, and apply health information was performed to point out the special information needs of low health literate patients.*

**Findings:** *Limited health literacy - as measured by the NVS screening tool - was slightly, but significantly associated with impaired patients' ability to deal with health-related information. Elderly, disadvantaged population, and less educated individuals were at special risk of living with limited health literacy. In particular, low health literate patients were found to meet difficulties in finding, collecting, and processing health information.*

**Limitations:** *Although the NVS is a reliable screening tool to assess health literacy skills, it focuses on the individual ability to understand and process textual and numeric health information (functional health literacy) and overlooks interactive and critical health-related competencies. Moreover, the findings of this study are not generalizable, but provide with interesting insights on the information needs of low health literate patients.*

**Implications:** *Limited health literacy is a common, but widely overlooked issue. Health care organizations should be encouraged to consider the special information needs of low health literate patients in designing and delivering digital health-related information.*

**Originality:** *Health literacy has been defined as a "silent epidemic" in most of Western Countries. However, still little is known about the special information needs of people living with problematic health literacy.*

**Key words:** *Health literacy; Health information; Health information needs; Patients' behavior; Value co-creation*

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## 1. Introduction: health literacy as a “two way street”

Scholars and practitioners are consistent in arguing that time is ripe for patient engagement and value co-creation in the health care service system (Prigge, *et al.*, 2015). However, still little is known about the implementation issues which affect patient empowerment (Hardyman, *et al.*, 2015). Information technologies and digital tools have been assumed to perform as important catalysts of enhanced patient-provider relationships and greater patients' willingness to be involved in the design and delivery of health care (see, among the others, Bitton, *et al.*, 2015 and Barello, *et al.*, 2013). In fact, technologies are argued to strongly contribute to improve quality of care, facilitating the access of patients to health services and reducing nonessential costs in the delivery of care (Massey, 2016).

However, the introduction of information technologies paves the way for several side effects on the process of patient empowerment, including greater difficulties in finding, understanding, and using health-related information by the side of specific categories of patients (Benigeri and Pluye, 2003). As a consequence, the ultimate effects of health information technology use on patient empowerment are at least questionable (Lyles and Sarkar, 2015). This is especially true for people affected by digital divide and living with limited health literacy, that is to say those who are not able to handle and properly use health-related information (Lyles, *et al.*, 2015). For the sake of the argument, health literacy has been claimed to be a strong predictor of internet and information technologies use; besides, it deeply affects the ability of vulnerable individuals to use digital sources for health and medical information (Levy, *et al.*, 2015).

Health literacy was formerly discussed as a crucial social policy to bridge the gap between education and health by Simonds (1974), who claimed that health-related topics should be included in school education programs to improve the individual competencies in the field of health protection and promotion. In fact, people living with inadequate numeracy and literacy skills have been variously found to meet difficulties in accessing health information and in properly using these information for the purpose of health protection and promotion (Williams, *et al.*, 1995). This early conceptualization relied on a functional interpretation of health literacy (Baker, *et al.*, 1999). Actually, health literacy was understood as the individual ability to use and apply reading, writing, and computational skills at a level adequate to perform basic tasks in the health care environment (Parker, *et al.*, 1995). In line with this proposition, health literacy was conceived as a one-way street, concerning the ability of patients to function in the health care service system.

Nutbeam (2008) suggested an alternative understanding of the health literacy concept, claiming that it included both interactive and critical-related skills beyond functional ones. According to this interpretation, it is assumed that health literate patients are able to improve their ability to navigate the health care system, by establishing friendly and co-creating partnerships with the providers of care (“interactive health literacy”, Rubin, *et al.*, 2011), and by examining the *pros* and *cons* of available health treatments in order to select the best option to face their health-related problems (“critical health literacy”, Chinn, 2011). Therefore, a context-specific conceptualization of health literacy emerged, involving the degree to which people are able to access, process, understand, communicate, and use relevant health information at any point of contact with the health care service system (Baker, 2006). Health care organizations themselves play a critical role in enhancing the patients' ability to navigate the health care system, by providing the patients with easy-to-access and easy-to-understand health information and by designing a health-literate health care environment (Brach, *et al.*, 2012). From this point of view, health literacy should be understood as a two-way street, concerning both individual and organizational attributes (Paasche-Orlow and Wolf, 2007).

In the light of these insights, several scholars have presented limited health literacy as a silent epidemic, which produces momentous consequences on the appropriate functioning of the health care service system, but which is widely overlooked by health care providers (Parker, *et al.*, 2008). In fact, people living with limited health literacy have been found to report adverse health outcomes (DeWalt, *et al.*, 2004), low medication adherence (Palumbo, 2015), and unwillingness to be

involved in the provision of care (DeWalt, *et al.*, 2007). On the other hand, health care providers are likely to overlook health literacy-related issues, due to either time constraints in professional practices (Whitehouse, *et al.*, 2013) or poor awareness of the drawbacks of patient disengagement on health outcomes (Palumbo, 2016).

In sum, inadequate attention has been paid to the special information needs of people living with problematic health-related functional, interactive, and critical skills. Indeed, health care environments and initiatives aimed at patient empowerment have been usually designed by assuming unlimited health literacy skills by the side of users (Hernandez, 2012; Paasche-Orlow, *et al.*, 2006). The lack of a health literacy concern paved the way for the unwillingness of patients to be involved in the design and delivery of health services, as well as for professional dominance in the provision of care (Ishikawa and Yano, 2008).

## 2. The special information needs of low health literate patients

As anticipated, patients are especially likely to meet difficulties in interacting with health care professionals when the relationship between them is mediated by information technologies and digital tools. In fact, the impaired ability of patients to deal with health-related issues could be compounded by their poor familiarity with information technologies. In these circumstances, there is a significant risk that health information technologies turn out to be a tool which constricts the behaviors and the decisions of patients rather than as an abilitating tool (Mort, *et al.*, 2013). To deal with this issue, scholars have introduced the digital health literacy construct, which is understood as the ability of meaning-making with health information which are mediated by new technologies (Mein, *et al.*, 2012). Drawing from the prevailing literature in the field of health literacy, the Directorate-General for Communication Networks, Content and Technology of the European Commission depicted digital health literacy as “*the ability to seek, find, understand and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem*” (European Union, 2014, p. 2). Sticking to this definition, it could be argued that digital health literacy ultimately concerns the functional, interactive, and critical abilities of patients to handle health information which are communicated or provided through information and communication technologies.

To the knowledge of the authors, the extant scientific literature mainly conceived digital health literacy as a province of health communication, discussing, on the one hand, information technologies and digital tools as new possibilities and modes of communication in the health field and investigating, on the other hand, the effectiveness and efficiency of digital health information to fill the knowledge gaps of patients (Eysenbach and Jadad, 2001). Alternatively, the special information needs of people living with limited health literacy skills have been neglected, with only few exceptions (Harrington, 2015). From this point of view, there is a significant risk that digital tools devised for the purposes of patient empowerment and patient engagement are not able to achieve the expected results when addressed to low health literate patients. In fact, their design is generally affected by the lack of evidence about the particular information needs of people living with limited health-related competencies, who could be not able to draw benefits from health information technologies. This paper aims to contribute in filling the current gaps in the scientific knowledge, by shedding light on the special information needs of people living with limited health literacy skills. Eventually, this manuscript attempts to provide scholars and practitioners with some exploratory insights on the opportunity to adopt a health literacy perspective in devising and implementing the initiatives which are intended at patient empowerment, including the introduction of digital health information. The following research questions inspired this paper:

R. Q. 1: Does limited health literacy involve impaired ability to access, process, understand, and use health information?

R. Q. 2: If so, what are the special information needs of people living with limited health literacy?

R. Q. 3: And, last but not least, what categories of patients are at special need of targeted communication strategies in order to improve their ability to navigate the health care service system?

This paper is organized as follows. The third section describes the research design which was arranged for the purpose of this research and provides with several methodological notes to contextualize the relevance and the originality of this study. The fourth section summarizes the main findings of the research, which are critically discussed in the fifth section in an attempt to provide an answer to the three research questions. The sixth and concluding section points out the twofold relevance of this manuscript: first of all, it discloses the special information needs of people living with limited health literacy, inspiring further theoretical developments; moreover, it provides health care practitioners with some insights on the proper design of patient empowerment initiatives based on information technologies.

### 3. Research design and methods

For the purpose of this study, a convenient random sample was built. Even though this sampling method did not allow to enhance the reliability of this research and to generalize its findings, it was assumed to be consistent with the primary purpose of this manuscript to develop an exploratory understanding of a complex and dynamic issue (Marshall, 1996), such as the investigation of the special information needs of low health literate people. Going more into details, a single site to identify and approach the members of the sample was conveniently selected by the authors among the top multi-speciality health care institutions operating within the Italian National Health Service (INHS). To determine the site, the authors agreed on a short list of the leading Italian multi-speciality health care organizations, which was devised drawing from the data provided by the National Outcome Evaluation Program (Agenas, 2015). Among the health care organizations included in this short list, the one with the largest population served was identified as elected research site. It was a generic public hospital operating in central Italy. This health care organization had 10 specialist departments with 467 beds available for inpatients services. It provided an average number of about 15.000 inpatient services per year.

The members of the sample were randomly selected among the patients who were assisted by this health care organization within the period from October, 1<sup>st</sup> 2015 to December, 11<sup>th</sup> 2015. The focus on patients who were dealing with a health-related issue at the moment of data collection allowed to minimize the risks of biases, by including in the sample only respondents who had to handle and use health information materials to deal with their health conditions. People aged 18 or more were included in the sample. Going more into details, 10 sampling points were established within the research site, 1 for each department. Therefore, 50 patients were randomly approached for each sampling points. They were asked to participate in an exploratory study aimed at assessing their health literacy skills and at investigating their special health information needs. In line with the suggestions of the scientific literature (Barnes, 1977), ethical and moral issues were handled by providing in advance to the respondents a full-fledged explanation of the aims of the research. As a result, the sample ultimately consisted of 500 members. The respondents were asked to fill a mixed survey, which was aimed at measuring their health literacy skills and assessing their ability to navigate the health care service system. A Paper Assisted Personal Interview (PAPI) method was used. All the data collected were arranged in an electronic worksheet, which was processed using IBM SPSS Statistics 20.0.

The Newest Vital Sign (NVS) test was identified as the most fitting screening tool to objectively assess individual health literacy skills. In fact, the NVS shows a high sensitivity for detecting limited literacy levels (Osborn, *et al.*, 2007) and allows a quick screening of the patients' ability to handle health-related information (Weiss, *et al.*, 2005). In particular, the NVS assessment tool consists of a standardized nutrition facts label and 6 accompanying questions, which are provided to the respondents to test their basic reading and numeracy skills. Each correct answer is

scored 1, while both incorrect and “do not know” answers are scored 0. Hence, the minimum NVS score is 0, while the maximum score is 6. People scoring between 0 and 1 are assumed to live with high likelihood of limited health literacy, while those scoring between 2 and 3 are considered to live with medium to high risks of limited health literacy. Alternatively, respondents scoring between 4 and 6 are expected to have adequate functional health-related skills.

The original English version of the NVS screening tool was independently translated in Italian by two professional translators, one of whom was a native English speaker and the other a native Italian speaker. These two outputs were formerly confronted in order to identify and settle potential inconsistencies. When the two translators agreed on a final draft of the translated tool, it was delivered to the authors, who accepted it and tested it on 30 patients. The results of the pilot tests paved the way for several minor revisions, which were agreed by both the authors and the translators. The amended tool was tested again on 30 patients. The results were satisfactory and the assessment tool was administered to the members of the sample. The respondents took on the average 3 minutes to complete the test.

In addition to the NVS test, the survey also included a questionnaire to assess the respondents' self-reported ability to obtain, understand, process, and apply health information. Drawing from the assessment tool devised by the HLS-EU consortium to measure self-reported health literacy levels across Europe (Pelikan, *et al.*, 2012), a 47-items survey was arranged for this purpose. The items were conceived as formative measures (Coltman *et al.*, 2008) and were organized in 4 semantic groups:

- 13 items concerned the individual ability to access and obtain health related information;
- 11 items concerned the self-reported individual proficiency in understanding health-related information;
- 12 items concerned the capacity to interpret and evaluate health information;
- and 11 items concerned the ability to use health information in order to make informed decisions on health-related issues.

The items of the survey were formulated as direct questions. A 4-point Likert scale was attached to each item, where 1 indicated poor individual proficiency and 4 high individual proficiency. A “do not know/do not answer” possibility was available, which was coded as 5. The respondents took about 13 minutes to complete this section of the survey. 5 indices were built to evaluate self-reported health literacy skills. A general index (GEN-HL) involving all the 47 items of the survey provided information about the overall self-assessed ability of respondents to navigate the health system. Besides, 4 indices concerning the different stages of health information processing - that is to say obtain (OI-Index), understand (UI-Index), process (PI-Index), and apply (AI-Index) health information - were built.

In line with the HLS-EU methodology (Pelikan, *et al.*, 2012), these indices were standardized on a scale 0-50, where 0 suggested poor health literacy and 50 excellent health literacy. The respondents were classified in 4 groups, according to their scores for each index: people who scored between 0-25 were included in group 1 (“inadequate health literacy”); people who scored between 25,01-33 were included in group 2 (“problematic health literacy”); people who scored between 33,01-42 were included in group 3 (“sufficient health literacy”), and people who scored between 42,01-50 were included in group 4 (“excellent health literacy”). Both group 1 and group 2 were assumed to include the respondents who showed limited health literacy skills.

Last but not least, the patients were asked to complete a brief socio-demographic survey. It consisted of 16 items, providing information on both the main socio-demographic determinants of health literacy skills (including: age, gender, education, employment, financial deprivation, and self-assessed social status) and the consumption behavior of the respondents in the health care service system. A correlation analysis was performed between the NVS scores, the indices measuring self-reported ability to navigate the health care system, and the socio-demographic variables included in the survey.

Table 1 provides some details about the sample characteristics. Most of the respondents were female (about 54%); nonetheless, the sample was balanced in terms of gender, with 231 out of 500

respondents (about 46%) being male. The main age of the respondents was 46.68, with a minimum of 18 years and a maximum of 90 years. About a quarter of the sample was aged between 28 and 37 years (24.8%). 60 out of 500 respondents were aged 27 or less, while 63 out of 500 respondents were aged 68 or more.

*Tab. 1: The sample's characteristics (n=500)*

Variable	Total	
	No.	%
<b>Gender</b>		
Male	231	46.2
Female	269	53.8
<b>Age Group</b>		
18-27	60	12
28-37	124	24.8
38-47	79	15.8
48-57	93	18.6
58-67	81	16.2
68-77	40	8
78+	23	4.6
<b>Education</b>		
Pre-primary	0	0
Primary	68	13.6
Lower secondary	88	17.6
Upper secondary	115	23
Post-secondary	106	21.2
First stage of tertiary	56	11.2
Second stage of tertiary	66	13.2
Don't know	1	0.2
<b>Household living situation</b>		
Single and living alone	126	25.2
Shared household	345	69
In a serious relationship, but not living together	18	3.6
Don't know/do not answer	11	2.2
<b>Status of employment</b>		
Unpaid work, traineeship and/or apprenticeship	39	7.8
Full time	144	28.8
Part time	83	16.6
Unemployed	39	7.8
Student	40	8
Retired	73	14.6
Permanently disabled	10	2
Full-time homemaker	52	10.4
Inactive	11	2.2
Other	5	1
Don't know/do not answer	4	0.8

Source: Authors' elaboration

Most of the respondents reported either a lower, an upper, or a post-secondary education level (61.8%). 68 people held a primary education (13.6%) and none of them disclosed a pre-primary education level. About a quarter of the sample stated to hold either the first stage (11.2%) or the second stage (13.2%) of tertiary education. Most of the respondents lived together with their families or their partners (69%). Only 1 out of 4 sample members reported to live alone and to not be engaged in a serious relationship. 227 respondents (45.4%) declared to have either a full-time (28.8%) or a part-time (16.6%) job. About 15% of the respondents were either students (7.8%) or trainee and/or apprentice (7.8%). About 8% of the sample was unemployed. 73 respondents (14.6%) were retired, while 52 of them were full-time home-makers. The remaining part of the sample consisted either of permanently disabled (2%) or inactive people (2.2%).

In sum, the convenient sample showed a satisfactory distribution in terms of gender, age, education, living situation, and employment. From this point of view, it could be argued that the sample's characteristics contributed in improving the reliability of this research. Encouraging

insights were also drawn from the internal consistency analysis of the measures used for the purpose of this study. Actually, the NVS screening tool presented a good internal reliability ( $\alpha=0.888$ ). The GEN-HL index, which measured the general self-reported ability of patients to access, understand, process, and use health information showed a strong internal reliability ( $\alpha=0.929$ ). As well, the four specific indices concerning the respondents' ability to deal with health information exhibited either acceptable or good internal reliability, as summarized in Table 2.

Tab. 2: Internal consistency analysis for health literacy-related measures

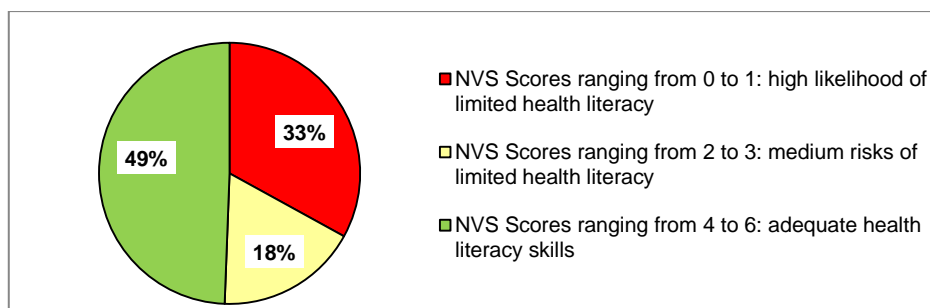
Index	Number of items	Cronbach's Alpha	Internal consistency
NVS	6	0.888	Good
GEN-HL	47	0.929	Excellent
OI-Index	13	0.814	Good
UI-Index	11	0.714	Acceptable
PI-Index	12	0.874	Good
AI-Index	11	0.761	Acceptable

Source: Authors' elaboration

#### 4. Findings

About a third of the sample (33%) was found to live with high likelihood of limited health literacy, as measured by the NVS score. In particular, 141 respondents (28.2%) failed all the questions of the NVS screening tool, scoring "0"; in addition, 24 respondents (4.8%) scored "1". In the light of these findings, it could be argued that about 1 each 3 respondents was not able to understand and process health-related information, meeting significant difficulties in properly functioning in the health care service system. In addition, 88 people (17.6%) scored either "2" or "3" in the NVS screening tool, being subject to medium risks of problematic health literacy. About a quarter of the sample (23.4%) correctly answered to all the questions included in the NVS tool. Moreover, 130 respondents (26%) scored either "4" or "5", disclosing a good proficiency in dealing with health-related issues. In sum, as shown in Figure 1, about half of the sample (49.4%) was found to live with either acceptable or excellent functional skills to navigate the health care service system. Alternatively, 1 out of 2 people reported medium to high risks of living with limited functional health literacy skills.

Fig. 1: NVS scores and likelihood (%) of limited health literacy (n=500)



Source: Authors' elaboration

The self-assessment of the individual ability to deal with health-related issues seemed to confirm the results of the NVS screening tool. In fact, about half of the sample (45.6%) disclosed problematic general health literacy skills, self-reporting an impaired ability to navigate the health

care environment and to make timely and appropriate health choices. In addition, 81 out of 500 respondents (16.2% of the sample) pointed out inadequate self-assessed general health literacy skills, stating to be unable to perform the basic functional tasks in the health care service system. Only 22 patients (4.4%) were found to live with excellent health literacy-related abilities, claiming to be able to properly deal with health issues and to establish friendly and co-creating partnership with the providers of health services. 169 people (33.8% of the sample) self-reported sufficient general health literacy skills, identifying the complexity of the health care service system and the difficulty to access relevant health information as the most important barriers to their engagement in the design and delivery of care. Table 3 depicts the distribution of the sample in the four health literacy groups, emphasizing that more than half of the respondents were found to live with limited general health literacy skills.

The indices measuring the respondents' self-perceived ability to obtain, understand, process, and apply health-related information provided more insightful evidence on the self-experienced health literacy skills of the patients involved in this study. More than half of the sample (62.2%) disclosed either an insufficient (22%) or a problematic (42.2%) ability to find and access appropriate information about illnesses' symptoms, health treatments, health services, healthy lifestyles, and psycho-physical well-being (OI-Index). The poor friendliness of written health materials and the inability to access timely sources of health information were identified as the main issues which affected the individual capability to obtain and collect health information. Slightly more than a third of the sample (37.8%) disclosed either a sufficient (32.6%) or an excellent (5.2%) ability to access timely and relevant health information.

Tab. 3: Distribution of the sample for general health literacy (GEN-HL) self-reported skills

	Frequency	Percent	Valid Percent	Cumulative Percent
Inadequate Health Literacy (GEN-HL scores ranging from 0 to 25)	81	16,2	16,2	16,2
Problematic Health Literacy (GEN-HL scores ranging from 25.01 to 33)	228	45,6	45,6	61,8
Sufficient Health Literacy (GEN-HL scores ranging from 33.01 to 42)	169	33,8	33,8	95,6
Inadequate Health Literacy (GEN-HL scores ranging from 42.01 to 50)	22	4,4	4,4	100,0
Total	500	100,0	100,0	

Source: Authors' elaboration

The results concerning the self-assessed ability to understand health-related information (UI-Index) were better as compared with the OI-Index. Actually, 60 patients (12%) reported to be able to understand the health information verbally provided by health care professionals, to grasp with the textual and numerical data included in medications' leaflets, and to properly stick to health care providers' instructions on how to follow health treatments. Similarly, 37% of the respondents were found to live with adequate understanding skills, stating to meet some difficulties when dealing with numeric health-related data. On the other hand, 1 out of 2 patients disclosed limited health literacy as measured by the UI-Index. Going more into details, 64 respondents (12.8%) reported inadequate understanding ability, pointing out to meet significant difficulties in understanding medical jargon and in interacting with health care professionals. In addition, 191 patients (38.2%) showed problematic understanding skills, identifying the complexity of written health information as the most important determinant of misunderstandings by the side of patients.

Interestingly, 2 out of 3 patients were found to be not able to effectively evaluate and process health-related information. In fact, 67.2% of the sample self-reported either inadequate (28.8%) or problematic (38.4%) processing skills, as measured by the PI-Index. In particular, people with low scores in the PI-Index were likely to state impaired proficiency in judging the *pros* and *cons* of different treatment options, evaluating the appropriateness of health information provided by health

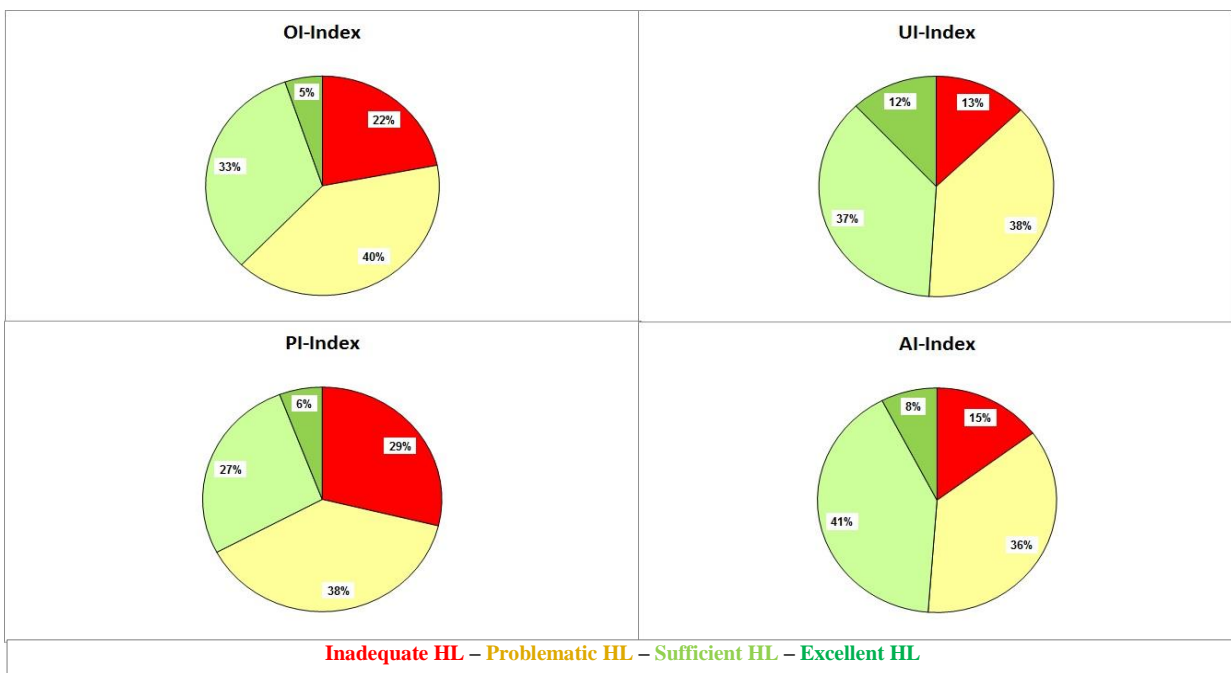


care professionals or informal caregivers, and appraising the reliability of health information retrieved from information and communication technologies. Only 29 patients (5.8%) self-reported excellent processing-related abilities, while 135 respondents (27%) were found to be confident in handling health information, even though they met some difficulties when accessing emergency care and dealing with unexpected health issues.

In spite of the evident frustration perceived by the respondents in evaluating and processing health information, about half of them reported to be able to apply health-related information. Indeed, 206 patients (41.2%) considered to have sufficient critical skills to properly use the written and oral information provided by health care professionals to assist them in making appropriate health decisions, to decide whether to use prevention services, and to make timely decisions to promote the individual health status. Besides, 38 respondents self-reported excellent skills to apply health information, as measured by the AI-index. On the other hand, 1 out of 2 patients exhibited either inadequate (14.8%) or problematic (36.4%) ability to apply health information.

Figure 2 depicts the distribution of the sample in the four health literacy-related groups for each of the indices which were used to assess the individual ability to obtain, understand, process, and apply health information. It is compelling to note that the OI-Index and the PI-Index showed similar characteristics. In both the cases, about 2 out of 3 patients were found to live with limited health literacy skills, disclosing to meet significant barriers in timely accessing health information and in evaluating their relevance for the purpose of health protection and promotion. In other words, most of the respondents were consistent in reporting that they were not proficient in collecting written and oral health information and that they perceived cognitive limitations when interpreting the health information available. The UI-Index and the AI-Index showed better results as compared with both the OI-Index and the PI-Index. Actually, about half of the sample self-reported sufficient to excellent skills to correctly understand and apply health information. However, the remaining half of the population exhibited an impaired ability to follow health care professionals' instructions and to make timely health choices, especially when dealing with unexpected health issues.

Fig. 2: Distribution of the sample per OI-, UI-, PI-, and AI-indices (n=500)



Source: Authors' elaboration

A correlation analysis was performed to point out the relationship between functional health literacy skills - as objectively assessed by the NVS screening tool - and the self-reported ability of

patients to navigate the health care system. As shown in Table 4, all the indices used for the purpose of this research showed positive and statistically significant (0.01 level, 2-tailed) Pearson's correlations. In particular, the NVS score exhibited a weak positive association with all the indices measuring the self-assessed individual ability to obtain, understand, process, and apply health-related information. As expected, the NVS showed relatively higher Pearson's correlations with the UI-Index ( $r = 0.181$ ). Moreover, the relationships between the NVS score and the AI-Index ( $r = 0.177$ ), the FI-Index ( $r = 0.178$ ) and the GEN-HL Index ( $r = 0.189$ ) were weak, but remarkable. Alternatively, the NVS score was only slightly related with the PI-Index ( $r = 0.137$ ). These findings suggested that the NVS tool was not able to provide a full-fledged representation of the patients' ability to navigate the health care service system. Indeed, this screening tool focused on the respondents' ability to understand and apply health information, overlooking both interactive and critical competencies, which are crucial to access, evaluate, and apply health-related information.

Tab. 4: Pearson's correlation between health literacy measures

	NVS Score	GEN-HL	OI-Index	UI-Index	PI-Index	AI-Index
NVS Score	1					
GEN-HL	.189**	1				
OI-Index	.178**	.865**	1			
UI-Index	.181**	.839**	.650**	1		
PI-Index	.137**	.882**	.665**	.653**	1	
AI-Index	.177**	.840**	.640**	.613**	.708**	1

\*\* . Correlation is significant at the 0.01 level (2-tailed).

Source: Authors' elaboration

As expected, the 4 indices measuring the self-reported ability to navigate the health care service system were positively and significantly associated each other. These results suggested that the ability of patients to access, understand, process, and use health information presented similar trends and provided interesting insights on the individual ability to deal with health-related issues. As well, the GEN-HL index exhibited strong and positive Pearson's correlations with all the other measures of self-reported health literacy skills, thus performing as the best single measure to assess the ability of patients to navigate the health care service system.

To explore the relationship between socio-demographic variables and the respondents' health literacy skills, an additional correlation analysis was performed through Spearman's rank correlation, which involved the main determinants of limited health literacy as suggested by the prevailing scientific literature (see, among the others, Cunha, *et al.*, 2015 and Sørensen, *et al.*, 2015), including: gender, age, education, status of employment, and financial deprivation. As shown in Table 5, gender turned out to be not associated with any of the health literacy measures used within this study. This finding was in contrast with the arguments of several scholars, who have presented gender as a significant factor influencing the behavior of patients in the health care service system (Adinolfi, 2013; Cotton, *et al.*, 2006). In a quite similar way, the status of employment was found to be not related with most of the health literacy measures. However, it showed a weak, but statistically significant (significant at the 0.01 level, 2-tailed) negative Spearman's correlation ( $\rho = -0.161$ ) with the NVS score and a slight significant (0.05 level, 2-tailed) negative Spearman's correlation ( $\rho = -0.100$ ) with the UI-Index. In sum, it could be assumed that the employment status affected the functional ability of patients to understand and apply numeric and textual health information, with those having either a full time or a part time job and students performing better as compared with unemployed, retired, and inactive in both the NVS screening tool and in the UI-Index.

Age showed negative and statistically significant associations with most of the health literacy measures, thus supporting the arguments of scholars who pointed out that elderly are at special risk of living with limited functional, interactive, and critical abilities (Baker, *et al.*, 2000). Indeed, age was weakly, significantly (0.01 level, 2-tailed), and negatively related with the NVS score ( $\rho = -0.284$ ), the GEN-HL index ( $\rho = -0.157$ ), the OI-Index ( $\rho = -0.161$ ), the UI-Index ( $\rho = -0.183$ ), and the AI-Index ( $\rho = -0.143$ ). Alternatively, age was not associated with the self-reported ability of patients to evaluate and process health-related information (PI-Index). On the one hand, these findings suggested that elderly were consistent in reporting poorer scores in the NVS screening tool and in meeting great difficulties when accessing, understanding, and applying health information. On the other hand, they emphasized that older adults were likely to exhibit adequate ability to process available health information and to make proper choices in the health care environment. From this point of view, it is supported the idea that cognitive problems - including lapse of memories and impaired reading skills - are the most important determinants of limited health literacy among older adults (Kobayashi, *et al.*, 2014).

Financial deprivation and education revealed the highest Spearman’s correlations with the measures of health literacy. In particular, financial deprivation was significantly (0.01 level, 2-tailed) and negatively correlated with the NVS score ( $\rho = -0.262$ ), the GEN-HL Index ( $\rho = -0.289$ ), the OI-Index ( $\rho = -0.283$ ), the UI-Index ( $\rho = -0.237$ ), the PI-Index ( $\rho = -0.235$ ), and the AI-Index ( $\rho = -0.287$ ). In other words, people suffering from financial deprivation were more likely to exhibit poor functional health literacy and to self-report impaired ability to access, understand, evaluate, and use health-related information as compared with those who did not suffer from financial problems. It is compelling to emphasize that financial deprivation seemed to affect not only the functional competencies of patients, but also their critical and interactive skills, including their willingness to establish a friendly and co-creating partnership with the health care professionals. These findings echoed the arguments of the scientific literature which argued that the disadvantaged population is at high risk of living with limited health literacy (Rudd, 2007; Williams, *et al.*, 1995).

As expected, education showed the strongest correlation with the NVS score ( $\rho = 0.442$ , significant at the 0.01 level, 2-tailed). In fact, people reporting higher education levels were consistent in achieving better performances in terms of NVS scores as compared with their less educated counterparts, being more proficient in processing and applying numeric health-related data. Besides, education was found to be related with the UI-Index ( $\rho = 0.327$ , significant at the 0.01 level, 2-tailed). Respondents with upper secondary and tertiary education levels self-reported greater ability to comprehend and follow oral and written health instructions provided by health care professionals. Education was also positively and significantly (0.01 level, 2-tailed) related with GEN-HL ( $\rho=0.286$ ), OI-Index ( $\rho=0.238$ ), PI-Index ( $\rho=0.244$ ), and AI-Index ( $\rho=0.219$ ), suggesting that education performed as the most important factor affecting individual health literacy levels.

Tab. 5: Spearman’s correlation between health literacy measures and selected socio-demographic variables

	Gender	Age	Education	Employment	Financial Deprivation
Spearman's rho ( $\rho$ )					
NVS Score	-.014	-.284**	.442**	-.161**	-.262**
GEN-HL	.071	-.157**	.286**	-.050	-.289**
OI-Index	.085	-.161**	.238**	-.056	-.283**
UI-Index	.047	-.183**	.327**	-.100*	-.237**
PI-Index	.052	-.071	.244**	-.013	-.235**
AI-Index	.071	-.143**	.219**	-.047	-.287**

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

Source: Authors’ elaboration

## 5. Discussion

Limited health literacy was common among the patients who were approached for the purpose of this study. According to the results of the NVS screening tool, 1 out of 3 respondents was found to live with high likelihood of inadequate functional health literacy. If also those who were at a medium to high risk of problematic health literacy skills are considered, more than half of the sample showed an impaired ability to comprehend and use numeric and textual health-related information. These findings were echoed by the self-assessment of health literacy skills. Actually, 6 out of 10 patients disclosed either inadequate or problematic general health literacy competencies. In particular, the members of the sample were likely to meet significant difficulties in accessing and collecting health information, as well as in evaluating and processing them for the purpose of health protection and promotion. Even though more than half of the sample revealed low proficiency in comprehending and using written and oral health information, it emerged that understanding and applying barriers were less frequent as compared with accessing and processing ones.

In sum, it could be argued that poor health literacy was a prevailing issue, which deeply affected the individual ability to navigate the health care system and to timely access health services. This result is in line with the findings of the international scientific literature, which pointed out the prevalence of limited health literacy in different health care environments (see, among the others, Koster, *et al.*, 2015; Sørensen, *et al.*, 2015; and Paasche-Orlow, *et al.*, 2005). People living with limited functional, interactive, and critical health-related competencies are expected to disclose specific health information needs, which should be taken in serious consideration when designing and delivering health information materials (Rowell, *et al.*, 2015).

This study confirmed this assumption. In fact, the NVS scores showed slight, but statistically significant positive Pearson's correlations with all the indices measuring the patients' self-reported ability to deal with health-related information and to perform basic tasks within the health care service system. As expected, the NVS scores exhibited relatively stronger relationships with the UI-Index and with the AI-Index. Obviously, this result was affected by the particular attributes of the NVS screening tool, which focuses on the respondents' ability to comprehend numerical and textual health information and to apply them to make appropriate health-related decisions. As a consequence, this assessment tool overlooks several competencies which are essential to properly function in the health care environment, that is to say the ability to access, organize, evaluate, and process oral and written health information. In spite of these considerations, people living with high likelihood of limited functional health literacy as measured by the NVS screening tool were consistent in reporting to meet great difficulties in accessing and obtaining health information, in understanding and following health care professionals' prescription, in processing health information available, and in applying them when navigating the health care service system.

In the light of these findings, the following answer to *R.Q.1* could be provided: patients living with limited health literacy are likely to meet significant difficulties in navigating the health care environment and, in particular, in obtaining and processing health information for the purposes of health protection and promotion. In fact, low health literate patients have been found to rely on health care professionals to collect relevant health information and to be unwilling to be involved in the process of health services' delivery and design. Interestingly, the assessment of functional health literacy was only partially related to the special information needs of people reporting problematic health literacy skills. As anticipated, this circumstance was produced by the particular characteristics of the NVS screening tool, which is aimed at objectively assessing the patients' numeracy and literacy skills. On the other hand, it neglects both information accessing and processing competencies, which are nonetheless crucial to enhance the individual ability to function in the health care service system.

From this standpoint, it is interesting to discuss the special information needs which were perceived by the patients who reported an impaired ability to navigate the health care environment. Indeed, they identified the difficulty to find reliable and easy-to-access information on illnesses' symptoms, health treatments, and preventive services as an important barrier to patient

empowerment and patient engagement. As well, the complexity of health information materials and medical jargon were considered to prevent their ability to evaluate, process, and apply health information in everyday life situations. What is even more compelling is that people with self-reported problematic health literacy skills pointed out to meet greater difficulties in accessing and using health information as compared with their health literate counterparts when dealing with unexpected health problems and when accessing emergency care services. In particular, they perceived poor self-efficacy when they could not rely on the support of either health care professionals or informal caregivers. In turn, this situation affected the appropriate use of health services, engendering the exacerbation of their health status.

Inadequate health literacy was also found to be related with lower patients' involvement in health-related decision making. Actually, people with problematic functional, interactive, and critical skills were likely to entrust health care professionals when making decisions concerning health treatments, being not able to self-assess the reliability and the relevance of health information available. In addition, low health literate patients were also less likely to make timely and autonomous decisions to improve their health-related conditions, by changing their everyday lifestyles. Inadequate health literacy seemed also to pave the way for biased patient-provider relationships. In fact, those living with limited health literacy claimed to be unwilling to disclose to health care professionals their inadequate understanding of verbally provided health information, being at significant risk of misjudgement and misuse of health resources.

Therefore, with regard to *R.Q. 2*, it could be emphasized that patients living with inadequate health literacy skills are likely to express two special information needs as compared with health literate individuals. On the one hand, they were found to be less able to access and collect relevant health information when facing a decline in their health status. From this point of view, the friendliness of health information sources and the easy access to health information sources should be improved, in order to allow people with impaired health literacy skills to handle them. This is especially true with regard to health information provided through information and communication technologies and digital contents, which are usually designed by assuming limitless health literacy skills by the side of users (Pálsdóttir, 2015). As well, reliability (Massey, 2016) and ethical (Solomonides & Mackey, 2015) issues are critical when arranging digital health information materials. On the other hand, people living with limited health literacy have been found to be at special need of professional support in evaluating and using health information. However, they are likely to conceal their impaired ability to handle health information due to the fear of stigma (Parikh, *et al.*, 1996). Therefore, specific initiatives and tools should be designed to assist low health literate patients in processing health-related information, thus bridging the gap between education and health. Even though understanding and applying issues were common in the sample, they seemed to be less compelling as compared with accessing and processing ones, which were found to perform as barriers to the appropriate access to care.

Information and communication technologies and digital tools could play a significant role in improving the ability of low health literate patients to navigate the health care service system and to access health-related services. The scientific literature has recently emphasized that specific health information technologies tailored to the underserved population may help disadvantaged people in accessing appropriate care and in improving health outcomes (Tang, *et al.*, 2016). Drawing from the results of this manuscript, it could be maintained that digital tools should focus on accessing and processing information issues, which are prevailing among people living with limited health literacy. With regards to the access issues, health information technologies could allow the patients to overcome the complexity of the health care service system when looking for and obtaining health information: actually, digital tools pave the way for an immediate access of patients to health information, thus enhancing their ability to collect and gather health-related information. At the same time, the design of digital health information should be inspired by the purpose of increasing the patients' ability to process health-related materials. Therefore, the friendliness of health information technologies, the use of a clear and familiar language which is free from jargon, and the reliability of the information provided should be the key criteria to guide the arrangement of digital

health information provided to low health literate patients. Besides, since people living with limited health literacy skills have been found to rely on the support of health care professionals to navigate the health care service system, health information technologies should facilitate a more direct and comfortable relationship between the patients and the health care providers. In particular, the development of digital tools aimed at promoting the establishment of a continuous and co-creating relationship between the users and the providers of care is momentous to improve the appropriateness in the access to care and to achieve greater health outcomes and enhanced sustainability.

Dealing with the last research question, gender was found to be not related to the individual ability to navigate the health care service system. However, on the average male patients performed better in the NVS screening tool, while women were more likely to self-report adequate ability to find, understand, evaluate, and use health-related information. This finding is consistent with the assumption that men are not willing to participate in health care design and delivery independently of their health-related competencies, sticking to the myth of masculinity (Adinolfi, 2013; Courtenay, 2000). From this point of view, gender concerns should be included in the design and delivery of tailored health information through both traditional and digital channels. The status of employment was found to be related with functional skills and self-reported understanding abilities. Indeed, unemployed, retired, and inactive people were consistent in reporting lower NVS scores and impaired ability to comprehend health information as compared with the active members of the sample, maybe due to poorer numeracy and literacy skills.

Education, financial deprivation, and age showed the higher Spearman's correlations with the indices measuring health literacy skills. Less educated patients, those suffering from financial deprivation, and elderly were likely to misunderstand and misuse health information. They usually reported poor self-efficacy in dealing with health-related issues. In particular, older adults were found to show more problematic functional and interactive abilities as compared with their younger counterparts, while differences in terms of critical skills were not evident. These findings echoed the arguments of the extant scientific literature, which argued that older adults exhibit distinguishing behavior when accessing health information (Flynn, *et al.*, 2006), being at risk of inappropriate access to care due to memory and/or cognitive impairments (Insel, *et al.*, 2006).

In sum, to provide a tentative answer to *R.Q. 3*, it could be maintained that less educated individuals, disadvantaged population, and elderly were at special risk of living with limited health literacy skills and expressed specific information needs to properly function in the health care service system. While both elderly and less educated people seemed to primarily suffer from processing and understanding barriers, patients who reported financial deprivation were more likely to self-report poor self-efficacy in accessing and using health information.

It could be supposed that, beyond inadequate functional and critical skills, the unwillingness of disadvantaged patients to establish a friendly and co-creating relationship with the health care providers and to disclose their poor understanding of health-related information due to the fear of stigma performed as the most important barriers to their ability to navigate the health care environment. From this point of view, specific information strategies and tailored information tools should be devised to meet the information needs of this particular category of patients. In particular, health information technologies and digital tools may help in creating a shame-free health care environment, encouraging the patients to disclose their impaired understanding of health-related issues to health care providers. This is possible by introducing a digital interface between the users and the providers of care, which reduces the risks of discomfort by the side of patients to show limited proficiency in processing and understanding health information.

The findings of this manuscript should be read in the light of its limitations. The results above discussed are not generalizable, since they are drawn from a convenient random sample which involved 500 patients who were assisted in a public general hospital operating within the INHS. However, the sample composition was balanced in terms of gender, age groups, social status, employment, and education levels. Therefore, it could be argued that the decision to use a convenient sample did not significantly affect the reliability and the consistency of this manuscript.

In addition, even though the NVS screening tool is considered to be a quick and consistent test to assess functional health literacy skills, it implied a focus on the patients' ability to understand and apply health related information. As a consequence, it overlooked both accessing and processing competencies, which are crucial to function in the health care service system. Nonetheless, the shortcomings of the NVS were balanced by asking the patients involved in this study to self-rate their ability to obtain, comprehend, evaluate, and use health information materials. The significant statistical associations between the objective and subjective measures of health literacy skills which were used for the purpose of this paper contributed in improving its dependability. Last but not least, the correlation analysis allowed to discuss the relationship between the variables included in this research, but did not provided insights about the causation relationship between them.

## 6. Conclusions and practical implications

This study confirmed that inadequate health literacy is a common issue among Italian patients. More than half of the sample involved in this study was found to show limited functional health literacy skills, as measured by the NVS screening tool. In addition, 2 out 3 patients were likely to self-report an impaired ability to access and process health-related information. Similarly, about half of the sample revealed to meet great difficulties in understanding and applying health information. People living with problematic health-related competencies disclosed specific information needs as compared with their health literate counterparts. In particular, they were likely to state impaired ability to obtain timely and relevant health information and to evaluate such information for the purposes of health protection and promotion.

Digital health information could be exploited to enhance the ability of patients to navigate the health care service system. Actually, health information technologies allow to improve the access of patients to health-related information and support them in making wise choices within the health care environment. However, to realize the full potential of health information technologies, a specific health literacy concern should be adopted in designing and delivering digital contents. Indeed, in most of the cases digital health information materials are arranged by assuming unlimited health literacy skills by the side of users. As a consequence, the information needs of people living with limited health literacy skills are at risk of being unmet, with momentous drawbacks on their empowerment and their involvement in the provision of health services.

The relevance of this study is twofold, paving the way for both conceptual and practical implications. There is a desperate need for further developments aimed at exploring the issues which affect the ability of low health literate patients to access, understand, process, and use health-related information. To the knowledge of the authors, the scientific literature paid most of its attention to the consequences of limited health literacy and to its determinants. Alternatively, the special information needs of people living with limited health literacy are still widely neglected. This manuscript pointed out that - among the other issues - problematic health literacy engenders significant barriers to access and obtain timely health information. In addition, it prevents the involvement of patients in health-related decision making, involving impaired ability to evaluate the relevance of health information and to assess the *pros* and *cons* of health treatments available. From this point of view, scholars are encouraged to explore in-depth the effects of limited health literacy on the interactive and critical abilities of patients, which turn out to be crucial to empower the latter and to encourage them to play an active role in the process of value creation. As well, greater attention should be paid to the interventions intended at bridging the gap between education and health, here included the introduction of digital tools to improve the access of low health literate patients to health information.

Health care providers are likely to overlook the side effects of limited health literacy. In general, time constraints and poor awareness of negative consequences produced by inadequate health literacy on health outcomes are the main determinants of poor ability of health care organizations to meet the special information needs of people living with limited health-related

competencies. Friendly health information technologies and digital tools could perform as universal precautions to identify and satisfy the demands of low health literate patients. In particular, health information technology should pave the way for a more friendly and prompt access to health-related information and should enhance the patients' ability to evaluate and process the evidence available for the purposes of health protection and promotion. Policy makers should encourage the use of tailored health information technologies to improve the ability of low health literate patients to navigate the health care service system. In fact, the use of policy and legislative tools to incite the adoption of a health literacy concern among health care providers is crucial to fight this silent epidemic (Clark, 2011).

Since elderly, disadvantaged patients, and less educated individuals are at special risk of living with limited health literacy skills, specific information strategies should be devised to incite their involvement in patient empowerment initiatives. With particular regard to digital information, the patients' ability and willingness to use information technology should be enhanced. On the one hand, the digital gap which is still affecting a significant part of the population should be filled, introducing easy-to-use and easy-to-access interfaces. On the other hand, a health literacy concern should inspire the design of digital health information, with the eventual purpose of minimizing the risks of patients' misunderstandings and consequent disengagement in the provision of health care services.

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