

Health Literacy Status of the Patients' Informal Caregivers; Turkey Example

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Abstract

Introduction: Health literacy affects the ability to access and use the right information. The purpose of our study was to evaluation of health literacy status of patients' informal caregivers in a research hospital services.

Methods: This study was conducted as a descriptive study. The caregivers of 228 patients who volunteered to participate in the study on March 1, 2016 in all the services of a hospital.

Results: The caregivers' knowledge about important decision-making information as well as their health-related behavior and staying healthy. In the culture of Turkey, particularly in chronic and long-term diseases, there is a care system mostly consisting of family members or relatives. The health literacy of patients' caregivers related to treatment, diagnosis, medicine, care and education materials throughout the treatment is affected by the fact that discharge education is not at the desired level in Turkey. This study has provided important results, such as caregivers' lack of adequate information about patient-related procedures, inadequate communication with the healthcare team, the lack of information on patient rights, and the lack of reading complete documents of the patient's illness. In the analysis of simple health responsibility behavior regarding the patient and daily life, it has been determined that the educational level of the caregivers is an important factor.

Conclusion: We recommend that strategies be urgently determined and passed on to raise Turkey's health literacy level.

Keywords: Hospital; Caregivers; Health literacy; Turkey

Introduction

It is necessary for people to know their rights and responsibilities in the health care system in their country in order to be able to benefit from it effectively. The modern health system is extremely complicating for those who have received and will receive services in the world. In this system, people who apply for health services have different roles such as being informed about health problems and services, knowing their responsibilities / rights and making decisions about their own health. Especially in the developing countries like Turkey, owing to the rapid changes in the health system, these roles become even more important [1]. The fact that people act with the awareness of health literacy (HL) to be able to cope with health issues affects these roles positively [2].

Many literacy and health education programs have had difficulty in significantly affecting caregivers of patients, all patients' family and other health staffs [3]. The Interdisciplinary Model includes multidiscipline study for understanding health literacy for everybody. This model discussed relationship between literacy, health, and culture and provides rationale for the interdisciplinary literacy for health model. The model's synthesis of anthropology, linguistics, literacy, nursing, and community partnership guides development of culturally and linguistically appropriate materials for successful adoption and diffusion within a priority population [3].

Literacy is a unique process by which reading and writing convey meaning of speech and thought [4,5]. The concept of HL was first used by Scott Simonds in 1974 in the title of an article called "Health Education and Social Policy" [6]. It derives its origin from the research done in the fields of literacy, adult education and health promotion [7]. By emphasizing the link between general literacy and health literacy, The World Health Organization redefines health literacy as "HL is associated with general literacy and means people's desires and capacities to develop an idea and make decisions on health care issues throughout their lives; to access relevant sources of information to protect, maintain and improve their health; increase their quality of life; and perceive and understand health information and messages correctly" [8-12].

It has been determined that there is a limited number of studies to determine the level of health literacy in Turkey, and the vast majority of these studies are about patients or people working for their own health [13-15]. In the culture of Turkey, particularly in chronic and long-term diseases, there is a care system mostly consisting of family members or relatives [16,17]. The health literacy of patient caregivers related to treatment, diagnosis, medicine, care and education materials throughout the treatment is affected by the fact that discharge education is not at the desired level in our country. It has been observed that during the clinic and home treatment process, the fact that patients and patient caregivers feel a need to ask for information through telephones or to return to hospitals indicates that the discharge training is inadequate and they want to receive support related to health literacy based on individuals. The caregivers' knowledge about important decision-making information as well as their health-related behavior and staying healthy. Literature review demonstrates that the studies conducted on health literacy of the caregivers who are responsible for the care of patient primarily are inadequate [18,5].

In the light of this lack in the literature, this study was carried out in order to determine the health literacy status of the patient caregivers who were hospitalized on 1 March 2016 in all the services of a hospital in Trabzon, Turkey.

Methods

Study setting and design

This descriptive and cross-sectional study was undertaken in a research hospital consisting of all services (N=16 services) voluntarily participating of caregivers in the study on 1 March 2016. After obtaining the necessary permits from the hospital, service personnel, caregivers and patients researchers conducted the study on a day determined by the administrators.

Participants

It was completed with a total of 341 caregivers who were at the hospital services on the day of study without sample selection. The number of patients' caregivers was obtained from the units that had the caregivers' records by taking the necessary permission. Each service of the hospital was visited by the researcher and the study was completed with 228 voluntary caregivers (Internal Medicine service: 101 caregivers, Surgery service: 127 caregivers).

Data collection and instruments

The data collection tool that was developed by the researchers depends on literature. This survey was including 10 questions for determining socio demographic characteristics of the participants and 31 questions for assessing their health literacy status. The survey were applied with face-to-face survey method and lasted an average of 10 minutes.

Ethical considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors. The study has been approved by a suitably constituted Ethics Committee of the rural institution within which the work was undertaken and that it conforms to the provisions of the Declaration of Helsinki. The approval needed to complete such questionnaire was obtained from the Director of the Hospital. Before completing the questionnaire, the written informed consent was signed by the subjects participating voluntarily. They were informed about the purpose and the length of the research. They were explained that the participation would be voluntary and they could withdraw from the study at any time. They were assured about the confidentiality, protection and anonymity of data.

Data Analysis

In the data analysis of the research, number, percentage, mean, standard deviation, chi-square test and Pearson Chi-Square test were performed using SPSS version 15.0 software. The level of statistical significance was accepted when the p-value less than 0.05.

Results

Descriptive Statistics of study variables

According to the demographic characteristics of the caregivers, the average age was 39.88 (SD 10.7), 71.9% were female (n=164), 78.5% were married (n=179), 58.8% were primary school graduates (n=134), 50.4% were living in the city (n=115), 56.6% were living in the same house with the patients (n=129), 41.7% were the children of the patients (n=95), 25.9 % had at least one chronic

illness (n= 59), 80.4% had pain (n=14),0.8% had hearing problems (n=2), 11.4% had visual problem, 55.8% were stayed in surgical medicine services, 57.1% visited 4-6 times to emergency department (Table 1).

	Mean +-S.S	
Age	39.88+-10.7	
Socio-demog. Characteristics	n	%
Gender		
Female	164	71.9
Male	64	28.1
Marital Status		
Married	179	78.5
Single	49	21.5
Education Status		
Primary School	134	58.8
High School	54	23.7
University	40	17.5
Place of Residence		
City	115	50.4
District	113	49.6
Living with the patient		
Yes	129	56.6
No	99	43.4
Degree of kinship		
Spouse	38	16,7
Children	95	41,7
Parents	42	18,4
Sibling	20	8,8
Relative	33	14,5
Disease presence		
Yes	59	25.9
No	169	74.1
Type of the disease		
Endocrine	25	10.9
Cardiovascular	12	5.2
Neurological	8	3.5
Physics/bone/pain	14	80.4
Hearing problem		
Yes	2	0.8
No	226	99.2
Visual problem		
Yes	26	11.4
No	200	88.6
The Services of Accompanists		
Internal Medicine	101	44.2
Surgical	127	55.8

Table 1: Socio-demographic characteristics of the caregivers

Assessment of the caregivers’ behaviors related to health literacy

A significant correlation was not found between caregivers’ hearing health literacy concept, age ($X^2=0.73$, $p=0.69$), gender ($X^2=0.01$, $p=0.91$), education ($X^2=0.41$, $p=0.81$) and marital status ($X^2=0.33$, $p=0.84$); caregivers’ reading the prospectus, age ($X^2=8.08$, $p=0.00$),education ($X^2=16.29$, $p=0.00$) and marital status ($X^2=9.64$, $p=0.00$); caregivers’ reading the effects of prospectus and education ($X^2=10.34$, $p=0.00$); reading the adverse effects and education ($X^2=5.06$, $p=0.00$), reading the adverse effects and marital status ($X^2=6.54$, $p=0.03$); caregivers’ source of disease information as nurse and marital status ($X^2=11.96$, $p=0.00$); source of disease

information as chemist and gender ($X^2=7.59$, $p=0.05$); caregivers' reading the whole of acceptance forms and education ($X^2=8.87$, $p=0.02$); caregivers' understanding the warning signs in the hospital, gender ($X^2=19.07$, $p=0.00$) and education ($X^2=14.38$, $p=0.00$); caregivers' taking enough information about procedure applied to your patient and education ($X^2=0.45$, $p=0.00$); caregivers' taking enough communication with health staff and education ($X^2=4.21$, $p=0.00$); caregivers' having enough information about the patient rights and education ($X^2=8.87$, $p=0.02$) (Table 2).

			Age	Gender	Education	Married
	n	%	X ² p	X ² p	X ² p	X ² p
Have you heard the concept of health literacy before?						
Yes	33	14.5	0.73	0.01	0.41	0.33
No	195	85.5	0.69	0.91	0.81	0.84
Do you read drug prospectuses?						
Yes	126	53.3	8.08	0.00	16.29	9.64
No	102	44.7	0.00	0.97	0.00	0.00
Which sections of the prospectuses do you read?						
Formula	19	8.3	1.09 0.57	0.20 0.65	0.32 0.56	0.06 0.96
Effects	122	53.5	5.07 0.77	2.02 0.15	10.34 0.00	2.87 0.23
Adverse effects	118	51.8	0.98 0.61	0.66 0.41	5.06 0.00	6.54 0.03
Usage and dosage	81	35.5	4.08 0.13	1.01 0.31	3.64 0.16	6.39 0.04
From whom have you received the information about your patient and his/her illness?						
Physician	135	59.2	0.51 0.77	0.07 0.78	0.72 0.69	0.90 0.85
Nurse	39	17.1	3.28 0.19	0.64 0.42	1.02 0.60	11.96 0.00
Chemist	92	23.7	0.35 0.83	7.59 0.05	1.92 0.38	0.01 0.99
Have you do any research about your patient's illness?						
Yes	33	14.5	0.73	0.01	0.41	0.33
No	195	85.5	0.69	0.91	0.81	0.84
Do you read the whole acceptance form about the procedure applied to your patients?						
Yes	24	10.5	6.20	0.16	8.87	3.36
No	204	89.5	0.04	0.68	0.02	0.18
Do you understand the warning signs at the hospital?						
Yes	155	68,0	19.07	0.02	14.38	0.20
No	73	32,0	0.00	0.87	0.00	0.65
Do you receive enough information about the procedure applied to your patient?						
Yes	109	12.8	12.03	0.03	0.45	0.06
No	119	87.2	0.19	0.65	0.00	0.96
Do you have enough communication with the health staff?						
Yes	112	49.2	4.62	0.05	4.21	1.43
No	116	50.8	007	0.75	0.00	0.42
Can you talk freely with the physician about the diagnosis of the patient and the procedursto be performed?						
Yes	30	13.2	0.60	0.03	2.03	0.04
No	198	86.8	0.31	0.82	0.11	0.76
Have you received enough information about the patient rights?						
Yes	24	10.5	6.20	0.16	8.87	3.36
No	204	89.5	0.04	0.68	0.02	0.18

Table 2: Assessment of the caregivers' behaviors related to health literacy

Assessment of the caregivers' health literacy behaviors about daily life

There was a significant relationship between gender and the type of product whose content caregivers read most ($X^2=4.04, p=0.04$); gender and reading the content of detergents ($X^2=4.04, p=0.04$); evaluation of food in terms of health and age ($X^2=4.98, p=0.00$); canned food consumption and education ($X^2=2.78, p=0.02$); gender and the point of attention in canned food consumption ($X^2=2.78, p=0.02$); the programs followed in the media and age ($X^2=0.19, p=0.04$), education ($X^2=0.04, p=0.042$) and marital status ($X^2=11.18, p=0.05$) (Table 3).

			Age	Gender	Education	Marital Status
	n	%	X ² P	X ² P	X ² P	X ² P
Do you read the content of the products you buy?						
Yes	125	54.8	0.68	5.73	2.24	0.90
No	103	45.2	0.71	0.07	0.32	0.63
What types of products' content do you read most?						
Food	68	29.8	0.87	4.04	1.60	0.87
Cleaning products	57	70.2	0.64	0.04	0.44	0.51
Do you read the contents of the cleaning products you use at home?						
Yes	84	36.8	0.87	4.04	1.60	2.85
No	144	63.2	0.64	0.04	0.44	0.24
Do you pay attention to consume healthy food?						
Yes	208	91.2	0.56	0.04	2.07	0.06
No	20	8.8	0.45	0.84	0.14	0.80
How do you evaluate the food in terms of health?						
Nutritious /fresh/ organic	174	76.3	4.98	1.36	2.77	8.48
Expiry date	54	23.6	0.00	0.24	0.09	0.58
Do you consume canned food?						
Yes	107	46.9	4.78	0.09	5.31	1.47
No	121	53.1	0.09	0.76	0.04	0.47
What kind of things do you pay attention in canned food?						
Production and expiry dates/ brand	224	98.2	1.81	2.78	0.15	0.03
Content	*4	1.8	0.29	0.02	0.69	0.85
Do you watch health programs in the media?						
Yes	122	53.5	0.57	1.57	0.99	0.45
No	106	46.5	0.75	0.21	0.60	0.79
What kind of programs do you follow in the media?						
The effects of herbal/nutrition/ sports products on health	48	21.1	0.19 0.04	0.66 0.88	0.04 0.02	11.18 0.05
Magazine /news/series	180	78.9				

*Pearson Chi-Square test

Table 3: Assessment of the caregivers' health literacy behaviors about daily life

Activities to maintain health of caregivers

A significant difference was determined between the belief in sport's influence on health, gender ($X^2=20.59, p=0.00$), education ($X^2=2.78, p=0.00$) marital status ($X^2=4.11, p=0.04$); weight tracking, age ($X^2=12.57, p=0.00$) and gender ($X^2=15.45, p=0.00$); breast self-examination, gender ($X^2=50.07, p=0.00$) and education ($X^2=6.40, p=0.04$); between mammography screening and gender

			Age	Gender	Education	Marital status
	n	%	X ² P	X ² P	X ² P	X ² P
Do you do sports regularly?						
Yes	50	21.9	1.10	0.31	3.68	1.99
No	178	78.1	0.57	0.57	0.00	0.36

			Age	Gender	Education	Marital status
	n	%	X ² P	X ² P	X ² P	X ² P
Do you believe in the impact of sports?						
Yes	223	97,8	1.52	20.59	2.78	4.11
No	*5	2,2	0.21	0.00	0.00	0.04
Do you follow your weight?						
Yes	213		12.57	*15.45	1.61	0.08
No	15	6,6	0.00	0.00	0.44	0.95
Are you given Influenze vaccination?						
Yes	79		5.22	17.39	0.98	4.44
No	149	65,4	0.073	1.00	0.61	0.11
Do you perform breast-self examination?						
Yes	79	34,6	1.48	50.07	6.40	1.98
No	149	65,4	0.47	0.00	0.04	0.37
Do you have mammography screening?						
Yes	68	29,8	0.26	41.14	0.93	1.21
No	160	70,2	0.87	0.00	0.62	0.54
Do you have Papsmear test?						
Yes	50	21,9	0.25	0.73	1.75	0.79
No	178	78,1	0.88	0.39	0.41	0.67
Do you perform self-testicular test?						
Yes	15	6,6	6.51	6.47	0.18	7.18
No	213	93,4	0.03	0.01	0.19	0.02
Do you have colon cancer screening?						
Yes	13	5,7	1.89	3.13	0.75	9.96
No	215	94,3	0.38	0.07	0.02	0.00
Do you have osteoporosis screening?						
Yes	27	11,8	13.54	10.42	2.91	0.93
No	201	88,2	0.00	0.00	0.08	0.33
Do you regularly see a dentist?						
Yes	76	33,3	0.51	2.82	0.49	0.45
No	152	66,7	0.77	0.09	0.77	0.83
Do you follow a special diet?						
Yes	23	10,0	0.35	2.48	4.05	5.38
No	205	90,0	0.55	0.11	0.04	0.06

*Pearson Chi-Square test

Table 4: Activities to maintain health of caregivers

($X^2=41.14$, $p=0.00$); testicular self- examination, age ($X^2=6.51$, $p=0.03$), gender ($X^2=6.47$, $p=0.01$) and marital status ($X^2=7.18$, $p=0.02$); colon cancer screening, education ($X^2=0.75$, $p=0.02$), and marital status ($X^2=9.96$, $p=0.00$); osteoporosis screening and age ($X^2=13.54$, $p=0.00$), gender ($X^2=10.42$, $p=0.00$), education ($X^2=2.91$, $p=0.08$); special dieting and education ($X^2=4.05$, $p=0.04$) (Table 4).

Discussion

Health literacy empowers the ability to access the right information and services, the ability to use these services, the use of resources correctly, the formation of quality requirements in health care, and the effect of individuals on their own health and community health [7,19]. It is obvious that the development of health literacy awareness affects the ability to deal with prescribed medication instructions, appointment cards, medical education brochures, doctors' explanations, acknowledgment forms, and complex health systems. It has been found that the vast majority of adult individuals in the United States do not have basic health literacy. The UNESCO 2009 report states that 776 million adults do not have primary health literacy in the world [20]. In our study, in parallel with the literature it has been found that companions have a very low rate of achieving such behavior and this indicates the lack of health literacy of the caregivers study group.

The burden of chronic diseases and their complications which are becoming increasingly common with the aging of society has resulted in reduction in the allocated time for a patient and the quality of care due to the increasing amount of health care systems. In addition, in the modern health service presentations, the changes in health presentation algorithms resulted from the patient-centered care concept which requires patient autonomy have imposed an obligation for the individuals in a society to be informed about their own health and illnesses, take part in the decision processes and take responsibility [21]. However, for a higher quality and cost-conscious system, when it is targeted to include the patient in the system and decision mechanism, it is not known in many cases how well prepared patients are to cope with this responsibility [22]. Putting responsibilities on the shoulders of caregivers/ patients/ individuals' who are not ready yet on this issue has a potential to threaten patient safety and the sustainability of the system rather than protecting the patient and the system. For this reason, it is primarily necessary to determine the health literacy levels of people and societies, while evaluating their ability and motivation in participating in the health system and taking responsibility for their own health. In our study, concept of HL has been found low.

Literature review studies in our country show that HL is not at the desired level at the social level [13,18,23]. It is noteworthy that awareness training programs in our country for these deficiencies are inadequate.

In Turkey, the responsibility of caring for a sick person is met mostly by the caregivers at home as a necessity of our culture [24,25]. Caregivers in our country usually consist of people like patients' children, wives and close relatives. These individuals whether in hospital or at home take responsibility of making decisions and being primer responsible for the patient [17]. The majority of caregivers in our study are the children of the patients.

According to the results of the literature studies, it has been reported that those whose HL is insufficient result in inadequacies in their knowledge of health, disease; treatment and disease management related to chronic conditions; the necessary skills to reach the health care system; an increase in health care costs, medical and drug mistakes and mortality rates; and less utilizations of health care services [19,26,27]. In our study, it was found that accompanists lack knowledge about receiving information about the patient, patient rights and communicating and these results support the results mentioned above regarding the lack of care.

It is known that the countries with developed health literacy also have high health level [28,29]. Even in the developed countries such as America, the adequate level of health literacy has not been achieved yet [20,30]. The studies conducted in our country show that health literacy is not at the desired level [1]. Many people have difficulties accessing information and services due to the lack of HL and cannot benefit from adequate services. In our study, a meaningful relationship was found between the education level of the accompanists and their health literacy behavior.

It has also been proven through the studies that people with low levels of health literacy use less of the preventive health services and that they receive their treatment from the major emergency services [20,28,30,31]. In our study, the fact that the vast majority of the accompanists took their patients to the emergency service 4-5 times overlaps this result.

Individuals with poor health literacy are reported to have problems in understanding the words used by health personnel, online information, information provided by health service providers, patient education brochures, compliance with treatment, responding to the tools used to identify cognitive deficits and expressing the information and symptoms of their medical condition appropriately [32]. The results of our study revealing that accompanists had deficiencies in both daily activities (reading the foods' content they consume), health promotion activities (doing sports regularly, early diagnosis, vaccination) and in reading the patient's information (reading the patient's process acceptance forms, getting information about the patient, disease research) support the results mentioned above.

Advanced age is a known risk factor for limited health literacy. The results of a study by Tanriöver, *et al.*, show that the highest levels of health literacy are clustered in younger age groups and linearly health literacy decreases with age [22]. In current study, the relationship between the educational status and health literacy was determined while no correlation was found between age and marital status.

It is known that the overall literacy rate in Turkey is over 80% in women and 96% in men [33]. The studies on the distribution of women and men in health literacy in our country are at regional level. In our study, gender factor did not show any significant difference on HL. This shows us that there is a lack of knowledge about HL in both men and women.

It is a known fact that low literacy level is a much bigger problem than many health professionals think. According to a national study in the USA, the basic literacy skills required for independent functions in a society are reported to be low in 21-23% of adults. It is emphasized that most people cannot read appointment papers, drug effects, prospectuses and thermometer [34]. Tanriöver *et al.* pointed out that there was a linear increase in the health literacy index as the level of education increased in a research conducted in 2014 [22]. Our study also found a significant relationship between health literacy awareness and the education of individuals.

One of the first studies showing that health literacy is related to drug use habits and proper drug use belongs to Williams *et al.* The study was conducted within an asthma clinic and emergency room and reported a strong association between inadequate health literacy, misinformed knowledge, and mild dose inhaler asthma medication [22,33]. In current study, a significant relationship was found between reading drug prescriptions and education and marital status. This result can tell us that educated individuals mostly read the effects and side effects part of the drugs, that is, the parts that are necessary for them.

In another research, 61.1% of the elderly people stated that they did not have any information about the medication and 22,1% of them got the information from the physician when asked about their information sources [32]. In current work, it was also found that the companions received information about the medicine mostly from the physicians. A study conducted in our country reported that only 54.5% of the patients read surgical approval forms [33]. Our study shows that the majority of the companions do not read the whole of the forms of accepting the treatment applied to the patients in health institutions and there is a meaningful relationship between reading and education.

The studies regarding the importance of hospital warning signs indicate that 88.1% of warning signs (eg, radiation shields) in hospitals can always be understood [18]. This result supports the result of current work.

Conclusion

The results of this study show us that the caregivers of the patients who are in the hospital and mostly looked after by their children do not know the concept of health literacy and enough knowledge. This study has provided important results, such as caregivers' lack of adequate information about patient-related procedures, inadequate communication with the healthcare team, the lack of information on patient rights, and the lack of reading complete documents of the patient's illness. In the analysis of simple health responsibility behavior regarding the patient and daily life, it has been determined that the educational level of the caregivers is an important factor.

It is very important for caregivers who are decision- makers and doers on behalf of the patient to have continuous hospital and home-based training for the safety of the patient. It is a known fact that initiatives to be introduced and the policies to be created by the government to take steps to improve health literacy at the institutional level will be guiding and supporting. From this perspective, we recommend that strategies be urgently determined and passed on to raise Turkey's health literacy level. Only in this way, cost effectiveness and patient satisfaction can be brought to the desired level, and the level of health literacy which is a developed state indicator can be increased.

Limitations of the study

The study has several limitations. The convenience sample is not representative of Turkey's entire population, thus limiting the generalizability of the results. The study design (observational and cross sectional) limits the reliability of the results and the ability to establish cause and effect.

The needs for the future research

The results of our study show us that the caregivers of the patients who are in the hospital and mostly looked after by their children do not know the concept of health literacy and enough knowledge. This study has provided important results, such as caregivers' lack of adequate information about patient-related procedures, inadequate communication with the healthcare team, the lack of information on patient rights, and the lack of reading complete documents of the patient's illness. In the analysis of simple health responsibility behavior regarding the patient and daily life, it has been determined that the educational level of the caregivers is an important factor.

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The study can be replicated in other setting and different cultures to provide cross-cultural comparisons.

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