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#### editorial

## Health literacy: Emerging evidence, applications and new directions

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Health literacy represents the communication among patients, their social networks, providers, and health systems to promote patients' understanding

and engagement in their care. This is widely relevant in all aspects of health care irrespective of populations or settings.

Various conceptual models to depict the role of health literacy and patient outcomes and numerous measures have been developed to measure the constructs and its dimensions. While methodologies across studies may differ, there is consensus that low HL is associated with poor outcomes including less preventive health behaviors, more hospitalizations, and a higher risk of mortality. Empirical research work across various populations and setting is growing rapidly. This special issue brings together a selection of papers to highlight the multimodal perspectives on HL and raise interesting questions for further research.

Paul Gellert and Florian Tille in their paper "What do we know already? The role of health knowledge within theories of health" attempt to disentangle the relation between health literacy and health knowledge. They argue for the clarification of the role of health knowledge within HL theories in order to better conceptualize and design interventions to improve health literacy.

Since living in an era of technology, we cannot talk about health literacy without addressing the issue of eHealth literacy. Efrat Neter, Esther

Brainin and Oran Baron-Epel in 'The dimensionality of health literacy and eHealth literacy' examine the dimensionality of health literacy and eHealth literacy constructs using established measures.

In order to improve health literacy, one may intervene either at the level of health professionals or at the level of patients. The paper by Alden Yuanhong Lai, Aya Goto and Rima Rudd in "Advancing health literacy from a system perspective: Health literacy training for health care professionals" discusses the issue of health literacy training in health professionals, using a concrete example of a training conducted in Fukushima.

Julia Amann, Sara Rubinelli and Gary Kreps in Revisiting the concept of health literacy. The patient as information seeker and provider address health literacy from the perspective of patients, namely the importance of the patient as health information seeker and provider. This paper names current shortcomings of the health literacy debate by drawing attention to the currently under-investigated role of the patient as information provider. Recognizing the potential of peer-to-peer health communication, the authors highlight the importance of conceptualizing and operationalizing health literacy in the context of information sharing.

Mahatti Chitem, Venkatesh Boddu, Ramesh Babu Byrapaneni, Kirsti Sarham Anthun explore in their paper "What has access and skills got to do with it? A qualitative study exploring health literacy among Indian IT employees" the issue of health literacy in a particular group of IT employees, showing how the work place can

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become an important venue where one measures and changes health literacy levels.

Peter Kolarcik, Andrej Belak and Richard Osborne in "Using health literacy alongside grounded and participatory approaches to develop interventions in partnership with marginalised populations: The Ophelia (OPtimise HEalth Literacy and Access) Process" raise the issue of improving health literacy in Roma marginalised groups such as the population. They report on findings from intervention studies and emphasize that health literacy is especially relevant when working with vulnerable groups. They use the case example of the Roma population in Chech Republic to illustrate the potential of a newly developed, grounded and participatory approach to development of health-literacy and health-care access interventions for equity - the Ophelia (OPtimising HEalth Literacy and Access) process (Batterham et al., 2014). Their paper raises attention to the relation between health literacy and equity.

We hope you enjoy this issue!

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Kolarcik, P., Belak A., & Osborne, R. (2015). Using health literacy alongside grounded and participatory approaches to develop interventions in partnership with marginalised populations: The Ophelia (OPtimise HEalth Literacy and Access) Process. The European Health Psychologist, 17(6), 297-304.

Lai, A. Y., Goto, A., & Rudd, R. (2015). Advancing health literacy from a system perspective: Health literacy training for healthcare professionals. The European Health Psychologist, 17(6), 281-285.

Neter, E., Brainin, E., & Baron-Epel, O. (2015). The dimensionality of health literacy and eHealth literacy. The European Health Psychologist, 17(6), 275-280.



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#### References

Amann, J., Rubinelli, S., & Kreps, G. (2015). Revisiting the concept of health literacy. The patient as information seeker and provider. The European Health Psychologist, 17(6), 286-290.

Chitem, M., Boddu, V., Byrapaneni, R. B., & Anthun, K. S. (2015). What has access and skills got to do with it? A qualitative study exploring health literacy among Indian IT employees. The European Health Psychologist, 17(6), 291-296.

Gellert, P., & Tille, F. (2015). What do we know already? The role of health knowledge within theories of health. The European Health



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#### original article

# What do we know so far? The role of health knowledge within theories of health literacy

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Health knowledge has been linked to health literacy (HL) frequently, yet the role of health knowledge remains theoretically inconclusive and empirically understudied. A sele-

ctive overview on the role of health knowledge within HL theories is presented. Three existing reviews of HL theories have been inspected with regard to the role of health knowledge within these reviews. Summarising the reviews, health knowledge is conceptualised either as an antecedence, a dimension HL, or a consequence of HL. The present paper argues that there is a need for disentangling health knowledge from HL and other sub-concepts to develop a clear and shared language on what is meant by HL and how these sub-concepts are interrelated. This might open a road to better conceptualise, measure, and ultimately alter health knowledge, HL, as well as health outcomes.

## Health literacy (HL) and health knowledge

There is a clear association of low HL with inefficient use of health-care services and adverse health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Less clear is the definition of HL itself (Martensson & Hensing, 2012). While narrow definitions refer to HL as the ability of reading, writing, and numeracy in the health-care setting (usually

referred to as functional HL), broader definitions for instance by the WHO (1998) describe HL as "the cognitive and social skills which determine the motivation and ability of individuals to gain, to access, to understand, and to use information in ways which promote and maintain good health" (comprehensive HL).

Part of this disaccord between the various definitions of HL concerns health knowledge in relation to HL. Though health knowledge has been typically treated as an outcome of functional HL (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011: Berkman, Sheridan, Donahue, Halpern, Viera, et al., 2011) in HL theories the position of health knowledge is mixed. Health knowledge serves either as an antecedence (e.g., von Wagner, Steptoe, Wolf, & Wardle, 2009), as an integral dimension of HL itself (e.g., Freedman et al., 2009), or as a consequence of HL (e.g., Speros, 2005).

What does health knowledge mean exactly? Health knowledge denotes facts, information, and skills acquired through experience or education, as well as the theoretical or practical understanding of a subject related to health and health-care (Chin et al., 2011). Schulz and Nakamoto (2005) further subdivide the concept into declarative health knowledge (factual knowledge related to health issues, e.g. to identify symptoms of an health condition), procedural health knowledge ('know-how' to apply factual knowledge and use health information in a specific context), and judgment skills (the ability to judge based on factual knowledge necessary to deal with novel situations). In their model, the authors define functional HL skills as a possible antecedence of the acquisition of health knowledge (Schulz & Nakamoto, 2005).

Empirical studies have examined the relation of health knowledge and HL. For instance, disease-specific health knowledge in relation to HL was reported on hypertension and diabetes (Williams, Baker, Ruth, & Nurss, 1998), chronic pain (Devraj, Herndon, & Griffin, 2013), oral health (Hom, Lee, Divaris, Baker, & Vann, 2012), and HIV (Ciampa et al., 2012).

### Health knowledge within systemic reviews on HL theories

Three recent systematic reviews on HL theories (Frisch, Camerini, Diviani, & Schulz, 2012; Martensson & Hensing, 2012; Sørensen et al., 2012) are inspected on the role of health knowledge within HL theories.

Martensson and Hensing (2012) narratively reviewed 200 articles (including books, policy documents, and dissertation abstracts) on HL theories. Based on this narrative review we could not identify the role of health knowledge clearly, as descriptions of the single theories were presented without any detail. Authors solely classified the articles and documents into two broad categories that they labelled 'HL as a polarised phenomenon' (most similar to functional HL) and 'HL as a complex phenomenon' (most similar to comprehensive HL).

Sorensen et al. (2012) systematically studied and reported on twelve HL theories within seventeen articles on HL theories and generated an integrative model based on their theory review. Table 1 summarises the 12 theories and the role of health knowledge within this theories (based on the Sørensen et al. paper as well as on our re-reviewing of the original papers). Looking

into the role of health knowledge, four of the theories which have been reviewed conceptualised health knowledge as a dimension of HL. Eight theories named increased health knowledge as a consequence of increased HL. Although five theories named education as a predicting factor explicitly, only four of the models referred to health knowledge as an antecedent of HL. Sørensen et al. summarise the 12 theories by conceptualising health knowledge as a dimension of HL next to competencies and motivation.

Frisch et al. (2012) took an explicit focus on health knowledge within their review of literacy theories. They reviewed 863 articles on other literacy domains (e.g. media literacy and information literacy) on the existence of subconcepts of literacy to inform HL theories, detecting functional literacy, factual knowledge, and procedural knowledge among the most frequently named sub-dimensions of literacy.

## Process models of social cognitions in relation to HL and health knowledge

HL and health knowledge have also been incorporated into process-oriented social-cognition models – see Nutbeam (2008), von Wagner et al. (2009), and Baker et al. (2006).

Nutbeam's (2008) model of HL is one of the most cited as well as one of the most comprehensive ones. HL was defined as a person's ability to access, understand, and use health information (comprehensive HL). Three hierarchical HL-levels (functional, interactive, and critical) were introduced on an individual, social, and societal level. Prior knowledge was established as an antecedence of HL (Nutbeam, 2008). Improved knowledge of health risks and health services and compliance with prescribed

Table 1 Health knowledge within health literacy theories

Re	ference	Brief Description of Theoretical Concept of HL	Role of Health Knowledge
Re	view article		
O	Sørensen et al., 2012	Integrated model of comprehensive HL incorporates the definitions of models 1 to 12. Knowledge, motivation, and competencies to access, understand, appraise, and apply health information within the domains of healthcare, disease prevention and health promotion. Additionally the models provides pathways linking HL to health outcomes.	(D): Next to competence and motivation, knowledge a key dimension within the theory
Sej	parate articles review	ed in Sørensen et al. 2012	
1	Nutbeam, 2000, 2008 <sup>a</sup>	Conceptual model of HL. Functional, interactive, and critical HL. Personal, social, and societal levels and bidirectional relations between individual and society were outlined. Intervention strategies and causal pathways were integrated into the model.	A: Prior and developed knowledge and capabilities. D: Functional and critical HL are on the transmission of functional and on provision of knowledge on social and economic determinants of health. C: Improved health-related knowledge and knowledge of health determinants and of health risks.
2	Lee, Arozullah, & Cho 2004 <sup>a</sup>	A simplified model of mechanisms linking HL to health outcomes, incorporating intermediate factors	C: Disease and self-care knowledge.
3	Institute of Medicine (IOM), 2001 <sup>a</sup>	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. IOM-model: Education system, culture and society influence HL, whereas health system and individual HL interact with each other. HL is related to health outcomes and costs.	care system to provide health information appropriately. D: HL includes reading, writing,

(continued)

Table 1 (continued) Health knowledge within health literacy theories

Re	erence	Brief Description of Theoretical Concept of HL	Role of Health Knowledge
Sep	arate articles reviewe	ed in Sørensen et al. 2012 (continued)	
4	Zaracadoolas, Pleasant, & Greer, 2005 <sup>a</sup>	An expanded model of HL and the constituent domains of fundamental literacy, science literacy, civic literacy, and cultural literacy.	D: HL was defined as the ability to apply health information to novel situations. Ability to participate in public and private dialogues on health knowledge. Next to skills and awareness, knowledge is a dimension of each HL domain within the model.
5	Speros, 2005 <sup>a</sup>	With means of concept analysis, themes were derived from the literature. Dimensions of HL: Reading skills, numeracy skills, comprehension, capacity to use health information in decision-making, successful functioning in the patient role. Antecedents of HL: Literacy, ability to read, ability to comprehend written words, numeracy skills, health related experience, exposure to medical vernacular, logical context within cognitive framework. Consequences of HL: Improved self-reported health status, lower health care costs, increased health knowledge, shorter hospitalizations, decreased use of health services.	C: Increased health knowledge.
6	Baker, 2006 <sup>a</sup>	Conceptual path model of the relationship between individual capacities, health-related print, and oral literacy influenced by complexity and difficulty of content, and health outcomes (+ other factors such as culture and norms.	A: Prior knowledge related to vocabulary. Conceptual knowledge of health and healthcare is a resource of HL but does not in itself constitute HL.  C: attitudes, self-efficacy, health behaviour, acquisition of knowledge are outcomes of improved HL, which in turn affect health outcomes.
7	Paasche-Orlow & Wolf, 2007 <sup>a</sup>	Causal pathways between limited HL and health outcomes.	(A): Education. C: Within provider-patient interaction and self care, knowledge is one of the key patient factors influenced by HL.
			(continued)

Table 1 (continued) Health knowledge within health literacy theories

Re	ference	Brief Description of Theoretical Concept of HL	Role of Health Knowledge
Sej	parate articles reviewe	ed in Sørensen et al. 2012 (continued)	
8	Kickbusch & Maag, 2008 <sup>a</sup>	Functional, interactive, and critical HL as competency to make health decisions in the domains home, community, workplace, health-care system, in the market place, and politics. It is related to empowerment to people's control over their health, their ability to seek out information. The model takes an explicit perspective of a health-literate society.	A: Educational system. Good health information and the understanding of this information are essential for the development of HL.
9	Mancuso, 2008 <sup>a</sup>	A concept model of HL where HL consists of communication, capacity and comprehension and interacts with a set of competencies, i.e., contextual, informal, autonomous, operational, cultural, and interactive competency.	(A): Inadequate HL was described to be related to less knowledge of their diseases and treatments, but is not explicitly highlighted in the model.  C: HL is related to patient's health-care experience and the knowledge gained from health information.
10	Manganello, 2008 <sup>a</sup>	A HL framework where individual traits, family and peer influences, and educational and health care system were assumed to influence HL (functional, interactive, critical, media). HL was directly related to health outcomes.	Knowledge was not mentioned directly in the model.
11	Freedman et al. 2009 <sup>a</sup>	Public HL model explicitly takes an individual and a public perspective on HL. HL means obtaining, processing and understanding health information by individuals and by groups.	D: Public HL consists of various types of knowledge and skills. The conceptual foundations dimension includes the basic knowledge and information needed to understand and take action on public health concerns.
12	von Wagner, Steptoe, Wolf, Wardle, 2009 <sup>a</sup>	A framework of HL and health action that uses established constructs from social cognition models of health to integrate HL into a wider framework of health actions.	A: Knowledge as one of different cognition-related individual influences on HL.  C: Knowledge and understanding within the motivational phase of social-cognitive predictors of health-related actions.  (continued)

actions were consequences of improved functional HL. Next to others, improved capacity to act independently on knowledge was a consequence of improved interactive HL.

Baker (2006) assumed prior knowledge (vocabulary and conception of health and health-care) to be influential on functional HL, which creates new knowledge, positive attitudes, greater self-efficacy, and behaviour change. Von Wagner et al. (2009) – similarly to von Wagner et al. – conceptualised health knowledge as an antecedence of functional HL, which again is an antecedent of subsequent knowledge and understanding as a part of the motivational phase of their model. Thereby, knowledge and understanding create beliefs and attitudes, which further – beside system factors and volition –

influence health-related actions. Both theories describe a circular function of health knowledge in relation to HL and beliefs.

## Knowledge and beliefs about consequences

According to von Wagner (2009), knowledge will create beliefs about consequences of acting on certain health information, which in turn will form an intention to act on that health information. Baker (2006) and Nutbeam (2008) mention knowledge and attitudes next to each other without making the type of interrelation explicit, e.g. whether they influence each other directly, whether they work in parallel, or

Table 1 (continued)
Health knowledge within health literacy theories

Reference	Brief Description of Theoretical Concept of HL	Role of Health Knowledge				
Articles with specific the et al., 2012):	Articles with specific theories on HL and health knowledge (not listed in Sørensen et al., 2012/ added from Frisch et al., 2012):					
13 Schulz & Yamamoto, 2005	Functional HL was conceptualised as a basis for developing increasingly complex types of health knowledge that are declarative knowledge (understanding), procedural knowledge (implications and decisions), coherent knowledge (based on theory), and expert knowledge (by health care professionals).	(procedural knowledge), and critical (coherent knowledge or judgement skills) HL.				
14 Chin et al., 2011	Process-knowledge model of HL. Processing capacity, general verbal knowledge, and specific health knowledge influence functional HL, which in turn influences self care. Education and illness experience influence general verbal knowledge and specific health knowledge.	(A): Two facets of knowledge are general verbal knowledge and specific health knowledge, which influence functional HL.				

Note. Role of knowledge, summarized from Sørensen (2012) and from the original articles cited in Sørensen (2012). HL = Health literacy, A = Antecedence of HL, D = Dimension of the HL concept, C = Consequence of HL. (D) = Letters in brackets were not counted as antecedence, dimension or consequence in the respective chapter. <sup>a</sup> For full references, see Sørensen et al., 2012.

whether they interact in a certain way. Although not mentioned explicitly an assumed sequence from knowledge to attitudes might be most likely in their models.

In some cases, knowledge may work in parallel next to beliefs about consequences. Certain knowledge domains, e.g. correct identification of disease symptoms or knowing the number of the emergency medical service correctly, might be related to behaviour not via beliefs about consequences or attitudes but more directly (Dombrowski et al., 2015). In contrast, general health knowledge such as knowledge on the link between regular physical exercise and improved health outcomes might work indirectly by formation of beliefs about consequences of exercising regularly which in turn creates behavioural intentions.

#### Measures of health knowledge

Perceived knowledge is the belief about capacities to have acquired, to get access to, to understand or to apply health information. Actual knowledge is the capability to recognise or recall correct health information. While the first one is merely a belief about one's own capability, the second is a capability itself. Perceived and actual knowledge are interrelated concepts, but it is important to distinguish them on a conceptual level as well as in terms of measurement. Measures of actual knowledge test the knowledge based on false and correct answers. They are context- and disease-specific and therefore hard to compare across studies and diseases. Although there are few measures of disease-specific health knowledge tests available (Schulz & Nakamoto, 2005), there is a clear lack of studies examining the relation of actual health knowledge, comprehensive HL, and social cognitions. Measures of perceived knowledge refer to the self-reported perceived capability to understand or act on health information (e.g. HLS-EU-questionnaire). They are easier to administer and more context- and disease-general. Perceived health knowledge measures a person's beliefs about to act on knowledge and not knowledge itself. Therefore, it might be worth measuring both perceived and actual knowledge as they refer to different entities and might predict health and health-care independently of each other.

The attempt of the present article to disentangle health beliefs and health knowledge, as well as different measures of health knowledge, aimed at contributing to the clarification of the conceptual overlap between health knowledge and HL.

Outlook and implications

The provision of health information to increase health is an integral part and often the very starting point of most interventions followed by fostering motivation, self-regulation, and skills, which are critical components to promote health behaviour change. Nevertheless, the provision of information as part of intervention packages should be guided by health knowledge theories and should be tailored to a patient's needs accordingly. Provision may be considered an interactive act, including an active recipient. Both sides - the individual and the individual's environment – but also the features and skills of health-care professionals and the health-care system in providing health literate information should be taken into account. In this context, it may be assumed that particularly health literate systems and care providers reduce pressure on the individual health-care seekers to increase health-related knowledge for improved health outcomes, and vice versa.

#### Conclusion

The aim of the present paper was to shed light

on the interrelation of HL and health knowledge. Summarising the views of the role of health knowledge from systematic reviews of HL theories, most of the theories include health knowledge and HL as related concepts. Theories that conceptualise HL in a narrow way, i.e. functional HL, mostly refer to health knowledge as a consequence of HL. This is in line with systematic reviews focusing on the effects of low levels of functional HL which has been linked to low health knowledge. Theories of HL that follow a broader, more comprehensive approach of HL conceptualize health knowledge mostly as a dimension of HL although there is more variability between theories in their use of health knowledge. For instance, the integrated model of Sørensen et al. (2012) states knowledge, motivation, and competencies components of comprehensive HL. Process models of HL mainly refer to health knowledge as antecedence as well as consequence of (functional) HL. Nutbeam (2008), Baker et al. (2006) and von Wagner et al. (2009) for instance establish a causal chain from prior knowledge via HL and via acquired knowledge to beliefs and attitudes. To conclude, health knowledge plays an important role within theories of HL, though its exact position varies across models and definitions. This largely reflects the inconsistency between different theories and definitions of HL. Clarifying the role of health knowledge might be a step to structuring the diversity of HL theories and help us to better understand HL in order to improve HL and health outcomes.

#### References

Baker, D. W. (2006). The meaning and the measure of health literacy. Journal of General Internal Medicine, 21(8), 878-883.

- doi:10.1111/j.1525-1497.2006.00540.x Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health
  - literacy and health outcomes: An updated systematic review. Annals of Internal Medicine, 155(2), 97-107. doi:10.7326/0003-4819-155-2-201107190-00005
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . . Viswanathan, M. (2011). Health literacy interventions and outcomes: An updated systematic review. Evidence Report/Technology Assessment, 199, 1-941.
- Chin, J., Morrow, D. G., Stine-Morrow, E. A., Conner-Garcia, T., Graumlich, J. F., & Murray, M. D. (2011). The process-knowledge model of health literacy: Evidence from a componential analysis of two commonly used measures. Journal of Health Communication, 16(Suppl 3), 222-241. doi:10.1080/10810730.2011.604702
- Ciampa, P. J., Vaz, L. M., Blevins, M., Sidat, M., Rothman, R. L., Vermund, S. H., & Vergara, A. E. (2012). The association among literacy, numeracy, HIV knowledge and health-seeking behavior: A population-based survey of women in rural Mozambique. PLoS One, 7(6), e39391. doi:10.1371/journal.pone.0039391
- Devraj, R., Herndon, C. M., & Griffin, J. (2013). Pain awareness and medication knowledge: A health literacy evaluation. Journal of Pain & Palliative Care Pharmacotherapy, 27(1), 19-27. doi:10.3109/15360288.2012.751955
- Dombrowski, S. U., Ford, G. A., Morgenstern, L. B., White, M., Sniehotta, F. F., Mackintosh, J. E., . . . Skolarus, L. E. (2015). Are there differences between US and UK adults in stroke preparedness? Evidence from parallel population-based community surveys. Stroke, 46, 3220-3225.

doi:10.1161/STROKEAHA.115.009997

Freedman, D. A., Bess, K. D., Tucker, H. A., Boyd, D. L., Tuchman, A. M., & Wallston, K. A. (2009). Public health literacy defined. American Journal of Preventive Medicine, 36(5),

446-451. doi:10.1016/j.amepre.2009.02.001
Frisch, A. L., Camerini, L., Diviani, N., & Schulz, P. J. (2012). Defining and measuring health literacy: How can we profit from other literacy domains? Health Promotion International, 27(1), 117-126. doi:10.1093/heapro/dar043

Hom, J. M., Lee, J. Y., Divaris, K., Baker, A. D., & Vann, W. F. (2012). Oral health literacy and knowledge among patients who are pregnant for the first time. The Journal of the American Dental Association, 143(9), 972-980. doi:10.14219/jada.archive.2012.0322

Martensson, L., & Hensing, G. (2012). Health literacy - a heterogeneous phenomenon: A literature review. Scandinavian Journal of Caring Sciences, 26(1), 151-160. doi:10.1111/j.1471-6712.2011.00900.x

Nutbeam, D. (2008). The evolving concept of health literacy. Social Science & Medicine, 67(12), 2072-2078.

doi:10.1016/j.socscimed.2008.09.050

Schulz, P. J., & Nakamoto, K. (2005). Emerging themes in health literacy. Studies in Communication Sciences, 5(2), 1-10.

Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., . . . European, C. H. L. P. (2012). Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health, 12(1), 80. doi:10.1186/1471-2458-12-80

Speros, C. (2005). Health literacy: Concept analysis. Journal of Advanced Nursing, 50(6), 633-640. doi:10.1111/j.1365-2648.2005.03448.x

von Wagner, C., Steptoe, A., Wolf, M. S., & Wardle, J. (2009). Health literacy and health actions: A review and a framework from Health Psychology. Health Education & Behavior, 36(5), 860-877. doi:10.1177/1090198108322819

WHO (1998). Health Promotion Glossary. Geneva: WHO.

Williams, M. V., Baker, D. W., Ruth, M. P., & Nurss, J. (1998). Relationship of functional health literacy to patients' knowledge of their

chronic disease. Archives of Internal Medicine, 158(2), 166-172. doi:10.1001/archinte.158.2.166



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original article

# The dimensionality of health literacy and eHealth literacy

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Health literacy is both a personal asset and a risk factor (Nutbeam, 2008). It is defined by the World Health Organization (WHO, 1998) as "the cognitive and social

skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (WHO, 1998). Nutbeam (2000) further elaborated and suggested the construct included functional (i.e., basic reading, writing, numeracy skills), interactive and critical skills. Health literacy was found to be a major predictor of adverse health outcomes (e.g., Baker et al., 2007; Dewalt et al. 2007; Schillinger et al. 2002; Yin et al. 2007), with outcomes ranging from difficulty following medication instructions, to applying for benefits and to all-cause mortality.

The Internet-era equivalent to health literacy is eHealth literacy, which includes basic literacy as well as information, media, health, computer and scientific literacies (the Lily model, Norman & Skinner, 2006). eHealth literacy was also found to be associated with more effective contact with the attending physician, enhanced use of medical insurance, self-management of health needs and higher perceived understanding of a disease/condition (Neter & Brainin, 2012).

## Assessment of Health literacy and eHealth literacy

Health literacy is measured both through performance and self-report. Screening tools for clinical settings such as Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) (Parker, Baker, Williams, & Nurss, 1995), Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and Newest Vital Sign (NVS) (Weiss et al., 2005) measure performance, focusing on domains that are thought to be markers of an individual's overall capacity (Baker, 2006). Comprehensive measures such as the Health Activity Literacy Scale (HALS) (Rudd, Kirsch, & Yamamoto, 2004) that include tasks in various health domains (health promotion, protection, maintenance, disease prevention, system navigation) also exist, yet a recent review on the use of health literacy measures (Mackert, Champlin, Holton, Munoz, & Damasio, 2014) found low use of these measures and called for the development of measures that can be administered remotely online. Such self-report measure that relates both to the above health domains and also to the cognitive skills involved - seeking, understanding (basic literacy and numeracy), evaluating and applying health information – was recently developed and tested in several European countries (Sorensen et al., 2012; European Health literacy Scale (HLS-EU) project).

eHealth literacy is assessed most often by the self-report measure eHEALS (Norman & Skinner, 2006). The measure focuses on finding information on the Internet and assessing it.

Norman and Skinner (2006) found that the measure consists of one factor in an exploratory factor analysis, but recent work (Soellner, Huber, & Reder, 2015) uncovered 2 factors: seeking and appraising.

#### Present work

The present report examined the dimensionality of the HLS-EU and eHEALS, from the perspective of the cognitive skills required in health literacy and eHealth literacy (rather than health domains). The hypotheses were that the HLS-EU had a structure of 3 factors: seeking, understanding and evaluating/applying; that the eHEALS had a 2-factor structure of seeking and appraising, and lastly that these concepts are distinct and are moderately correlated.

#### Methods

#### Data collection and sample characteristics

Data analyzed in this report was collected from a nationally representative random-digital-dial (RDD) telephone household survey of Israeli adult population (21 and older) conducted in November 2014 (landlines and mobile combined).

The sampling procedure through which the RDD worked (landlines only) began by dividing statistical areas into four layers according to: (a) population groups, geographical districts, different sizes of settlements (big cities to small towns and villages), and social economic status index based on the Israeli Central Bureau of Statistics classification. Sampling employed a dual-frame design, incorporating two selection stages without stratification in either frame. The larger frame was designed to provide national coverage of the eligible population. Calls were

placed to 1789 residential households to identify 1628 eligible potential respondents, of whom 819 agreed to be interviewed, representing 50.3% response rate. The interviewers conducted the telephone survey using CATI (Computer Assisted Telephone Interviewing) software.

Measurements (only some of the survey is described below)

Health Literacy (perceived) was assessed by the European Health literacy Scale (HLS-EU) (Sorensen et al., 2012, 2013). The 15-item short version of the scale was used. The scale was translated and validated by Levin-Zamir and Baron-Epel (2013), using a 16-item questionnaire, and 1 item was deleted in the pilot stage of the present administration due to comprehension problems of respondents.

eHealth Literacy was assessed by the eHEALS tool (Norman & Skinner, 2006). The scale comprises of eight items on a 5-point Likert scale (1 = strongly disagree, to 5 = strongly agree). The scale was previously translated to Hebrew (Neter & Brainin, 2012).

Socio-demographic information on age, gender, education, ethnicity, country of birth, self-rated health and the existence of chronic conditions was obtained as part of the background variables.

#### Data analysis

Confirmatory factor analysis was carried out with SAS v. 9.4 and MPLUS v 7.31 (Muthén & Muthén, 2010). Quality of model adjustments were made through the following fit indices: Comparative Fit Index (CFI) and Tucker-Lewis Index (TLI), with reference values of adjustment above 0.90; Parsimony CFI with acceptable values above 0.06; Root Mean square Error of Approximation (RMSEA) below 0.05, and Akaike Information Criterion (AIC). The reference values

are accordingly to those suggested by Kline (2011). Items' individual reliability was assessed through squared multiple correlation (R2>0.20).

In order to assess the dimensionality of the constructs, Confirmatory Factor Analysis (CFA) was computed for 2 different models in each of the constructs. The first model for the two constructs included only one factor. The second model of health literacy included 3 latent variables (seeking, understanding, and appraising/applying) and that of eHealth literacy included 2 latent variables (seeking and appraising).

#### Results

Preliminary analysis on the scales' reliability

showed that the internal consistency of the total scales was 0.86 and 0.89 for health literacy and eHealth literacy, respectively.

Model comparisons indicated that the initial one-factor model had a poor fit for both scales:  $(\mathbf{x}^2 (909) = 914.395, p=0.000; CFI = 0.659; RMSEA = 0.106, P(rmsea 0.05) = 0.000; AIC = 23570.648) for health literacy and <math>(\mathbf{x}^2 (20) = 145.550, p=0.000; CFI = 0.873; RMSEA = 0.126, P(rmsea 0.05) = 0.000; AIC = 7953.155) for eHealth literacy.$ 

The 3-factor model for health literacy presented good fit indices:  $\chi^2$  (87) = 213.502, p = 0.000; CFI = 0.948; RMSEA = 0.042, P(rmsea 0.05) = 0.000; AIC = 22630.309. The items of the health literacy scale, along with standardized factor loading, are presented in table 1. One item had low loading (on factor 1) and R<sup>2</sup> and was later

Table 1 Standardized Factor loadings in Confirmatory Factor Analysis (CFA) and  $R_2$  of Health literacy items (n = 816)

Item	Factor 1	Factor 2	Factor 3	$\mathbb{R}^2$
Find information on treatments of illnesses that concern you	0.681			0.464
Find information on how to manage mental health problems like stress or depression	0.689			0.474
Find out about activities that are good for your mental well-being (meditation, exercise, walking, Pilates etc.)	0.725			0.526
Find out where to get professional help when you are ill *	0.362			0.131
Understand your doctor's or pharmacist's instruction on how to take a prescribed medicine		0.819		0.671
Understand what your doctor says to you		0.859		0.737
Understand information in the media on how to get healthier		0.723		0.523
Follow instructions from your doctor or pharmacist?			0.582	0.399
Use information the doctor gives you to make decisions about your illness			0.609	0.371
Judge when you may need to get a second opinion from another doctor		0.558		0.311
Understand health warnings about behavior such as smoking			0.672	0.452
Understand why you need health screenings			0.672	0.451
Judge which everyday behavior is related to your health (drinking and eating habits, exercise etc.)			0.758	0.575
Decide how you can protect yourself from illness based on information in the media			0.598	0.358
Understand advice on health from family members or friends			0.618	0.382

*Note*. \*item removed from further analyses

removed from further analyses. When the model for health literacy was collapsed into 2 factors (combining two factors), the fit indices were poor:  $\chi^2$  (89) = 377.125, p = 0.000; CFI = 0.063; RMSEA = 0.106, P(rmsea 0.05) = 0.001; AIC =22850.693), as well as when the model was collapsed into one factor:  $(\chi^2 (90) = 914.352, p =$ 0.000; CFI = 0.659; RMSEA = 0.106, Prmsea 0.05) = 0.000; AIC = 23570.648). Reliabilities were calculated for each factor in the final 3-factor model: seeking,  $\alpha = 0.72$ , understanding,  $\alpha = 0.85$ , and appraising/applying,  $\alpha = 0.83$ . Correlations between seeking and understanding was 0.38, between understanding and appraising/applying was 0.41, and between seeking appraising/applying 0.56 Finally, the  $R^2$  of individual items ranged from 0.382 to 0.478.

The 2-factor structure for eHealth literacy, as found by Soellner et al. (2015), was tested on the sample and yielded a poor fit:  $\chi^2$  (19) = 135.164, p = 0.000; CFI = 0.882; RMSEA = 0.124, P(rmsear0.05) = 0.000; AIC = 7939.799. We therefore conducted an exploratory factor analysis (common factor analysis) on the eHEALS on half the sample (n = 199) with promax rotation. The analysis yielded a two-factor solution with 1.06% explained variance of prior communality estimates (e.g., estimates of the variance of the factor), all items revealing communalities of .49 and above, and

factor loadings higher than .48. The results of this analysis are displayed in Table 2. A reliability test on the two factors showed high internal consistency (Cronbach's  $\alpha$  = 0.83 and  $\alpha$  = 0.83) with a correlation of 0.67 between the two factors. The scale's descriptive statistics showed that it was normally distributed (Mean = 3.41; Median = 3.50; SD = .80; Skewness = -.29; Kurtosis = 0.33).

The dimensions uncovered in the above analysis on eHEALS were tested in a CFA using the second half of the sample and yielded good fit indices:  $\mathbf{x}^2$  (19) = 33.158, p = 0.000; CFI = 0. 974; RMSEA = 0.061, P(rmsea 0.05) = 0.000; AIC = 3910.724. Finally, the R<sup>2</sup> of individual items ranged from 0.406 to 0.506. Collapsing the model into one factor yielded poor fit:  $\mathbf{x}^2$  (20) = 83.212, p = 0.000; CFI = 0.882; RMSEA = 0.126, P(rmsea 0.05) = 0.000; AIC = 3973.064.

In summary, the health literacy scale yielded 3 dimensions of seeking, understanding and appraising/applying; the eHealth literacy scale yielded 2 dimensions of seeking and appraising. The correlation between health literacy and eHealth literacy is moderate (r = .36, p < .05).

Discussion

Table 2 Standardized Factor loading and R2 of eHEALS items in confirmatory factor analysis (n=199)

Item	Factor 1	Factor 2	$\mathbb{R}^2$
I know how to find helpful health resources on the Internet	0.907		0.566
I know where to find helpful health resources on the Internet	0.901		0.812
I know how to use the Internet to answer my questions about health	0.753		0.822
I can tell high quality health resources from low quality		0.714	0.557
I feel confident in using information from the Internet to make health decisions		0.642	0.441
I know how to use the Internet to answer my questions about health		0.747	0.509
I have the skills I need to evaluate the health resources I find on the Internet		0.664	0.412
I know what health resources are available on the Internet		0.637	0.406

The study uncovered that both health literacy and eHeath literacy are multi-dimensional constructs rather than one dimensional and that they are moderately related.

The structure uncovered concurs with the literature, though it is not identical with previous findings. Though the theoretical underpinning of health literacy upholds four skills - seeking, understanding, evaluating and applying (Sorensen et al., 2012) – the latter two higher cognitive abilities (evaluating and applying) seem difficult to distinguish, at least in terms of the items, and they indeed hang together in the present analysis.

eHealth literacy was found to be made of 2 factors, similar to recent findings by Soellner, Huber, and Reder, (2015), albeit the two factors were found to harbor slightly different items.

The results of the study indicate that an overall index of health literacy and eHealth literacy should be computed as a mean of their underlying factors and not as a simple mean, as often practiced. The different dimensions should also be looked at separately in order to enrich our understanding of patients' difficulties and challenges in making sense of their health.

#### References

- Baker, D. W. (2006). The meaning and the measure of health literacy. Journal of General Internal Medicine, 21(8), 878-883. doi:10.1111/j.1525-1497.2006.00540.x
- Baker, D. W., Wolf, M. S., Feinglass, J., Thompson, J. A., Gazmararian, J. A., Huang, J. (2007). Health literacy and mortality among elderly persons. Archives of Internal Medicine, 167(14), 1503-1509. doi:10.1001/archinte.167.14.1503
- Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W., & Crouch, M. A. (1993). Rapid estimate of adult literacy in

- medicine: A shortened screening instrument. Family Medicine, 25(6), 391–395.
- DeWalt, D. A., Dilling, M. H., Rosenthal, M. S., Pignone, M. P. (2007). Low parental literacy is associated with worse asthma care measures in children. Ambulatory Pediatrics, 7(1), 25–31. doi:10.1016/j.ambp.2006.10.001
- Falsh Eurobarometer (2014). European citizens' digital health literacy. A report to the European Commission. doi:10.2759/86596
- Kline, R. B. (2011). Principles and Practice of Structural Equation Modelling (3rd ed.). New York, NY: Guilford.
- Mackert, M., Champlin, S. E., Holton, A., Munoz, I. I., & Damasio, M. J. (2014). eHealth and health literacy: A research methodology review. Journal of Computer-Mediated Communication, 19(3), 516-528. doi:10.1111/jcc4.12044
- Muthén, L. K., & Muthén, B. O. (2010). Mplus User's Guide: Statistical Analysis with Latent Variables: User's Guide. Los Angeles, CA: Muthén & Muthén.
- Neter, E., & Brainin, E. (2012). eHealth literacy: Extending of the digital divide to the realm of health information. Journal of Medical Internet Research, 14(1), e19. doi:10.2196/jmir.1619.
- Norman, C. D., & Skinner, H. A. (2006). eHEALTH: The eHealth literacy scale. Journal of Medical Internet Research, 8(4), e27. doi:10.2196/jmir.8.4.e27
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. Health Promotion International, 15(3), 259-267. doi:10.1093/heapro/15.3.259
- Nutbeam, D. (2008). The evolving concept of health literacy. Social Science & Medicine, 67(12), 2072-2078.
  - doi:10.1016/j.socscimed.2008.09.050
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for

- measuring patients' literacy skills. Journal of General Internal Medicine, 10(10), 537–541. doi:10.1007/BF0264036
- Rudd, R., Kirsch, I., & Yamamoto, K. (2004). Literacy and health in America. Policy information report. Educational Testing Service. Retrieved from:
  - http://www.ets.org/Media/Research/pdf/PICH EATH.pdf
- Soellner, R., Huber, S., & Reder, M. (2015). The concept of eHealth literacy and its measurement. Journal of Media Psychology, 26, 29-38. doi:10.1027/1864-1105/a000104
- Schillinger, D., Grumbach, K., Piette, J., Wang, J., Osmond, D., Daher, C., ... Bindman, A. B. (2002) Association of health literacy with diabetes outcomes. Journal of the American Medical Association, 288(4), 475-482. doi:10.1001/jama.288.4.47
- Sørensen, K., Broucke, S. V. D., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., ...(HLS-EU)
  Consortium Health Literacy Project European (2012). Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health, 12(1), 80. doi:10.1186/1471-2458-12-80
- Sørensen, K., Van den Broucke, S., Pelikan, J. M., Fullam, J., Doyle, G., Slonska, Z., ... & Brand, H. (2013). Measuring health literacy in populations: Illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). BMC public health, 13, 948. doi:10.1186/1471-2458-13-948
- Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., . . . Hale, F. A. (2005). Quick assessment of literacy in primary care: The newest vital sign. Annals of Family Medicine, 3(6), 514–522. doi:10.1370/afm.405
- Yin, H. S., Dreyer, B. P., Foltin, G., van Schaick, L., & Mendelsohn, A. L. (2007) Association of low caregiver health literacy with reported use of nonstandardized dosing instruments and

- lack of knowledge of weight-based dosing. Ambulatory Pediatrics, 7(4), 292–298. doi:10.1016/j.ambp.2007.04.004
- Zamir D., Baron-Epel, O., & Elhayani, A. (2013). A report to the Israel National Institute of Health Policy Research.



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#### original article

# Advancing health literacy from a system perspective: Health literacy training for healthcare professionals

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Harvard T.H. Chan School of Public Health Health literacy (HL) refers to the ability to acquire, assimilate, and apply health-related information in ways that are appropriate for one's health (Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013). The increasing interest in and prominence of HL research are reflected by the growth

in published peer reviewed articles, from under 300 peer reviewed publications in the 1990s to several thousand by 2015 (Nutbeam, 2015; Rudd, Anderson, Oppenheimer, & Nath, 2007; Rudd, Anderson, Oppenheimer, Rosenfeld, & Mandic, 2007). In the early stages of HL studies, researchers focused most of their attention on the literacy skills and deficits of individuals and the association between measured skills and a variety of health outcomes. As a result, numerous tools have been developed and validated to assess patients' HL levels (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014), forming the basis of research aimed to explore the links between literacy skills and health outcomes. We now have strong evidence of the associations between low levels of HL and a myriad of negative health outcomes, including increased use of emergency care, lower use of preventive health services, poorer treatment adherence, likelihood of tobacco use, lessened ability to manage disease. and higher rates hospitalization, depression, and mortality (Berkman, Sheridan, Donahue, Halpern, & Crotty,

2011: DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004).

However, HL research needs to continue to build on the knowledge we have accumulated in order to bring about efficacious change. Despite the evidence provided by over 1,500 articles (in English) establishing a mismatch between skills of the public and complexity of health information being provided (Rudd, 2014; Rowlands et al., 2015), calls for examining the communication skills of health professionals and the literacy related barriers in healthcare are only now starting to be heeded (Koh & Rudd, 2015). Advancing HL from an individual focus to a system perspective is challenging, in part, because the majority of research has disproportionately focused on the patient, such as measurement of patient HL levels without the concordant measurement of clinical communication or complexity of materials and tools. The key to advancing HL research is to expand the scope of inquiry and action to include the communication abilities of all health professionals and staff who interact with the patients, individuals, and communities to ensure the appropriateness and accessibility of healthrelated information, and collectively build a care environment and culture that effectively integrates HL in its activities (Rudd, 2015).

In this paper, we briefly review several articles that can shed insight on needed action along with a brief description of a HL training program conducted in Japan. Specifically, we highlight an adaptation of the "Eliminating Barriers-Increasing Access Workshop" developed in the US and modified for a series of HL training for

healthcare professionals (HCPs) following the Fukushima triple disaster (earthquake-tsunaminuclear accident). We hope to prompt behavioral scientists to extend their HL research from a patient-focused perspective to one that also encompasses the interactions between patients and providers, between patients and healthcare systems, and between providers and healthcare organizations and care systems. In doing so, we highlight the need for an expanded notion of health literacy — one that takes into account health interactions and health contexts.

## Health literacy training for healthcare professionals

The importance of HL in the training of those who communicate with patients and with the public has been recognized globally. In 2003, Schillinger et al. focused on clinicians and found that they rarely assessed patient recall and the comprehension of new concepts in diabetes patients. The authors called for greater attention to the patient-physician exchange during clinical encounters (Schillinger et al., 2003). After a series of studies examining the efficacy of "Teach Back", this exercise to check for clarity was instituted in several medical schools. One article, for example described how this approach was integrated into the curricula of the University of Chicago and Northwestern University Medical Schools and taught as a means for appropriately closing the encounter (Harper, Cook, & Makoul, 2007).

In a 2007 white paper, the Joint Commission articulated the link between patient safety and HL. The Joint Commission noted that healthcare practitioners have the responsibility to understand the beliefs, values and cultures that are influencing the ways health-related information are being shared and received by

patients. Furthermore, thev noted that healthcare organizations have the responsibility to make sure that patients understand (Joint Commission, 2007). Attending to this call for institutional action, a region-wide effort in Italy's Emilia Romagna Region was implemented to raise HL awareness amongst oncologists, nurses, and hospital communicators in ten regional hospitals, helping them be attentive to their language and explanations (Gazotti, 2013). An example of national level change can be seen in New Zealand where the Ministry of Health issued a Framework for Health Literacy, calling for a system-wide approach to narrow the gap between the population's HL skills and complex demands of health institutions so as to create a health-literate system (New Zealand Ministry of Health, 2015). This Framework also clearly demarcated the actions needed at each specific level of the individual, health workforce, health organization, and system.

Following the complex series of disasters in Fukushima City, Japan in 2011, we conducted a study that revealed the community's needs to understand risk information and shaped HL training for public health nurses (PHNs) to help meet these informational needs (Goto, Rudd, Lai, Yoshida, et al., 2014). The challenges that mothers faced in interpreting radiation-related risks were leading to family migration from Fukushima City, family discord due to differing perceptions of risk, and concerns for the safety of their children (Goto, Rudd, Lai, Yoshida, et al., 2014; Morioka, 2014). Residents in Fukushima experienced anger, distrust and fear, in part due to the lack of robust communication plans and materials following the disaster (Slovic, 2012). Certainly, risk is a complex numerical concept and the task of risk assessment constitutes a high-level cognitive task. It is understandable that the lay public faces difficulty (Apter et al., 2008). In addition, the specific risk of radiation also evokes a strong reaction in people as a risk

factor that is even more than handguns and mountain climbing (Fischhoff et al., as cited in Slovic, 2012). The conduct of HL training for PHNs was thus devised as a HL as well as psychoeducational intervention to better equip HCPs with communication skills for improved informational access in the community.

The HL Training Workshop in Fukushima was conducted as a 2-session pilot program that introduced HL concepts, research findings, and assessment tools. It focused on building skills to improve communication practices and norms among PHNs. This, in turn, would increase community residents' access to information. The content of the workshop, adaptations, and program evaluations are described in detail elsewhere (Goto, Rudd, Lai, & Yoshida-Komiya, 2014). During a one-month follow-up, workshop participants reported applying their newly acquired skills in HL to develop written materials that were more accessible to the community. On the other hand, PHNs reported that they faced difficulties as they tried to change work norms toward one that is more HL-centric. They noted difficulties in sharing their new HL skills with colleagues who were unfamiliar with the concept of HL. As a follow-up to this study, a multi-site project delivering the identical HL training in various regions within Fukushima Prefecture has been implemented and evaluated (Goto, Lai, & Rudd, 2015).

#### Future work

Certainly, expanded efforts are needed to increase the skills of those who communicate with the public – including a wide range of HCPs. In addition, focused efforts are needed to impact the norms and practices of healthcare organizations. The Institute of Medicine has advocated for the need of health-literate healthcare organizations and describes the

permeation of HL in all operations of health services providers (Brach et al., 2012). While our HL Training Workshop has allowed PHNs to apply the principles of HL so as to develop plain language materials that were more accessible to community residents, more active work represents a substantial leap to achieving a state of health-literate organizations. Part of our future work therefore aims to raise the awareness of HL as an important entity that exists across the spectrum of the community, patients, clinicians and institutions. This directly corresponds to the results from our program evaluation - HCPs faced difficulties in changing their work norms to be more HL-centric, suggesting that educating on HCPs on HL alone is insufficient to effect changes at the institutional level. Future HCP training interventions in HL perhaps integrate principles can frameworks that are concerned with embedding and sustaining practices within organizations (May & Finch, 2009). Such frameworks shed insight into the implementation and uptake of health intervention programs, and will prove valuable in our pursuit to advance HL to the institutional and systems level.

#### Conclusion

Research in HL has witnessed considerable progress over the past 25 years. However, researchers will need to move beyond the patient level to examine the communication skills of HCPs, the barriers and facilitating factors in organizations, and then test out approaches that facilitate the creation of health-literate healthcare organizations. Our work in Fukushima used HL training for HCPs as a mechanism to improve the acquisition, assimilation and application of health-related information for the community to make better decisions in the context of radiation-risks. This is, however, only

one of the ways to advance HL from a focus on individuals to a healthcare system perspective. HL transcends a myopic patient-level construct, and it is only when researchers and practitioners adopt different lenses for HL studies and/or interventions to include the community, clinicians and institutions, that we can then advance the scientific study of HL.

#### References

- Apter, A. J., Paasche-Orlow, M. K., Remillard, J. T., Bennett, I. M., Ben-Joseph, E. P., Batista, R. M., ...Rudd, R. E. (2008). Numeracy and communication with patients: They are counting on us. Journal of General Internal Medicine, 23(12), 2117–2124. doi:10.1007/s11606-008-0803-x
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. Annals of Internal Medicine, 155(2), 97–107. doi:10.7326/0003-4819-155-2-201107190-00005
- Brach, C., Keller, D., Hernandez, L. M., Baur, C., Parker, R., Dreyer, B., ... Schillinger, D. (2012). Ten attributes of health literate health care organizations (IOM Roundtable on Health Literacy). Institute of Medicine. Retrieved from http://www.ahealthyunderstanding.org/Portal s/O/Documents1/IOM\_Ten\_Attributes\_HL\_Paper.pdf
- DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and Health Outcomes. Journal of General Internal Medicine, 19(12), 1228–1239. doi:10.1111/j.1525-1497.2004.40153.x
- Gazotti, F. (2013). Health Literacy in Italy's Emilia Romagna Region. In Health Literacy: Improving health, health systems, and health policy around the world: Workshop Summary (pp. xxx-xxx). Washington, DC: The National Academies

- Press.
- Goto, A., Rudd, R. E., Lai, A. Y., Yoshida, K., Suzuki, Y., Halstead, D. D., ...Reich, M. R. (2014). Leveraging public health nurses for disaster risk communication in Fukushima City: A qualitative analysis of nurses' written records of parenting counseling and peer discussions. BMC Health Services Research, 14, 129. doi:10.1186/1472-6963-14-129
- Goto, A., Rudd, R. E., Lai, A. Y., & Yoshida-Komiya, H. (2014). Health literacy training for public health nurses in Fukushima: A casestudy of program adaptation, implementation and evaluation. Japan Medical Association Journal, 57(3), 146–153.
- Goto, A., Lai, A. Y., & Rudd, R. E. (2015). Health literacy training for public health nurses in Fukushima: A multi-site program evaluation. Japan Medical Association Journal, 58(3), 1–9.
- Harper, W., Cook, S., & Makoul, G. (2007).

  Teaching medical students about health
  literacy: 2 Chicago initiatives. American Journal
  of Health Behavior, 31(Suppl 1), S111–S114.
  doi:10.5555/ajhb.2007.31.supp.S111
- Haun, J. N., Valerio, M. A., McCormack, L. A., Sørensen, K., & Paasche-Orlow, M. K. (2014). Health literacy measurement: An inventory and descriptive summary of 51 instruments. Journal of Health Communication, 19(Suppl 2), 302–333. doi:10.1080/10810730.2014.936571
- Joint Commission (2007). "What did the doctor say?" Improving health literacy to protect patient safety. Illinois: The Joint Commission.

  Retrieved from http://www.jointcommission.org/assets/1/18/improving\_health\_literacy.pdf
- Koh, H. K., & Rudd, R. E. (2015). The arc of health literacy. JAMA, 314(12), 1225–1226. doi:10.1001/jama.2015.9978
- Lai, A. Y., Ishikawa, H., Kiuchi, T., Mooppil, N., & Griva, K. (2013). Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. Patient

Education and Counseling, 91(2), 221–227. doi:10.1016/j.pec.2012.12.018

May, C., & Finch, T. (2009). Implementing, embedding, and integrating practices: An outline of Normalization Process Theory. Sociology, 43(3), 535–554. doi:10.1177/0038038509103208

Morioka, R. (2014). Gender difference in the health risk perception of radiation from Fukushima in Japan: The role of hegemonic masculinity. Social Science & Medicine, 107, 105–112. doi:10.1016/j.socscimed.2014.02.014

New Zealand Ministry of Health. (2015). A framework for health literacy. Retrieved from http://www.health.govt.nz/publication/frame work-health-literacy

Nutbeam, D. (2015). Defining, measuring and improving health literacy. Health Evaluation and Promotion, 42(4), 450–55. doi:10.7143/jhep.42.450

Rowlands, G., Protheroe, J., Winkley, J., Richardson, M., Seed, P. T., & Rudd, R. (2015). A mismatch between population health literacy and the complexity of health information: an observational study. The British Journal of General Practice, 65(635), e379–386. doi:10.3399/bjgp15X685285

Rudd, R. E. (2015). The evolving concept of health literacy: New directions for health literacy studies. Journal of Communication in Healthcare, 8(1), 7–9.

doi:10.1179/1753806815Z.000000000105

Rudd, R. E., Anderson, J., Oppenheimer, S., & Nath, C. (2007). Health literacy: An update of public health and medical literature. In J. Comings, B. Garner, & C. Smith (Eds.), Review of Adult Learning and Literacy (Vol. 7, pp. 175–204). Mahwah, N.J.: Lawrence Erlhaum Associates.

Rudd, R. E., Anderson, J., Oppenheimer, S., Rosenfeld, L., & Mandic, C. (2007). Health Literacy. In R. Wallace (Ed.), Maxey-Rosenau-Last Public Health and Preventive Medicine (15th ed., pp. 1035–1040). New York, N.Y.: McGrawHill Medical.

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C., ...Bindman, A. B. (2003). Closing the loop: Physician communication with diabetic patients who have low health literacy. Archives of Internal Medicine, 163(1), 83–90. doi:10.1001/archinte.163.1.83

Slovic, P. (2012). The perception gap: Radiation and risk. Bulletin of the Atomic Scientists, 68(3), 67-75. doi:10.1177/0096340212444870



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#### original article

# Revisiting the concept of health literacy. The patient as information seeker and provider

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In the light of increasing user-generated online health information, the changing role of the patient, and the shift toward patient-driven care, it is timely to revisit the concept of health literacy by

considering the twofold role of the patient as information seeker and provider. We claim that rather than limiting the patient's role to that of a passive information recipient, more attention should be devoted to the patient as an active information provider, particularly in the context of peer-to-peer communication. Consequently, individuals should not only be supported in developing their skills to search, evaluate, and apply health information, but also to share relevant health information.

#### The Patient as Information Seeker

Prior research in the field has conceptualized health literacy as a requirement to find, understand, evaluate, and apply health information to one's personal health situation (Altin, Finke, Kautz-Freimuth, & Stock, 2014). It has further been suggested that health literacy can be regarded as a measurable outcome describing a number of task and skill related capacities of an individual that are essential in different health contexts (Nutbeam, 2009). These capacities may be influenced by factors like health education (Nutbeam, 2000), aging, or

cognitive impairments (Baker, Gazmararian, Sudano, & Patterson, 2000).

Much research has focused on identifying the antecedents and consequences of health literacy, highlighting its crucial role in relation to individual health outcomes, access to and utilization of health care services, patientprovider relationships, and self-management (Sørensen et al., 2012). A number of different trait variables related to demographic, psychosocial, and cultural factors have been identified as antecedents of health literacy while authors have also recognized the role of individual characteristics and experiences (Sørensen et al., 2012). Interestingly, little attention has been paid to the impact of situational characteristics, or state variables, such as fatigue, fear, or physical discomfort. It is very challenging to communicate meaningfully to consumers of health care who are experiencing significant physical, cognitive, and psychological challenges due to their health conditions. We therefore believe that it is critically important to recognize such state variables that often limit consumer understanding when presenting complex health information to other consumers.

In order to assess health literacy, scholars have developed a variety of different measurement tools, such as the TOFLA, REALM, and HALS (Nutbeam, 2009). These tools, however, all focus on consumers' interpretation of health information rather than capturing their abilities to share health information. Indeed, our review of the literature suggests that, apart from a few noteworthy exemptions (Crook, Stephens, Pastorek, Mackert, & Donovan, 2016), current

efforts in the field of health literacy are predominantly focused on aspects related to individuals' capacities as information seekers or recipients, neglecting their role as information providers (Sørensen et al., 2012). When patients' communication skills were addressed, this was usually done in a formal context, such as patient-provider interactions, rather than looking at informal information exchange as found it in the peer-to-peer context (Crook et al., 2016).

We believe that this is a serious limitation to research in this area, especially given the growing demand for effective peer-to-peer sharing of relevant health information among consumers to promote health and well-being. The demand for sharing health information among consumers has increased with the growth in consumer participation in online health networks. It is important for participants in these online health networks to be able to share health information in ways that other consumers will be able to understand and use this information, emphasizing the importance of health literacy skills in providing health information to others.

This paper contributes to the health literacy debate by drawing attention to the role of the patient as information provider in the context of peer-to-peer health communication. Prior research on health literacy does not account for situational influences resulting from an individual's health or emotional state nor does it adequately address issues arising from the role of the patient as information provider. The objective of this paper is therefore to highlight the importance of conceptualizing and operationalizing health literacy in the context of peer-peer health communication while taking situational factors into account.

#### The Patient as Information Provider

The idea of the patient as an information

provider becomes particularly relevant in the context of online information and revolutionizing role of health information technologies (Kreps & Neuhauser, 2010). The ever increasing interactivity on the internet has supported the trend of user-generated content on an unprecedented scale and scope. In fact, everyone with internet access and the ability to navigate the online world can become a selfproclaimed expert. Plenty of health-related online communities exist where individuals openly share their experiences in a peer-to-peer format (Eijk et al., 2013). However, this information exchange does not come without risks. As pointed out by Chalmers (2001), "invalid health information is potentially lethal". This threat becomes more concrete when considering patients' suboptimal health literacy in terms of identifying and evaluating online health information (Morahan-Martin, 2004). Even the delivery of technically accurate information that does not make complete sense or is misinterpreted by consumers due to health literacy constraints is problematic. Therefore, it is important to help consumers who share health information develop strategic health literacy skills to enable them to share messages that other consumers are likely to understand and apply effectively.

The push toward patient-driven health care (Swan, 2009) and the rise of patient-helpers who share their knowledge and experiences online with other patients (Ferguson, 2000) further underline the importance for recognizing patients as providers of information. To illustrate this, take Karen as an example of a highly health literate patient who shares important health information with other health care consumers. After being diagnosed with lung cancer, she sought help and information from an online support community. Once recovered, she decided to start her own website to share her knowledge and information resources with peers. Her

website is widely acknowledged as one of the top consumer-initiated websites for lung cancer (Ferguson, 2000). On the one hand, Karen was able to find, understand, evaluate, and apply health information to her personal situation. On the other hand, Karen possessed the necessary skills to produce knowledge with the purpose of helping others.

Patients like Karen are invaluable resources for other patients and their families who find themselves in similar situations. Their personal experiences coping with serious health issues provide them with a special level of experiential credibility when sharing health information. They have the ability to connect with other health care consumers on a very personal and experiential level. Often they have unique insights into strategies for overcoming the challenges that other consumers face when seeking care and managing their health conditions.

#### Strategies of Empowerment

Given the increased amount and popularity of user-generated content online, there seem to be at least three strategies of reducing the risk of peer-to-peer health communication leading to misinformation and causing harm; 1) increasing availability and accessibility of high-quality health information so consumers have easy access to the best, most up-to-date, and complete health information, 2) improving patients' health information searching and processing skills, and 3) improving patients' health information sharing skills. In the light of current debates on the quality of online health information, much research has been conducted on patients' information seeking behavior (Morahan-Martin, 2004), but only very little is known about their ability to make sense of the information they gather and to effectively share relevant health information (Oh, 2012).

Patients can receive support in processing health information, particularly through educational efforts, but they often need more support to be able to make sense of the information they gather. Online forums, especially conversations with health care providers, educators, scientists, and other knowledgeable consumers can help improve their understanding of health information. Access to online health databases, health information portals, and reference works can further help to enhance access to and understanding of complex health information. In addition, consumers need to develop skills at evaluating the meanings, credibility, and applications of health information they gather, especially the information they find online. Once they find relevant health information, they also need to learn how to adequately share health information with others.

This suggests the need to develop strategic communication skills for designing health messages that match the communication competencies and orientations of the audiences that consumers share health information with. A key part of developing these competencies involves careful audience analysis so that messages can be adapted to meet the audience characteristics. In addition, it is important for communicators to become adept at seeking feedback from those they share health information with to determine how well they understand information provided.

We suggest that informed patients can take on a more active role in the health care process if they are well prepared to seek relevant health information, make sense of the information they find, and share that information effectively with others who may also need the information. Empowered by information technologies, patients can not only seek to exert control over their own health, but to also become health

advocates for others.

#### Conclusion

In the present paper we illustrate the power and potential of peer-to-peer health communication. We thereby draw attention to the role of the patient as active information provider and underline the importance of conceptualizing and operationalizing health literacy in the context of peer-to-peer health information sharing.

#### References

- Altin, S. V., Finke, I., Kautz-Freimuth, S., & Stock, S. (2014). The evolution of health literacy assessment tools: a systematic review. BMC Public Health, 14(1), 1207. doi:10.1186/1471-2458-14-1207
- Baker, D. W., Gazmararian, J. A., Sudano, J., & Patterson, M. (2000). The association between age and health literacy among elderly persons. The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 55(6), S368-S374. doi:10.1093/geronb/55.6.S368
- Chalmers, I. (2001). Invalid health information is potentially lethal. BMJ: British Medical Journal, 322(7292), 998.
- Crook, B., Stephens, K. K., Pastorek, A. E., Mackert, M., & Donovan, E. E. (2016). Sharing health information and influencing behavioral intentions: The role of health literacy, information overload, and the Internet in the diffusion of healthy heart information. Health Communication, 31(1), 60-71. Advance online publication. doi:10.1080/10410236.2014.936336
- Eijk, M. V. D., Faber, M. J., Aarts, J. W. M., Kremer, J. A. M., Munneke, M., Bloem, B. R., & Eysenbach, G. (2013). Using online health communities to deliver patient-centered care

- to people with chronic conditions. Journal of Medical Internet Research, 15(6), 1-1. doi:10.2196/jmir.2476
- Ferguson, T. (2000). Online patient-helpers and physicians working together: a new partnership for high quality health care. BMJ, 321(7269), 1129-1132. doi:10.1136/bmj.321.7269.1129
- Kreps, G. L., & Neuhauser, L. (2010). New directions in eHealth communication:
  Opportunities and challenges. Patient Education and Counseling, 78(3), 329-336.
  doi:10.1016/j.pec.2010.01.013
- Morahan-Martin, J. M. (2004). How internet users find, evaluate, and use online health information: A cross-cultural review. Cyber Psychology & Behavior, 7(5), 497-510. doi:10.1089/cpb.2004.7.497.
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. Health Promotion International, 15(3), 259-267. doi:10.1093/heapro/15.3.259
- Nutbeam, D. (2009). Defining and measuring health literacy: what can we learn from literacy studies? International Journal of Public Health, 54(5), 303-305. doi:10.1007/s00038-009-0050-x
- Oh, S. (2012). The characteristics and motivations of health answerers for sharing information, knowledge, and experiences in online environments. Journal of the American Society for Information Science and Technology, 63(3), 543-557. doi:10.1002/asi.21676
- Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health, 12(1), 80. doi:10.1186/1471-2458-12-80
- Swan, M. (2009). Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine

and quantified self-tracking. International Journal of Environmental Research and Public Health, 6(2), 492-525. doi:10.3390/ijerph6020492



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#### original article

# What has access and skills got to do with it? A qualitative study exploring health literacy among Indian IT employees

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Low health literacy is associated with worse health outcomes, poorer utilization of healthcare services, increased hospitalizations, and decreased adherence (e.g., Berkman et al., 2011; Kalichman et al., 1999). With 487 million workers and 121000 occupational deaths (CIA, 2012), it is surprising that only one study from has explored workers' health literacy. Haldiya et al. (2005)

examined knowledge and practices related to health issues among workers on salt manufacturing sites in Rajasthan. The authors found that despite having adequate awareness about the occupational health hazards, protective measures and the benefits of those measures, few workers used preventive techniques (e.g., wearing masks, goggles). Non-availability, nonaffordability, and physical discomfort were provided as reasons for not adhering to safety measures. This highlights a gap between health awareness, health information-processing and available opportunities to use this information. While this study addressed an important issue on health literacy in India, it focused only on healthprotective behaviours at the workplace. Further, it did not examine participants' sources of information and the experiential aspects of navigating the concepts of health literacy and related decision-making.

There is a significant increase in the number of people with chronic diseases in the IT industry in India (Jena, 2011) due to work-stress, engaging in unhealthy behaviours, and sedentary lifestyles. However, there is no research assessing health literacy among IT workers. Therefore, using qualitative methodology, the current study explores knowledge and sources of information about health, health behaviours, and chronic illnesses among Indian IT employees.

#### Method

#### **Participants**

Thirteen employees at an IT company in Hyderabad, India, were interviewed individually. None of them reported any diagnosed illness at the time of the study. Table 1 outlines participants' demographic and health behaviours information. The Institutional Ethics Committee at Medwin Hospital, Hyderabad, and the Chairman of the company gave ethical approval for the study.

#### Procedure

Participants were recruited using snowball sampling. The Department of Human Resources sent an email to all employees, detailing the study and requesting those interested to email the lead author (MC). Consenting participants were interviewed in a private room on the company premises. The semi-structured inter-

Table 1
Participant demographic and health behaviours information

Age	Mean	25 years
	Range	21 – 36 years
Gender	Male	10
	Female	3
Marital status	Single	11
	Married	2
Level of education	Undergraduate	8
	Postgraduate	5
Employment status	Entry-level	7
	Mid-level	4
	High-level	2
Months since employment	Mean	23.62
	Range	4 - 84
Salary (per annum)	Mean	Rs. 309307
	Range	Rs. 140000 - 650000
Shift	Morning (06:30 - 15:30)	4
	Evening (15:30 - 00:30)	2
	Regular (09:00 – 06:30)	7
Time spent commuting to work	Mean	46.15 minutes
	Range	15 – 75 minutes
Meals eaten at work (i.e., not home-cooked) per week	Mean	2
	Range	0 - 10
Number of hours spent on physical exercise per week	Mean	3.18
	Range	0 - 10.5
Number of hours of sleep per day	Mean	6.62
	Range	6 – 8

views with open-ended questions (see Table 2 for interview topics and sample questions) lasted on average 36 minutes. Following each interview, participants were requested to inform colleagues about the study and provide those interested with MC's email address.

pendently. Themes were then checked for developing patterns across participants, and the role of particular beliefs and behaviours. From these, five super-ordinate themes were developed and then used to group sub-ordinate themes when analyzing subsequent transcripts. Pseudonyms were used for all quotes.

#### Analysis

The study used interpretative phenomenological analysis (IPA; Smith & Osborn, 2003), a qualitative methodology chiefly exploring individuals' personal perceptions of a specific phenomenon. Each transcribed interview was read iteratively and the first (MC) and second (VB) authors identified emergent themes inde-

#### Results

#### 1. Lay definitions of health and illness

All participants defined health as the absence of illness and being physically able. Illness was,

Table 2 Interview topics and questions

Interview Topic

Beliefs about health and illness

Awareness and knowledge about health behaviours (diet, exercise, smoking, alcohol consumption)

Awareness and knowledge about chronic illnesses (diabetes, heart diseases, cancer) Sources of health information

however, defined as both a physical and psychological concept; where being ill impacted mental well-being.

- "When you are healthy only you can work better...you can achieve your goals." (Mansi, female, 24 years)
- "Illness is again, not keeping your body healthy...again it could be psychological as well.... illness will be something, it could be psychological as well as (physical) health wise..." (Rani, female, 30 years)
- 2. Awareness of and engagement in healthy behaviours (diet, exercise, smoking, alcohol use)

All participants acknowledged the importance of healthy behaviours and avoiding unhealthy ones. However, most participants (9) reported being unable to engage in healthy behaviours and cited reasons such as enjoyment of unhealthy habits, disinterest, peer pressure, lack of time and/or motivation, and lack of social support.

- "I don't like it (smoking) because it hampers our lives and we have good lives, you know, lungs are given by God, then why should we corrupt it by some other... by other means?" (Kartik, male, 36 years)
- "I eat lot of junk food, I am not health

Sample Question

What does 'having an illness' mean to you? What are your thoughts and behaviours in relation to diet?

Can you tell me what you know about cancer?

Where do you get information about health?

conscious...fries...oily food...I like dosa, I eat dosa every day or at least thrice a week, I eat cutlets, pizza and all that..." (Aravind, male, 21 years)

- "If 10 people are going somewhere... someday taking some party, then they (friends) will say, "You must drink!" Some people will be forced by friends, "If you don't drink I will not drink." ...like in that kind of difficult situation we must drink." (Chandra, male, 32 years)
- 3. Awareness of and knowledge about chronic illnesses (diabetes, heart diseases, cancer)

Most participants (9) were aware of and able to give a lay definition of chronic illnesses. However, some (4) were unaware about these illnesses, suggesting a need for health information. Interestingly, participants (4) able to accurately describe chronic illnesses used medical terms and had obtained this information through personal experiences, not because they were provided it (from formal/informal sources).

"If the blood pressure increases that will be exceeding the limit of the heart which it can pump or it can take...so, there at a particular time...air gets blocked in the lungs...so that causes, heart attack, heart stroke..." (Vishal, male, 22 years)

- "I don't have proper guidance like what is cancer... cancer is a disease that's it." (Sridar, male, 23 years)
- \* Cancer is a mutation in your cells which leads to uncontrolled growth in cells... seriously I had no idea regarding this until actually one of my uncles got it." (Anupama, female, 25 years)
- 4. Link between knowledge about health behaviours and medical explanations of chronic illnesses

Participants (6) aware of the benefits of healthy behaviours were also the ones able to describe chronic illnesses using basic medical terminology (i.e., not in layman terms).

Alok, male, 22 years:

- "Smoking it will affect our lungs, it may lead to cancer and TB, stuff like that lung problems."
- "Cancer is caused by not proper cell division and heart disease is caused by cholesterol."

Suresh, male, 23 years:

- "We must have food healthily...do exercise and whatever to be taken to be healthy...like juice...do exercise, otherwise it produces some fat...cholesterol so...just playing exercise... whatever, resource you have, use it...utilize it.."
- "Diabetes come because of sugar...much of insulin in their body or they have some deficiency of insulin in blood and causes some...deficiency in the other cells..."

#### 5. Sources of health information

Participants reported navigating the concepts of health, illness, and health behaviours on their own, with the internet (13) and family/friends (4) being the main sources of information.

"There used to be one of my buddies during

- graduation and we used to discuss these things (about exercise) a lot...so I got (information) from him. He used to share what he knew (about exercise) and made me do push-ups every day!" (Shiva, male, 23 years)
- "I am surfing (the internet)...about what things we need to do and not to do...to maintain our health...so basic tips I have been surfing (the internet)." (Brinda, female, 22 years)
- \*Internet is there na...if you don't know anything, you type on the Google... It comes!" (Giri, male, 23 years)

#### Discussion

Using IPA, the current study explored knowledge and sources of information about health, health behaviours, and chronic illnesses among Indian IT employees. The study raised two crucial issues with existing institutional (and governmental) support within the context of health literacy. First, the study found that employees obtained health information by themselves, through the internet and/or their social network. This suggests a need to provide authenticated health information to Indian IT employees. As Saiyed and Tiwari (2004) posited providing workplace health education is a matter of urgency in India.

Second, the study revealed that employees lacked ability to interpret health information and translate it into daily healthy lifestyle choices. Hence, efforts to increase health literacy at the workplace should include skills-building components on: (i) how to make sense of health information, and (ii) techniques to maintain healthy habits (e.g., health discussion groups, tips on handling peer pressure during social

events).

Interestingly, it was observed that participants aware of the benefits of healthy habits also understood and used medical terminology to describe chronic illnesses. This suggests that not only was medical language comprehensible to them but they may also be able to perceive a link between health behaviours and chronic illnesses. Therefore, future health literacy interventions could deliver health information that is both medically descriptive and defines the relationship between health behaviours and chronic illnesses.

The current study's strengths comprise the inclusion of topics on sources of health information and a sample of Indian IT employees thereby adding different cultural perspectives to existing health literacy literature. While a qualitative methodology was appropriate in gaining employees' accounts and experiences, the results may not be generalizable to the wider working population. Quantitative research to expand on these findings would be useful. Recommendations include further work with broader based populations of IT workers, workers in other occupations, and examining the link between a variety of demographic factors (e.g., age, gender, type of employment) and health literacy.

#### References

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An Updated Systematic Review. Annals of internal medicine, 155(2), 97-107.doi:10.7326/0003-4819-155-2-201107190-00005

Kickbusch, I. S. (2001). Health literacy: Addressing the health and education divide.

- Health Promotion International, 16(3), 289-297.doi:10.1093/heapro/16.3.289
- Central Intelligence Agency. (2012). The World Factbook: India. Retrieved from https://www.cia.gov/library/publications/the-world-factbook/geos/in.html
- Haldiya, K. R., Sachdev, R., Mathur, M. L., & Saiyed, H. N. (2005). Knowledge, attitude and practices related to occupational health problems among salt workers working in the desert of Rajasthan, India. Journal of occupational health, 47(1), 85-88. doi:10.1539/joh.47.85
- Jena, M. K. (2011). Indian IT industry and work: A study of health risk among BPO workers in Bangalore. Labour and Development, 18, 25-41. Retrieved from http://www.vvgnli.org/sites/default/files/publication\_files/Labour-Development-June-2011.pdf
- Kalichman S. C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. Journal of General Internal Medicine, 14(5), 267-273. doi:10.1046/j.1525-1497.1999.00334.x
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), Qualitative Psychology, A practical Guide to Research Methods (pp. 51-80). London: Sage.
- Saiyed, H. N., & Tiwari, R. R. (2004). Occupational health research in India. Industrial Health, 42(2), 141-148. doi:10.2486/indhealth.42.141



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Kolarcik et al. the Ophelia process

#### original article

### The Ophelia (OPtimise HEalth Literacy and Access) Process

Using health literacy alongside grounded and participatory approaches to develop interventions in partnership with marginalised populations

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Roma populations in the and Eastern Central Europe live shorter lives and Health Institute, Palacky and face greater burden of disease than their non-Roma neighbours (Cook, Wayne, Valentine, Lessios, & Yeh, 2013). For segregated Roma mmunities, where the health outcomes are ty-

pically the worst, the core intermediate determinants behind the disparity are well documented and known: radically poorer material circumstances, riskier health-related behaviours and greater health-care access barriers (European Union, 2014).

Several programs have been introduced to support Roma to live healthier lives but these have not generated many substantive improvements. Despite these findings, Roma health remains a European priority and there is strong policy promoting the need for innovative programs that generate improved outcomes while preserving Roma autonomy and cultural diversity (Koller, 2010).

In this setting, health literacy is a highly relevant construct. According to a recent WHO Health Literacy Toolkit from the South East Asia Regional Office (Dodson, Good, & Osborne, 2015), health literacy is the personal characteristics and social resources needed by individuals and communities to access, under-stand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact

these decisions. The construct of health literacy is therefore of great importance when working with disadvantaged and marginalised groups who may have a range of educational, cultural and structural barriers that limit their access to and understanding of health info-rmation and health services.

This paper seeks to explore the potential of a newly developed, grounded and participatory approach to development of health-literacy and health-care access interventions for equity - the Ophelia (OPtimising HEalth Literacy and Access) process (Batterham et al., 2014). The methodology involves undertaking a needs assessment of the target population using intensive qualitative and quantitative methods, developing vignettes of key sub-groups within the population based on their health literacy profile of strengths and weaknesses, and then engaging with frontline practitioners and community members in developing realistic solutions (Batterham et al., 2014). We will first review Ophelia's core components and then discuss why we believe this kind of approach might advance the current practice of interventions to promote health and access to timely healthcare within marginalized Roma.

The Health Literacy Questionnaire (HLQ) as a measure of health literacy needs

The HLQ was developed in partnership with patients, practitioners and managers in Australia and comprises nine separate dimensions that Kolarcik et al. the Ophelia process

Table 1 The Health Literacy Questionnaire scales with high and low descriptors of each construct\*

#### Low level of the construct

#### High level of the construct

#### 1. Feeling understood and supported by healthcare providers

People who are low on this domain are unable to engage with doctors and other healthcare providers. healthcare provider who knows them well and who They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.

Has an established relationship with at least one they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.

#### 2. Having sufficient information to manage my health

Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.

Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.

#### 3. Actively managing my health

People with low levels don't see their health as their Recognise the importance and are able to take responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.

responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.

#### 4. Social support for health

Completely alone and unsupported for health.

A person's social system provides them with all the support they want or need for health.

(continued)

provide comprehensive information on health literacy abilities, strengths and needs, as well as indicators of the experiences an individual may when attempting to engage practitioners or a health service (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). To assist users, practitioners policymakers to understand the health literacy dimensions, the constructs were organised into clear high and low descriptors (Table 1). The HLQ has been translated and culturally adapted to many languages and is being used in over 30 countries.

The HLQ provides a fine-grained profile of the independent health literacy needs of individuals and their communities and therefore provides a framework for health workers to take action to build upon strengths and to introduce ways to

improve weaknesses or assist people compensate for weaknesses

It is not always clear whose health literacy might be the most important (see Figure 1). When considering health literacy from an individual through to a whole-of-community perspective, integrated interventions that include the way individuals act, learn and behave within their family, with healthcare providers, and within their wider community can be considered. The intervention might include one-on-one coaching about risk factors, medical terminology or healthy food options, through to communitywide decision making.

The term 'interactive health literacy' proposed by Nutbeam (1998) includes literacy, but also social and other communication skills which enable a person to actively participate in everyday

activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. The HLQ covers these skills and interactions very well (Osborne et al., 2013), but the emphasis in practice, however, needs to also include community-level empowerment. marginalised communities, social cognitive processes need to be considered and this is akin. to Nutbeam's asset-based model of health literacy (Nutbeam, 2008). The challenge now is how to build assets and empowerment at the individual, family and community level in partnership with marginalised communities such that substantive benefits are experienced by all members of the community in an equitable

#### Table 1 (continued)

The Health Literacy Questionnaire scales with high and low descriptors of each construct\*

#### Low level of the construct

5. Appraisal of health information

#### No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.

#### High level of the construct

Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.

#### 6. Ability to actively engage with healthcare providers

i.e., they do not proactively seek or clarify information and advice and/or service options. They seek advice from additional healthcare providers questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. The do not have a sense of agency in interactions with providers.

Are passive in their approach to healthcare, inactive Is proactive about their health and feels in control in relationships with healthcare providers. Is able to accept information without question. Unable to ask when necessary. They keep going until they get what they want. Empowered.

#### 7. Navigating the healthcare system

Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do own behalf at the system and service level. not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.

Able to find out about services and supports so they get all their needs met. Able to advocate on their

#### 8. Ability to find good health information

dependent on others to offer information.

Cannot access health information when required. Is Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.

#### 9. Understanding health information well enough to know what to do

Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.

Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.

<sup>\*</sup> Note: Source: Batterham et al. (2014)

#### What is most important in determining health equity and outcomes?

- Is it the health literacy of the individual?
- Is it the health literacy of the person in the family who cares for domestic issues like buying and cooking food?
- Is it the average health literacy of people in a family?
- Is it the average health literacy of the individual's peer group?
- Is it the health literacy of the 'highest status person' in the individual's age group?
- Is it the health literacy of settlement leaders?
- Is it the health literacy of health navigators if they exist?

Figure 1. Levels of health literacy that are worth considering when seeking to improve health and equity outcomes in communities

manner.

# The use of locally-derived vignettes - finding hearts and wisdom of those targeted

In Ophelia, the health needs assessment doesn't finish with aggregate HLQ numbers. Among its premises belongs the understanding that in many communities, self-determination down to the level of individuals (such as it strongly is the case among the segregated Roma) paramount. Therefore, participatory approaches, which actively and overtly seek local wisdom, are often more effective - imported one-size-fits-all interventions may not match the distributions of local settings and priorities (Minkler & Wallerstein, 2011). While procedures for participatory community development have been in place for many years, e.g. the Assetbased community development (http://www.abcdinstitute.org/), the Ophelia process proposes a novel strategy for bringing the voice of all stakeholders to the table.

While the nine HLQ domains provide detailed profile of health literacy distribution and identify groups and subgroups with low, average or high health literacy, the application of a multivariate

technique (cluster analysis) to HLQ data makes the data much more powerful. Cluster analysis groups together individuals with similar scores across each of the individual HLQ scales. From the HLQ scales, demographic and clinical data where available, as well as from qualitative interviews to obtain data on context and a sense of the daily challenges of individuals within the cluster subgroups, vignettes (i.e., scenarios or short stories) are developed. Such vignettes, which represent the range of individuals across a community, are profoundly engaging stakeholders as they bring the HLQ data to life, enabling vivid visualisation of a range of community members (empirically selected), that become the focus in co-production workshops. In the Ophelia process about 5 to 7 vignettes are developed covering individuals with low, mixed and high health literacy scale score profiles (See Figure 2 for an example of a vignette). Community stakeholders are asked to respond to three questions:

- (1) Do you recognise the individual in the story as someone living in your community?
- (2) How can we work with this person so they have the best chance of getting and maintaining good health?
- (3) If we have a large number of people like this in our community, how can we organise the community

1.	2.	3.	4.	5.	6.	7.	8.	9.
Feeling	Having	Actively	Social	Appraisal of	Ability of	Navigatin	Ability to	Understanding
understood	sufficient	managing	support	health	actively	g the	find good	health
and	information	my health	for	information	engage	health	health	information
supported	to manage		health		with	system	information	well enough to
by	my health				health			know what to
healthcare					care			do
providers					providers			
Very High	Low- moderate	Moderate- high	Modera te-high	Low- moderate	Low	Low- moderate	Very low	Low

Giovanni is a 73 year old Italian man whose wife died 3 years ago. He now lives alone. Giovanni has type 2 diabetes and arthritis, and was recently diagnosed with heart failure. Although he trusts everything the doctor tells him and tries to follow instructions (scale 1), he gets very confused about how to manage all his new heart failure medications, and his fluid restriction (scales 2 and 9). He never feels certain that he is actually doing the right thing. He doesn't feel right about asking questions of the doctor (scale 6) because he was brought up to never question what a doctor says. He doesn't really look for information elsewhere either (scale 8). His daughter helps when she can (scale 4), but she doesn't always have the knowledge to explain things to him. The doctor referred him to a lifestyle education program at the community health center, but a lot of the information seemed very complicated, and because it doesn't come from his doctor, Giovanni doesn't try to take it all in.

(Giovanni is likely to score poorly on a health literacy screening test due to his poor reading and writing (scale 9) but this is partly compensated by his good relationship with his doctor. Health literacy interventions could focus on strengthening his social support further (scale 4) and building trust in the advice of social care services (scales 6) and provision of information endorsed by his doctor.)

Figure 2. Vignette representing a health literacy profiles derived from the nine dimensions of the Health Literacy Questionnaire (HLQ). Overall, this person doesn't really understand what to do, but would trust the doctor

to ensure they have the best chance of getting and maintaining good health?

While the questions are slightly reframed for professionals, the same vignettes and same rich discussion unfolds. A full range of ideas for improvement, redesign, or novel interventions are volunteered from stakeholders and these are organised into level of the system targeted for improvement (individual, family, community, practitioner, organisation or inter-agency). The ideas are then prioritised by local stakeholders for action and referenced against the published literature.

The marginalized Roma, healthmediation and Ophelia's promises

As indicated above, marginalized Roma might represent an ideal place to implement a wide range of published, well-tested public health interventions, each aspiring to be evidencebased, practical and scalable. It is critical to recognise that segregated communities have profound challenge, and compared to their non-Roma counterparts have: worst health; materially most deprived; worst socioeconomic position; in many respects quite heterogeneous both across and within communities. Plus, as it has been well documented for Roma and analogous groups across the continent (Stewart, 2013), the observed 'multi-dimensional social exclusion' is also supported also by a consistent practice of selfexclusion based а counter-cultures understanding particular aspects of non-Roma

Table 2
The Health Literacy Questionnaire scales with high and low descriptors of each construct

Original domain title	How most marginalized Roma might understand it*
1. Feeling understood and supported by	The healthcare providers are polite, not blaming for
healthcare providers	arising health needs, avoid technical healthcare jargon
	and take time to explain and facilitate more complex
	clinical procedures (medication intake, visits by other specialists, etc.)
2. Having sufficient information to manage	<u>.</u> ,
my health	and minor health issues, and of arranging for appropriate
my neuten	HC involvements with respect to the former; especially
	when children involved
3. Actively managing my health	Having (non-Roma like) interest in health issues; Taking
	care of minor health issues without involving HCP;
	Deliberately following generally known clinical or public
	health recommendations with respect to serious health
	issues
4. Social support for health	Having enough relatives in the extended family in the
	community of residence (solidarity in health issues comes here automatically within such social networks)
5. Appraisal of health information	Having some basic theoretical biomedical knowledge (=
5. Appraisar of nearth information	much higher than present level of formal education)
6. Ability to actively engage with	Sufficient income (access barrier), personal confidence
healthcare providers	and practical experience in dealing with the (mostly non-
F	Roma) HCP
7. Navigating the healthcare system	Sufficient income (access barrier), personal confidence
	and good practical knowledge of the HC system
	procedures (including patient rights and legal obligations
	of the HC providers)
8. Ability to find good health information	Access to and proficiency in the use of the Internet + Good
The Land of Paralle of the Comment	appraisal of health information
9. Understanding health information well	Ability to understand technical HC language (= much
enough to know what to do	higher than present level of formal education)  Health-system limitations of Roma health in Slovakia: A

Note: \* assessement based on: Belak, A. (2013). Health-system limitations of Roma health in Slovakia: A qualitative study. Bratislava: WHO Country office in Slovakia.

ways as socially and morally inappropriate (see also Table 2).

While this combination of challenges may sound intractable, over the last decade, in isolation from both government agencies and scientific communities, a new trend has emerged in the region, initiated by small local NGOs, which appears unprecedentedly promising – health-mediation for marginalized Roma communities (Open Society Institute, 2011; World Health Organization, 2013). Despite many voids

at the formal level, at least some of the programs appear to be very successful in their actual practice: apart from significantly decreasing healthcare access barriers, they also seem capable of dramatically increasing particular communities' social capital and improve their infrastructure directly significant for health (Dodson et al., 2015).

Ophelia appears capable of passing the marginalized Roma acceptability test because aspects that are working well in the health-

mediation programs are based and operationalized in a very similar way to Ophelia: they focus on broadly defined health-literacy elements including structural aspects such as healthcare access; participatory approach to health-needs assessment; and participatory approach to development of solutions through networking with other local stake-holders. In fact, the resonance between the emergent grassroots processes of the health-mediator program and the formalised Ophelia process is so striking, the health-mediator leadership in Slovakia since last year including the Slovakian Ministry of Health - have approached our team to apply HLQ as a key element of the evaluation to formally assess the impacts of health-mediator intervention.

# Going forward: Health literacy development and equity.

The use of local HLQ data (or other relevant health literacy data) that captures the voice of the target populations and feeds into real-world vignettes, uses co-production and local priority setting, not only assists with ensuring intervention are fit-for-purpose, increases trust and commitment by stakeholders to implement them. The Ophelia process is a promising mechanism to enable systems-level improvements. The evaluation of many current Ophelia projects will help this novel approach mature and hopefully generate wide ranging benefits across marginalised and other population groups experiencing health inequalities.

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#### References

Batterham, R. W., Buchbinder, R., Beauchamp, A., Dodson, S., Elsworth, G. R., & Osborne, R. H. (2014). The OPtimising HEalth LiterAcy (Ophelia) process: Study protocol for using health literacy profiling and community engagement to create and implement health reform. BMC Public Health, 14, 694-694. doi:10.1186/1471-2458-14-694

Cook, B., Wayne, G. F., Valentine, A., Lessios, A., & Yeh, E. (2013). Revisiting the evidence on health and health care disparities among the Roma: A systematic review 2003–2012. International Journal of Public Health, 58(6), 885-911. doi:10.1007/s00038-013-0518-6

Dodson, S., Good, S., & Osborne, R. (Eds.). (2015). Health Literacy Toolkit: For Low- and Middle-Income Countries - A series of information sheets to empower communities and strengthen health systems. New Delhi: World Health Organization, Regional Office for South-East Asia.

European Union. (2014). Roma Health Report.
Health status of the Roma population. Data
collection in the Member States of the European
Union. Brussels: European Union.
doi:10.2772/3140

Koller, T. (Ed.). (2010). Poverty and social exclusion in the WHO European Region: Health systems respond. Copenhagen: WHO Regional Office for Europe.

Minkler, M., & Wallerstein, N. (2011). Community-based participatory research for health: From process to outcomes. San Francisco, CA: John Wiley & Sons.

Nutbeam, D. (1998). Health promotion glossary. Health Promotion International, 13(4), 349-364.

doi:10.1093/heapro/13.4.349

Nutbeam, D. (2008). The evolving concept of health literacy. Social Science & Medicine, 67(12), 2072-2078.

doi:10.1016/j.socscimed.2008.09.050

Open Society Institute. (2011). Roma Health Mediators: Successes and Challenges. New York: Open Society Foundations.

Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health, 13(1), 1-17. doi:10.1186/1471-2458-13-658

Stewart, M. (2013). Roma and Gypsy "Ethnicity" as a subject of anthropological inquiry. Annual Review of Anthropology, 42, 415-432. doi:10.1146/annurev-anthro-092010-153348

World Health Organization. (2013). Roma health mediation in Romania. Copenhagen: World Health Organization Europe.



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### report

# Changing the World

# The United Nations millennium development goals and sustainable development goals

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At the ground-breaking Millennium Summit of the United Nations (UN) in 2000, the Member States adopted the Millennium Development Goals (MDGs), which together aimed to address the needs of poor and vulnerable countries

and groups around the world. During the past 15 years these goals have been a guiding force for action and change for UN member states, and their duration expires at the end of 2015. Almost all the MDGs were directly or indirectly related to health and wellbeing, and many adopted a preventative approach. Most impressive has been the progress made towards eradicating poverty (MDG1) over the last 15 years. The numbers of people living in extreme poverty globally, who earned less than one dollar a day, has been reduced by half. Improving gender equality became a serious aim (MDG3) and primary education for all now approaches universal coverage. Progress has been made in reducing child mortality (MDG4) and improving maternal health (MDG5), despite some departures from the path. New cases of HIV infection have begun to decline (MDG6), but malaria and common diseases like tuberculosis - now on the increase still require urgent concerted international action investment. Ensuring environmental sustainability (MDG7) is key in the future agenda, in the wake of rising global concern about climate change. For further reading, you can find many documents related to the MDGs complied by

<u>Taylor and Francis</u> to mark the final year of these goals.

The MDGs were timetabled to be achieved by 2010, but the deadline was extended through to 2015, when a new Agenda was needed to close existing gaps and to take into account the needs of a rapidly changing world. By 2012, an experts meeting in Bellagio had refocused this new global initiative onto Sustainable Development Goals (SDGs). Prudently, these would be founded on the evident successes of the MDGs. While the MDGs primarily addressed the needs of developing low and middle income countries, the SDGs indicate that during the next 15 years, all countries worldwide should endorse and adopt these commitments and responsibilities. Sustainability is defined as " development that meets the needs of the present without compromising the ability of future generations to meet their own needs".

The full SDG document was developed during a year of consultations, and was discussed during the UN Sustainable Development Summit in 2015, at UN Headquarters in New York. This was convened as a high-level plenary meeting of the General Assembly which on September 25th formally adopted the Resolution for the 2030 Agenda for Sustainable Development, which also includes directions for implementation. The 193 Member States of the United Nations reached consensus about the Agenda which contains 17 SDGs, with 169 associated targets. These are outlined in the document: "Transforming Our World: The 2030 Agenda for Sustainable Development"

The Psychology Coalition at the United Nations (PCUN) actively participated in the discussion of

psychological contributions to sustainable develoment, and to finalizing the SDG document. PCUN is composed of psychological societies and organizations accredited at the United Nations (UN), and psychologists affiliated with United Nations departments, agencies and missions. These include the American Psychological Association (APA), International Association for Analytical Psychology (IAAP), International Union of Psychological Science (IUPsyS), the Society for the Psychological Study of Social Issues (SPSSI), and now also the European Health Psychology Society (EHPS). Coalition members collaborate in the application of psychological principles, science and practice, to global challenges on the UN agenda including those outlined in the MDGs and new SDGs. PCUN ensured the impact of psychology in the SDG discussions in several ways. One notable achievement was the inclusion of well-being in the title of SDG3, alongside health. It insisted on including for the first time a separate target for mental health in the SDG agenda; however this has remained as part of the target 3.4.

## Health, Wellbeing and Resilience

The ambitious target of 'Ensuring good health and wellbeing for all and at all ages by 2030', (SDG3) remains a high priority among the new Sustainable Development Goals, following on from goals aiming for eliminating poverty and zero hunger. The tone of the SDG document is clear: 'No one must be left behind'. It addresses the needs of vulnerable people, including youths, older adults, disabled people, indigenous populations, those infected by HIV, refugees, migrants and internally displaced people. It also acknowledges the special needs of those facing complex humanitarian emergencies or affected by terrorism. Goal 3 adds a developmental feature, indicating how important it is to carry

out work across the lifespan in health and wellbeing, without age silos.

One of the new themes among the SDGs is the positive concept of resilience. SDG11 addresses 'making cities and human settlements inclusive, safe, resilient and sustainable'. Although resilience is utilised in other disciplines to describe materials and the economy, psychological resilience of communities to physical and mental illness forms an integral part of the contemporary agenda of community health psychology. 'Bouncing back' from disaster is seen as strength. Building resilience as a preventative strategy offers an optimistic, practical alternative to the relief from suffering, disruption, and economic damage that arises from natural disasters due to climate change.

Inevitably the SDG targets will need to be followed-up and evaluated, but measuring MDG achievements was contentious. It is internationally acknowledged that it is important to develop new broader indicators of progress for the SDGs, and that these will need to be high quality, timely, and reliable. Applying advanced psychometric skills could be an asset in developing suitable health and well-being assessments, to ascertain whether unequivocally, Sustainable Development Goals have been met.

## Gender Equality and Women's Empowerment

Millennial Developmental Goal 3 (MDG3) had a single aim of eliminating gender disparity at all levels of education. Achievement of that goal is being measured by gender ratios in school enrolment, paid employment and political participation of women in national parliaments. In many ways MDG3 had an undeniable effect on improving the status of women and girls around the world. Gender parity in primary schools has

## Box 1: Sustainable Development Goals (2030)

- Goal 1. End poverty in all its forms everywhere
- Goal 2. End hunger, achieve food security and improved nutrition and promote sustainable agriculture
  - Goal 3. Ensure healthy lives and promote well-being for all at all ages
- Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all
  - Goal 5. Achieve gender equality and empower all women and girls
  - Goal 6. Ensure availability and sustainable management of water and sanitation for all
  - Goal 7. Ensure access to affordable, reliable, sustainable and modern energy for all
- Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all
- Goal 9. Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation
  - Goal 10. Reduce inequality within and among countries
  - Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable
  - Goal 12. Ensure sustainable consumption and production patterns
  - Goal 13. Take urgent action to combat climate change and its impacts
- Goal 14. Conserve and sustainably use the oceans, seas and marine resources for sustainable development
- Goal 15. Protect, restore and promote sustainable use of terrestrial ecosystems, sustainably manage forests, combat desertification, and halt and reverse land degradation and halt biodiversity loss
- Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels
- Goal 17. Strengthen the means of implementation and revitalize the global partnership for sustainable development

almost been attained, UNDP reports 96 girls for every 100 boys enrolled between 2000 and 2010 around the globe. Some encouraging trends include improved maternal health, increased number of women in the labor market and progress in securing better education and training.

However, collective capacity of women to actively participate in decision making and to hold authorities accountable for their actions is still an ideal more than reality. On the global

front participation of women in the labor market (non-agricultural sector) has increased, from a global share of 35% in 1990 to 40% in 2012 including a 6% increase in the number of ministerial level positions held by women. Despite reports of a more prominent increase in female representation in parliaments of developing countries, globally, women still occupy less than a quarter of seats in parliament and 17% of all government ministerial posts.

These are only some of the indicators which

suggest a long road ahead. One of the main objections to the indicators embodied in MDG3 is that they too often served as token gestures asking governments to promote rather than achieve goals to expand women's choices and support empowerment of women and girls.

Sustainable development goal 5 (SDG5) is phrased more specifically in comparison to MDG3 with an emphasis on providing grassroots support to women that will ensure that they have skills and capabilities necessary to participate, monitor and make policy changes. SGD5 advocates for more access to assets and resources for women and challenges discriminatory laws and constitutions and protect women's sexual and reproductive health and rights. Separate targets are indicated for each of the issues:

- End all forms of discrimination against women and girls everywhere
- Recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family
- Ensure women's full and effective participation and equal opportunities for leadership at all levels of decision making in political, economic and public life

Some argue that the issue of actual participation of women in policy and decision making processes gained momentum because of the economic argument which suggests that gender inequality is negatively affecting economic growth.

There are also specific mentions of women's empowerment in other SDGs. SDG3 focuses on healthy lives and advocates for universal access to sexual and reproductive healthcare services, including family planning. SDG8 calls for equal professional opportunity for all women and men.

In SDG5 women's health issues are not mentioned specifically and are referenced in just

two targets. Women's reproductive rights are often a source of debate among different activist groups, however they are crucial for attaining any sustainable development. Being able to decide if and when to have children, not dropping out of school because of unwanted pregnancy or health risks due to unplanned pregnancies are associated with striking socioeconomic returns. For every dollar invested in contraception in developing regions the cost of pregnancy-related care including HIV care for women and newborns is reduced by 1.5 dollars. Beyond that, every girl that stays in school and delays childbirth is more likely to improve her participation in the labor force. In turn, living conditions improve and communities develop and grow when women fully participate.

It is crucial for policy and decision makers to understand that there is not going to be any poverty reduction or economic growth for that matter if half of the world population is lagging behind.

#### Conclusion

EHPS has been affiliated with the Division of Public Information/ NGO section at the United Nations since April 2011. This year, in April 2015, we had a major success when EHPS was accredited for consultative status with the Economic and Social Council of the UN (ECOSOC). This means that we can have the potential for significant influence on global health and wellbeing policies. Additionally, in 2016 EHPS becomes a member of the Psychology Coalition at the United Nations (PCUN). We believe that our affiliation with PCUN will allow the EHPS to play a more active role in shaping UN policies and future goals related to several areas including but not limited to ensuring healthy lives and promoting well-being for all at all ages.

We are looking forward to developing further

partnerships with the United Nations and the other professional psychological organizations affiliated with the UN. Please follow our updates on the European Health Psychologist and the EHPS website. Look for an announcement for the health policy workshop at the 2016 EHPS Conference in Aberdeen convened by Alden Lai, and facilitated by Dr. Julie Barnett and Dr. Hannah Durrant, The Institute for Policy Research, University of Bath: "Engaging Policy with Research: Building a Bridge over Troubled Waters." It will explore venues and strategies that health psychologists can use in our overarching goal of making a significant impact on global health and well-being policies.



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