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Re-thinking health literacy: using a capabilities approach perspective towards realising social justice goals

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Abstract

Health literacy has gained popularity as a useful concept to promote and protect health. Even though health literacy research has been prolific it has also been fragmented, facing challenges in achieving its empowerment and social justice-related aims. Crucial limitations make the application of its principles to the health of vulnerable and underrepresented groups problematic, even though these groups are disproportionately affected by ill health. Efforts to refine and make the concept more relevant have tended to expand health literacy models and situate health literacy “in context” to reflect environmental and social factors shaping health literacy. Context-related factors however, have not been consistently embedded in operationalisation and measurement efforts.

This paper argues for health literacy to be re-conceptualised through a capabilities approach lens. It proposes that the capabilities approach can uniquely address the conceptual and methodological criticisms applied to health literacy, whilst encompassing its critical conceptual

understandings of health. The advantage of this approach over and above other developments in health literacy theory and practice is its focus on both people's opportunities or freedoms to achieve desired health-related aims, and their ability to do so. It enables shifting the focus away from health literacy as individual skills and competencies and towards the enabling or inhibiting factors shaping health literacy. A participatory approach is seen as essential for realising this conceptual shift.

Key words:

critical health literacy; community health literacy, migrant and minority ethnic health; health capability; capabilities approach; participatory approaches; equity; empowerment

INTRODUCTION

Health promotion and health care delivery are informed by patient-centred concepts emphasising the role of the individual in their own health and care. Health literacy is one such concept capturing skills and abilities that enable positive health choices and patient participation during shared decision-making (1, 2). There are currently multiple health literacy models and no single agreed definition of health literacy (3). Research has also highlighted the challenges faced by health literacy interventions to result in positive outcomes (4), achieve social justice objectives (5, 6) and capture the needs and realities of vulnerable and underrepresented groups of the population (7). There is a need for a coherent, unified understanding of what health literacy is and how to achieve it.

This paper proposes a resolution to this discussion by re-conceptualising health literacy using a capabilities approach perspective. In order to do so, it will discuss the limitations in current conceptualisations and applications of health literacy and use research findings to explore how the capabilities approach can inform critical health literacy research and practice and embed social justice in health literacy applications.

The paper is structured as follows: Firstly, an overview of the health literacy literature and debates within is provided, with examples from research to illustrate the limitations in addressing the needs of vulnerable and underrepresented groups with emphasis on migrant and minority ethnic (MME) health. It will then provide an overview of the capabilities approach to introduce its principles and discuss how it has been applied to health and healthcare. Finally, it will discuss the idea for a health literacy capability, and the advantages of such a conceptualisation.

CURRENT DEBATES IN HEALTH LITERACY

Health literacy captures skills and abilities determining one's motivation and ability to access, understand and use information to promote and maintain health (2). Health literacy conceptualisations encompass several components, and often there are inconsistencies in the way it is conceptualised and operationalised within the literature. In a review trying to bring together the literature, Sorensen and colleagues (3) identified 17 definitions and 12 conceptual health literacy models.

Broadly however, health literacy conceptualisations fall within three groups: functional, interactive, and critical health literacies (8). These are distinguished by how much they acknowledge the role of care providers, health systems and broader social factors in individuals' health literacy levels. Functional health literacy relates to paternalistic understandings of the individual's relationship with the health system and medical profession and focuses on the individuals' ability to understand factual information. Interactive health literacy refers to the ability to not only understand the information given, but also being motivated and self-confident to use this information independently, for example through discussing concerns and values with healthcare professionals and interacting more effectively in a healthcare setting. Both understandings emphasise literacy and numeracy as necessary health literacy competencies. Critical health literacy adopts an emancipatory, empowerment-led understanding, where people are cognisant of social, economic and environmental determinants of health and are able to tackle these through community action.

When it comes to the settings in which health literacy has been used, Pleasant et al (9) talk about "a tale of two health literacies", one grounded in a clinical setting and focusing on individual information management skills, i.e. literacy and numeracy, and one grounded within a public health setting and focusing on individual and community empowerment (e.g. 10, 11). When operationalizing health literacy, both have adopted skills-based measures,

focusing on aspects of functional and interactive health literacy (12, 13), despite calls for multidimensional measures within public health (14).

In both settings, the focus on individual skills and competencies played out in “context-neutral” situations is narrow, and masks individual needs (15) and the contexts within which health literacy is enacted (16-18). It fails to situate individual health literacy in relation to the individuals’ social networks, or acknowledge social inequities and inequalities, a key component of critical health literacy (18, 19). At the same time, the distinction emphasised by some between clinical and public health health literacies (20) only reinforces the narrative of “two health literacies” and fails to unite this field of study.

When looking at the health and care experiences of vulnerable individuals and communities, research has highlighted the challenges faced by current – even critical - health literacy approaches to meet the needs and realities of vulnerable groups such as Migrant and Minority Ethnic groups (MME) (7, 21). MME groups have been consistently found to have low levels of health literacy, (7), poorer health outcomes and face inequalities in quality of care and barriers to healthcare access (4, 22). Research has highlighted the role of migratory factors, ethnicity and cultural identity (23, 24) as well as the quality of interactions with health providers (22, 25) in shaping expectations and perceptions of care. Clinician attitudes and biases towards patients have been found to impact in negative ways on quality of care (22, 26).

Health-related decisions and behaviours are in part the result of knowledge, literacy, help-seeking skills and motivation, and self-efficacy, but ultimately shaped and compounded by societal factors, including discrimination, oppressive immigration and employment policies, over which individuals have little or no control (22). In addition, people’s ability to engage

with what is going on during the clinical consultation is not only the result of literacy levels, but also of more complex psychosocial processes beyond the care context (22, 27). For example, research looking into access to breast screening services has found health literacy non-predictive of screening participation for women from minority ethnic backgrounds; emotional barriers such as fear and anxiety were central to participation (21).

Despite these findings, health education interventions tend to focus on factual information, targeting functional health literacy (22, 27, 28), rather than address the role of contextual and psychosocial factors in health and wellbeing promoting action (29). Perhaps because of the limited focus of health literacy interventions, they have yet to consistently prove their usefulness in promoting health (4, 30).

To address the robustness of the health literacy construct, authors writing from a public health perspective have elaborated on health literacy conceptual models to represent more holistic, biopsychosocial understandings of health literacy (e.g. 3, 31, 32), and more clearly define critical health literacy (e.g. 6, 33). Social determinants of health and health inequities become prominent (34) in these expanded health literacy models, and situate (critical) health literacy “in context” (16, 17). The role of environmental, social as well as personal factors in shaping individuals’ ability to navigate health and care choices are acknowledged.

Individuals who are highly health literate in one setting, can be less so in another making health literacy context and setting-specific (8).

This body of work emerging out of public health has resulted in useful insights into health literacy social and environmental facilitators. Sykes and colleagues describe critical health literacy conceptualisations as assets as well as competencies present in individuals and communities (5), taking into consideration the role of the individual and the social

environment in the creation of health (6). Rowland and colleague's bottom-up health literacy model is grounded in the health inequalities discourse, and encompasses family history, and ethnicity and culture, rather than individual competencies. This work emphasises the importance of family, community, and societal factors in shaping individual actions, and highlights the limitations when focusing on individual skills, abilities and motivations (35). The key role of social networks and community is echoed by de Wit and colleagues' description of critical health literacy, where social support and collaborative learning are seen as components of health literacy conceptualisations (33). Similarly, McCormack and colleagues (32) address the need to include individuals, populations, health professionals and health systems and not only patient-level outcomes in health literacy research; they propose a social ecological health literacy perspective resulting in multilevel interventions addressing not only the individual but also the context in which they reside.

What is evident is a conceptual shift emphasising critical aspects of health literacy and its determinants, over previously favoured narrow and paternalistic understandings. This is an important step to addressing the social justice goals of health literacy, but there is still a gap between theory and the application of health literacy in both public health and clinical settings.

An important reason for this is the lack of theoretical clarity and the absence of a unifying thread among the multiple conceptualisations and applications of health literacy (6). Even though theoretically context has become more prominent in health literacy discussions, in interventions and measurement narrow understandings of health literacy are still the focus of attention (5, 13, 14, 18), whilst even outcomes that attempt to measure aspects of critical health literacy, fail to capture broader determinants encompassed by critical health literacy models (for example: 19, 36). There is a challenge in creating a concise, conceptually

distinct, and robust theorisation of health literacy (6, 37, 38), and a robust evaluation of interventions (13) that moves away from individual skills to capture the barriers and opportunities that shape health literacy.

This paper proposes that the capabilities approach can uniquely address the conceptual and methodological issues raised so far, whilst encompassing health literacy's critical conceptual aspects. The capabilities approach is a normative framework emphasising one's freedom, or capability to achieve desired states, and provides the theoretical tools to conceptualise, and evaluate phenomena specific to poverty, inequality or well-being; and inform policy-making and resource allocation (39-41), in a way that other health literacy approaches cannot. The advantage of this approach over and above other developments in health literacy theory and practice is its focus on both people's opportunities or freedoms to achieve desired aims, and their actual achievement. In this way it can differentiate between people's preferences and abilities, and draw attention to barriers and facilitators of health literacy (39).

What follows is a brief overview of the capabilities approach and its application in the area of health and care, in order to illustrate the advantages of this approach and also how it can help address problems of social justice in health literacy theory, policy and empirical research.

THE CAPABILITIES APPROACH

The capabilities approach was developed by Amartya Sen as an alternative to welfarism, the dominant normative economic evaluation framework (42, 43). This approach to the design and evaluation of policies and interventions is based on the premise that "assessments of the well-being or quality of life of a person, and judgements about equality or justice, or the level of development of a community or country, should not primarily focus on resources, or on people's mental states, but on the effective opportunities or freedoms people have to lead the

lives they have reason to value” (39; pg.351). These “substantive freedoms” are what Sen has termed their Capabilities and form the broader context people reside in, i.e. opportunities to access education, health care, live in a healthy or health-promoting environment.

This approach has three central ideas:

1. People should be or do what they value and have reason to value, for example, a healthy lifestyle, a concept he termed Functioning;
2. People should have the freedom to enjoy various functionings to be or do things contributing to their well-being i.e. having the opportunities to engage in actions that enable one to be healthy, termed as Capability; and
3. Whether a person has the ability to pursue and realise goals she values and has reasons to value, i.e. her Agency

Sen sees capability to reflect an individual’s freedom to act as an agent in choosing between different opportunities and thus achieving functionings i.e. valued states of being (44). He argues for an evaluative system that “focuses on substantive freedoms” i.e. capabilities, instead of income and wealth (45) or in the case of healthcare delivery, moves away from unidimensional health-related outcomes (46).

In the case of health literacy, being health literate can be understood as a functioning, but whereas health literacy frameworks would focus on levels of health literacy as the measure of interest, the capabilities approach allows for directing attention towards people’s opportunities to be(come) health literate either as the target of intervention or measure of interest. Applications of the capabilities approach have focused on both functionings and capabilities (39).

The emphasis on capabilities rather than functionings is anti-paternalistic (39), and necessitates a participatory approach to intervention design and delivery in order to understand what people value, as well as to understand barriers and facilitators to achieving desired functionings and capabilities, e.g. accessing and using information in ways that are compatible with individuals' goals. Participatory approaches and critical consciousness principles, therefore, which have been linked to critical health literacy (47), fit comfortably within the capabilities approach.

Even though the capabilities approach has faced criticism for its unspecified nature (39, 48), Robeyns points out the capabilities approach is a “framework of thought” rather than a prescriptive theory, as Amartya Sen does not specify which capabilities should be used to assess individual well-being (49). Robeyns has argued different capabilities should be chosen reflecting different scenarios, recommending a participatory methodological process to identify what capabilities are necessary to enable individuals to achieve given functionings (39, 49, 50).

Taking a more prescriptive stance in identifying fundamental capabilities, Martha Nussbaum has proposed 10 basic capabilities that all individuals should achieve as a minimum, including capability to have good health (40, 50). Jennifer Ruger has further developed the idea of a health capability, in a process of operationalizing a “right to health” (51). Ruger describes health capabilities as one's confidence and ability to be effective in achieving optimal health, shaped by health agency i.e. the individual's ability to achieve health goals they value and act as agents of their own health, and health functionings, (i.e. a healthy state) (51). Ruger places health capability at the intersection of micro, mezzo and macro biopsychosocial forces, whereby individual health capability is shaped by: biological (e.g.

genetics, personality and behaviour); socio-cultural forces (e.g. social networks, culture and norms, life circumstances); public health and healthcare systems; and the broader social, economic, political and economic environment.

Health literacy is one component of such a health capability. Ruger however comments that existing approaches, including health literacy, are only marginally successful in improving health because of their limited focus on either outcomes or process. In this way, they fail to take into consideration barriers and facilitators on all levels which shape health and people's ability to make healthy choices i.e. both structural and agency related factors (52). As Ruger states: "*health capability enables us to understand the conditions that facilitate and barriers that impede health and the ability to make health choices. It offers a more accurate evaluation of the aims and success of social policies and change*" (52: pg.42). This is not possible within current health literacy approaches which emphasise individual ability.

The capabilities approach therefore offers a health justice-based (41) theoretical lens through which health literacy can be re-conceptualised. Embedding social justice principles in health evaluation and measurement is especially pertinent in the context of recent political developments where the rights of migrants, and especially the right to healthcare access, are being curtailed (53). The capabilities approach offers distinct advantages in informing health education interventions and measurement, policy and resource allocation, because of its flexibility in focusing on both capabilities and functioning, unlike other evaluative frameworks, for example cost-benefit analysis which does not capture context and its impact on individual outcomes, nor makes equity considerations (54).

The following section will examine in more detail how conceptualising health literacy as a capability can help the health literacy field through: (1) allowing for principles of social

justice to become ingrained in health and care research and decision making at a time of persistent health inequalities; (2) grounding health literacy in a normative framework that could unite the disparate understandings and applications of health literacy under a social justice based approach; and (3) allow for more robust operationalisations of the construct through the utilisation of methodologies already used by capability approach researchers to design patient-reported outcome measures (48).

TOWARDS A HEALTH LITERACY CAPABILITY

Embedding principles of social justice

The key contribution to be made by thinking of health literacy as a capability, is that it allows for equity considerations to become ingrained within health literacy discourses. Those health literacy models that address contextual and socio-ecological aspects of health literacy (17), do so with a focus on “reducing the situational demands, complexities and complexity in which an individual makes a health decision” (17: pg 1). Critical health literacy is where social justice discussions have taken place, but there has been limited interest in promoting psychosocial dimensions of critical health literacy through interventions (6), whilst achieving broader social justice objectives through these interventions has been problematic (5).

Sykes et al (6) point out that even though initial conceptualisations of health literacy adopted principles of empowerment, and social and political action, all components of a social justice approach, recent representations of the concept have marginalised these aims, in turn representing health literacy as a higher order cognitive individual skill. The same authors also point out the challenges in designing interventions that actually achieve these aims within the critical health literacy framework (5). Capability approach discourses provide useful theoretical and methodological insights, primarily through the emphasis on the

constraints on individual freedoms rather than process or outcome (52).

Uniting health literacy concepts

Re-thinking health literacy through a capabilities approach perspective allows for uniting the disparate conceptualisations and applications of health literacy under one robust social justice framework. Capability approach applications in health, including health capability (52) and health justice (41), offer conceptualisations that address multiple aspects of health literacy, and the opportunity to consider interventions or policies focusing on capabilities rather than skills. Capability approach-informed evaluation has as a starting point the capabilities people value, and assessment focuses on intervention and policy capability-enhancing properties, rather than on the health literacy levels or choices people actually make. For example, Nikiema and colleagues focused on individuals' ability to overcome barriers that obstruct their access to needed care (55). In this way intervention and evaluation are more aligned with social justice principles.

The objective is to situate (critical) health literacy alongside other health-promoting capabilities, and understand it in relation to health literacy-promoting capabilities, for example, enabling environments, access to social support, literacy-enhancing opportunities etc. This results in a multi-dimensional understanding of health literacy, both in conceptual, and operationalisation terms (10), one that encompasses literacy and numeracy but which does not weigh them more highly than, for example, community networks. In changing the focus from a health literacy to a health (literacy) capability, there is a shift away from individual skills towards factors enabling individuals to act in specific ways, while at the same time providing a common thread i.e. social justice, between theorising and operationalising health literacy. The health capability focus therefore better captures the

factors affecting an individual's health literacy, while accommodating a social justice perspective that current health literacy approaches neglect.

Adopting capability approach methodologies

Finally, the capabilities approach has been operationalised within health services research through the design of capability-based outcome measures (46, 56). These methodologies allow researchers to go beyond end-point outcomes i.e. skills and competencies, the outcomes of interest within current health literacy approaches, to capture the capabilities of value that allow individuals and communities to be health literate (see Robeyn's methodological process 39, 49). Research that explores what individuals and communities consider important components of health literacy (5, 33, 47, 57), and emphasises the role of social support, learning within social groups, culture, and social networks (e.g. 33, 47) can provide insights into what capabilities are important to inform the design of interventions, and into which capabilities should be assessed when considering the success of interventions. For example, interventions could be assessed not on whether they result in social and political action, but on whether individuals feel able to engage in such actions, if they wished to do so.

Participatory community approaches therefore are a good way to bring together the capabilities approach and health literacy fields as both have successfully utilised these methods. Critical health literacy researchers have placed community participatory approaches at the centre of health literacy research and implementation. For example, Suzie Sykes and colleagues (11) discuss the links between community development processes and critical health literacy building interventions, whereas capability approach authors have discussed the complementary nature of community participatory approaches to the capabilities approach (58). The use of participatory approaches in health literacy research,

grounded in a capability approach perspective, can not only inform community and individual health-literacy building initiatives, but also help identify health literacy capabilities important to individuals and guide the design of capability-based measures (46, 56, 59).

Participatory approaches are also now recognised to be of value to intervention implementation (60) and translational research (61).

CONCLUSIONS AND DIRECTIONS FOR FUTURE RESEARCH

Health literacy research has been prolific but fragmented, facing challenges in achieving its empowerment and social justice-related aims. Health literacy models have attempted to provide distinct and coherent conceptualisations of the concept, whilst applications have been divided between those that focus on individual information management skills, and community-based research emphasising empowerment and emancipation. Health literacy applications, including measurement, have been critiqued for focusing on narrow competency-related goals, which do not address the needs of vulnerable and underrepresented groups disproportionately affected by ill health (7).

This paper presented the capabilities approach as a useful framework to enable health literacy address social justice objectives and unify the disparate ways it has been conceptualised and operationalised so far. Looking at health literacy through a capabilities approach lens allows for conceptually situating health literacy within current applications of the capability approach in health and care, for example developments looking at people's abilities to achieve health states of value, in what Ruger has termed a "health capability" (52). This can be a useful starting point for further conceptual juxtaposition of these two concepts.

As a way forward, findings from community-based health literacy research exploring community understandings of health literacy, communities' values, beliefs and preferences

(for example: 5, 33) can be re-interpreted through a capabilities approach lens. This can be a first step to understanding the capabilities considered important for people to achieve health literate states and allow for illuminating possible differences or similarities between different groups of the population in terms of their health literacy needs or preferences. Further involving communities in understanding the barriers and facilitators to making health-promoting and health maintaining choices can help design interventions and services relevant to people's needs, focusing on enabling rather than imparting health literacy.

Using the capabilities approach to conceptualise health literacy allows for interventions, evaluation and policy to address the opportunities or ability of people to be(come) health literate (their capabilities), instead of focusing on people's competencies i.e. health literacy levels (their functionings). In this way, understandings of health literacy as context and setting-specific, and critical health literacy enhancing factors which have been highlighted by health literacy researchers can more meaningfully be operationalised within intervention and policy design.

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