



Constructions of patient agency in healthcare settings: Textual and patient perspectives



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ABSTRACT

In healthcare settings, patient agency is variously represented and circumscribed through the language of health information texts, the discourses of health practitioners, and patient/practitioner interaction. Patients, as well, construct their identity and act as agents in various ways as they encounter the healthcare system and strive to manage their health conditions. This paper explores the notion of patient agency in healthcare settings and healthcare texts. The data comes from a health literacy project, commissioned by a New Zealand primary healthcare provider, and a Ph.D. project exploring the mediation and use of health information texts in a hospital setting. It draws on multiple data sources: text analyses on over 100 cardiovascular and diabetes information brochures, focus group interviews with cardiovascular and diabetes patients, and observations of patients' interactions with text in a hospital cardiovascular unit. These sources of data show ways that patient agency is represented and restricted and that identity is often constructed in conflict with patients' own conceptions of agency. The focus group interviews and hospital observations show how patients contest, accept, reject, and negotiate the identities constructed of them. As well, our data shows the contrast between patients' enacting agency and healthcare professionals' prescribed agency as compliance. Our sources of data confirm that knowledge of condition and care and associated agency are contingent on a constellation of affordances.

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1. Introduction

Mention of health literacy is becoming more prevalent in the healthcare sector. Healthcare organisations appear to be paying more attention to the issues associated with it, and to ways of responding to the challenges posed by low levels of health literacy in patients. There also appears to be an increasing recognition of organisations' contribution to less than satisfactory health literacy encounters.

Health research, primarily driven by the healthcare sector and echoed in government policy documents, asserts that low health literacy is prevalent and its consequences are serious (Berkman et al., 2011; Koh et al., 2012). Consequences of low health literacy are widely recognised in the literature, with a range of poor health outcomes and healthcare noted (Adams et al., 2009; Brach, 2013; Ministry of Health, 2010). Low health literacy is also seen as a factor in increasing healthcare costs, and therefore represents a growing burden for governments across the world. It is not surprising then that health literacy has become an increasing concern internationally. This concern is reflected in the discourses representing patients and their conditions, and their responses to their conditions. Health literate patients are deemed to be patients who can more successfully self-manage.

In our view, a central underlying element in this discourse is agency, defined by Ahearn as “the socioculturally mediated capacity to act” (2001, p. 112). Ahearn, speaking as a linguistic anthropologist, sees language as social action, which serves as a vehicle for the interactive construction of agency. Further, agency is closely linked with identity, in that individual agency plays a part in the construction of both self and others' identities (Bucholtz and Hall, 2005). The healthcare system constructs identity, and thus agency for patients in the way it positions patients and the way it enables or constrains how patients position themselves. In healthcare settings, *patient agency* is variously represented and circumscribed through the language of health information texts, the discourses of health practitioners, and in the language of patient/practitioner interaction. Patients, as well, act as agents in various ways as they encounter the healthcare system, strive to manage their health conditions, and reconstruct their identities.

This article draws on two studies of health literacy among cardiac and diabetes patients in New Zealand. It examines patient agency as depicted in the literature on health literacy and patient health information. It then looks at how the positioning of patients aligns with their own constructions of agency regarding healthcare management.

2. Agency in health literacy

The notion of patient agency is inherent and often implicit in contemporary views of health literacy. The World Health Organisation

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(WHO) uses the following European Health Literacy Consortium definition:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in every-day life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Kickbusch et al., 2013, p. 4).

The WHO depicts health literacy as *acts of agency* (Ahearn, 2001; Janks, 2005) in the choice of the active verb phrases *access, understand, appraise, apply, make judgements, and take decisions* (Quigley, 2001). Similar language alluding to patient agency appears in the recent American Affordable Health Act definition of health literacy as “the degree to which an individual has the capacity to *obtain, communicate, process, and understand* health information and services in order to *make appropriate health decisions*” (italics ours) (Department of Health and Human Services, 2010, p. 1252). The addition of *communicate* in the US version has been noted as a deliberate inclusion to emphasise the importance of patients' active participation (Brach, 2013) in healthcare encounters and interactions.

In these definitions, patient agency is implicitly seen as residing within individuals; the influence of sociocultural mediation in Ahearn's (2001) definition of agency, that is contextual factors and social structures, is absent. Of note though in much of the health sector driven research, population cohorts with low health literacy are identified by sociocultural characteristics, which however are seen as fixed features of their identity. Those with low educational levels, the poor, the elderly, ethnic and racial minorities, and immigrants from non-dominant language backgrounds are frequently identified as having low health literacy. The same focus appears in the New Zealand Ministry of Health report on the low health literacy levels among Maori alongside the relative absence of other research on health literacy in the New Zealand population. There is relatively little exploration of how these characteristics might operate as mediators of patient agency.

Literacy studies take a different view of health literacy and make an important contribution to understanding the complexity of healthcare information, and healthcare encounters. Literacy studies focus on literacy in use, emphasising the relational meanings of text in sociocultural contexts as opposed to views of textual meaning solely as arising from an individual's set of cognitive strategies. Nutbeam (2008) alluded to this in his portrayal of health literacy as an asset, where the focus is on factors which give people more control over their own health.

Papen and Walters' view of health literacy, from a literacy studies perspective, fits more closely with Ahearn's (2001) view of agency in an explicit acknowledgement of sociocultural context as a mediating factor in patient agency. They define health literacy as

the ability to understand, access, and use health-related tools and services in a given location.... Health literacy has to do with the social and cultural practices that individuals and groups may engage in, in the process of understanding, accessing and using health-related tools and services (Papen and Walters, 2008, p. 10).

Also focussing on co-constructed meaning in use are discourse studies of health communication between patients and healthcare professionals. These have found diminished patient agency in healthcare encounters. As Engeström, Engeström and Kerusuo succinctly put it:

Both parties [the patient and the practitioner] are typically present simultaneously and construct the object—the illness and the care—interactively from the beginning to the end. The patient is literally a co-producer of the object. But usually the patient is a silent co-producer whose agency, if noticed at all is noticed mainly after the fact. (Engeström et al., 2003, p.286)

This situation is to some extent understandable, given the practitioner's extensive knowledge, experience, and responsibility for diagnosis and treatment. At the same time, there is growing recognition in the health sector internationally that the sector has an active role to play in promoting patient agency. One innovative response to this need is the work of Fischer and Ereaut (2012) specifically in the area of patient–practitioner consultations. They propose a cline of types of patient–practitioner interaction that increasingly places the patient in co-partnership with the practitioner. The most *evolved* interaction is where “the task of consultation would be joint exploration and ‘co-evolution’ of a course of action—how together the patient and doctor might work out what best to do” (Fischer and Ereaut, 2012).

A number of researchers (Brach, 2013; Kickbusch et al., 2013; Parker, 2009; Rudd, 2014) point to the need for more system-wide recognition of issues, and intervention. The communication skills of those in the health field, the focus of Fischer and Ereaut's (2012) work, need to be considered in conjunction with “the demands made by the health materials themselves... and the complicated nature of the healthcare and public health systems” (as cited in Rudd, 2014).

Development work has recently been underway in the healthcare sector to create schemes for establishing and evaluating *health literate organisations*, that is, provider organisations that promote health literacy through whole organisation awareness of patient capabilities and matching of health literacy demands with patient skills and competencies.

Thus, these contemporary perspectives on health literacy suggest a movement towards a greater acknowledgement that contextual factors play an important mediating role in patient agency.

The purpose of the present article is to identify the extent to which this movement was represented in practitioner discourses, in patient discourses, and in health information documents

3. Our research

We report here on observations gained in the context of two studies, the Midlands Health Literacy Project and the Ph.D. study, Cardiovascular Text, Context and Mediation study.

The Midlands Health Literacy Project was funded by a not-for-profit primary health provider serving nearly half a million people across the Midlands region of the North Island of New Zealand. The organisation aimed to improve patient health literacy as part of their research and development programme to improve the health outcomes of patients in the area. They were interested in cardiovascular disease and diabetes, two chronic conditions particularly associated with at-risk communities in New Zealand such as Māori and Pasifika. The patient cohort involved in the project included a wide range of socioeconomic levels, ethnicities, and urban/rural inhabitants. The data collection included multiple sources. Over 100 health information documents regularly given to diabetes and cardiovascular patients were collected from primary care providers across the region. Three patient focus group interviews were conducted over a period of 18 months in 2011 and 2012. They took place in three locations with different population cohorts. Focus group 1 was a metropolitan area with predominantly middle class white patients. Group 2 was in a small town centre in a semi-rural area with a declining resource economy. The focus group included a large number of Pacific Island patients. Group 3 took place in a town with a majority of Māori patients. In addition, we conducted a provider survey to gather information about providers' perceptions of patients' health literacy challenges. The provider survey found that agency was positively framed in terms of responsibility, compliance, and cooperative attitudes. Those who did not comply and who demanded undue attention from healthcare practitioners were seen negatively. The survey results are discussed in

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