



The importance of shared meaning-making for sustainable knowledge translation and health literacy

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Abstract

The aim of the present paper is to describe and discuss how recent theories about translation, bridging medical and humanistic understandings of knowledge translation, in the medical humanities can bring about a new understanding of health literacy in the context of patient education. We argue that knowledge translation must be understood as active engagement with contextual meaning, considering the understandings, interpretation, and expertise of both patient and health care provider (deconstruction of the distinction between biomedical and cultural knowledge). To illustrate our points, we will describe the case of Jim, a kidney transplant recipient who received standard patient education but lost the graft (the new kidney). If we apply Kristeva's view to this context, graft function is not merely biology but a complex biocultural fact. In this perspective, graft function is seen as a phenomenon that embraces translation between health as a biomedical phenomenon and healing as lived experience, and that opens for shared meaning-making processes between the patient and the health care provider. In Jim's case, this means that we need to rethink the approach to patient education in a way that encourages the patient's idiosyncratic way of thinking and experiencing, and to transform health information into a means for sustaining Jim's singular life – not biological life “in general.” The patient education programme did not take into consideration the singularities of Jim's biographical temporality, with its changes in everyday life, priorities, attitudes, and values. Hence, we claim that health literacy should involve a simultaneous interrogation of the patients and the health professional's constructions of knowledge.

KEYWORDS

health literacy, kidney transplantation, knowledge translation, medical humanities, patient education

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1 | INTRODUCTION

Knowledge translation is a term increasingly used in medicine to describe a process of exchange between research and practical application in clinical encounters.¹⁻³ Another seminal term in modern medicine is health literacy. This term refers to “the tasks that individuals and communities undertake to access, understand, appraise, remember and apply information about health in everyday life, continuously throughout the life course.”⁴, p.42 In this view, health literacy represents the final step in the translational chain wherein medical knowledge is transferred to patients. The World Health Organization points to health literacy as an important factor for sustainable health, for instance, in the prevention and control of noncommunicable diseases.⁵ Although related, the potential synergy between knowledge translation and health literacy approaches has not been sufficiently discussed. By relating knowledge translation to health literacy, the sustainability of knowledge translation activities can be strengthened by integrating patients' meaning-making of knowledge, for instance, in patient education encounters.

The translational turn in medicine implies an increased recognition of the importance of culture and context in knowledge application. From the late 1990s and onwards, there was a growing concern that despite increased efforts and investments into research, the output of novel therapeutics had not progressed accordingly.⁶ Some of the explanation was found in the lack of adaptability of experimental research to diverse and complex real-world situations. Thus, new methods for the systematic review of research literature and adaptation to clinical use through guideline recommendations were developed to bridge the gap, and facilitate the transition from bench to bedside. However, this recognition of the need for contextual adaptation was strongly based on an idea of fidelity to the source, and the methods used to adapt research to clinical situations were highly standardized. Guidelines and clinical decision-making tools are examples of attempts to make research applicable in clinical situations without altering or weakening the scientific message. Health literacy has also been dominated by standardized methods for information delivery and the education of patients. Research-based information is compacted into standardized information packages for various end-users as well as standardized models and frameworks for educating and dialoging with patients. This approach has been criticized for not taking into account patients themselves as “knowledge actors” and for how the “integration” of knowledge that is searched for is achieved.^{7,8}

One might claim that the aim of knowledge translation in medical encounters is to keep medical knowledge intact while at the same time adapting it to various contexts and users across the healthcare system – until it reaches the “end consumer,” namely the individual patient.¹⁻³ This confronts knowledge translation (including health literacy) with a paradox: On the one hand, knowledge translation is based on “fidelity” to the scientific message and presented merely as a scientific and technical process. On the other hand, efficient knowledge translation requires that human actors are able to make sense of the knowledge they acquire in their specific circumstances

and sociocultural contexts, including the meaning-making processes in which patients take part.^{2,3}

The widely used metaphor of the knowledge translational “pipeline” implies a somewhat simplistic and linear link between basic discoveries and their uptake and application. An alternative view sees knowledge translation as a messy, sociopolitical, conflict-ridden, and distinctly nonlinear process occurring mostly outside the university's walls, namely in industry, front-line clinical settings, and policy contexts.² This latter view complicates and challenges the traditional view of health information as a standardized delivery of information packages and provides a basis for new multidisciplinary theoretical approaches to patient education.

To reach application, knowledge must not only be understood or acquired but it must be interpreted and provide an insight into a given situation.⁹ Translation is not solely about acquiring knowledge, but about gaining a new insight. Accordingly, health professionals need to acquire the skills to articulate how patients actively construct interpretations of their own situation and not only whether or not they have received information. In the process of knowledge translation, in which patient education and health information could be placed, theories of translation from the humanities are of great value. Such theories can help us to rethink health literacy and the practice of patient education and health information. Hence, the aim of the present paper is to describe and discuss how recent theories about translation in the medical humanities¹⁰ can bring about a new understanding of health literacy in the context of patient education. We argue that knowledge translation must be understood as an iterative, active engagement with context, meaning, interpretation, and expertise from both the patient and the healthcare provider. This implies that knowledge translation is seen as an active engagement between the patient and the clinician to ensure that meaningful evidence is co-created out of guidance for treatment advice, information, and decision-making. In our view, health literacy depends not only on knowledge but also, more importantly, on knowing as an active process. Health literacy is a “singular biocultural process” dependent on shared reflections between the patient and the health care provider. To illustrate our points, we will describe the case of Jim, a kidney transplant recipient who received patient education to optimize graft function and well-being after the transplantation (a “fictive” case based on health professional experiences over time). Thereafter, we will discuss how co-creation of meaning, by the use of novel perspectives on knowledge translation as described in Kristeva et al.¹⁰ could enrich the understanding of health literacy in the encounter of patient education.

2 | THE CASE OF JIM: TRANSLATIONS IN KIDNEY TRANSPLANTATION

Renal transplantation is usually the preferred treatment for patients with end-stage renal disease, providing better patient survival and quality of life. However, transplantation brings new challenges for



patients, like Jim, in terms of caring for the graft, adhering to a life-long medication regimen, and respecting various restrictions.¹¹ If a patient's graft does not survive, he or she has to return to dialysis, leading to reduced functioning, fatigue and reduced quality of life, higher costs for society, and possibly retransplantation.¹¹ A transplanted organ, such as a kidney, is seen as a "stranger" by the host body, whose immune system goes into overdrive to deal with the intruder. To transplant solid organs, the recipient's immune system needs to be suppressed to avoid immunological rejection and facilitate long term survival of a functioning organ. Consequently, transplant patients require immunosuppressive therapy, which, in turn, requires a highly knowledgeable and strictly adherent patient.¹² Now we will turn to the case of Jim, for whom despite this the graft did not work.

Jim is 19 years old and is active in sports. He received a kidney transplant 2 years ago. Everything has proceeded smoothly up to now. However, at his last medical visit at the hospital, his blood values for graft function were alarming, indicating a rejection of the transplanted organ. The medical doctor asked Jim what had happened in his life lately that could explain the situation. Had he been sick or had trouble taking his prescribed medication (immunosuppressive treatment)? Jim was embarrassed telling the doctor that he had skipped his medication because he was training for a sports competition and wanted to be as fit as possible. Jim believed that the medication had a negative impact on his fitness. A tissue sample (biopsy) was taken from the kidney and the pathologist confirmed rejection. Jim underwent very tough treatment and about 20% of the graft function was restored. He will probably need a new transplant within a year. Unfortunately, his immune system was triggered to produce antibodies against HLA molecules (tissue types) and it will be hard to find a suitable new kidney. Due to non-adherence to prescribed medication he missed this and future sports competitions. Jim (like all patients receiving kidney transplants) was educated through a standardized education programme implemented at the hospital, comprising three meetings with a nurse during the hospital stay (8 weeks). This programme focused on three main areas of knowledge: medication, rejection, and lifestyle. The content was customized to each patient's knowledge needs related to these topics as determined by a knowledge test. Furthermore, all patients received a book (119 pages that contained the medical information needed to adhere to recommended regimens following organ donation). With all this information available and presented to Jim, how was it that he decided to stop taking his medication to do sports?

This case illustrates first of all the significance that everyday life has for patients' management and decision-making. Research has revealed poor adherence and challenges regarding uptake and use of medical

advice and information in renal transplant recipients.¹²⁻¹⁵ Health information and education is vital when it comes to keeping the new organ in good health. The traditional perception of how to take care of the new organ is through medication, as prescribed by transplant professionals, monitoring blood concentrations of immunosuppressive drugs, and controlling for physiological functions dependent on renal function and those affected by immunosuppression—for example, measuring plasma creatinine and screening and treating for cardiovascular risk factors, infections, and cancer. Immunosuppressive therapy consists of a combination of several drugs that need to be taken within a relatively narrow time window every day for the rest of the patient's life. Non-adherence to this protocol increases a person's risk of acute rejection episodes, as Jim's case illustrates, which can lead to the ultimate negative outcome of a graft loss, which is what happened with Jim.¹²⁻¹⁵ Hence, the transplant organ function involves more than an understanding of the biological aspects of the graft – it involves a greater mechanism and machinery than the organ itself.

Jim had to translate the medical knowledge delivered by the patient education programme into everyday practice when he returned home from the hospital. Jim's adherence and health literacy depended on his ability to seek out and interpret knowledge, assess the relevance of different (often ambiguous) information in relation to his own health and life situation, and then act accordingly. He had been trained to do this. Jim received standard information that made no mention of participation in sports at a high level. At the time of transplantation and patient education, Jim was not doing sports at this level. *This shows that a patient's life situation can change over time and that there needs to be continuous communication between health personnel and patients.* There are examples of transplant recipients playing football in the Bundesliga and participating in the Olympics while taking medication. Thus, Jim misjudged; he could have done his sports while following his prescribed drug regimen and he did not realize the consequences of not taking the medication. But he lacked the relevant knowledge to be a health literate actor in his own life situation.

Jim's case provides an opportunity to rethink traditional biomedical approaches to knowledge translation and health literacy by considering the clinical encounter of patient education and health information as a cultural phenomenon in the sense that it involves translation between health as a biomedical phenomenon and healing as a unique lived experience.¹⁰

3 | NOVEL PERSPECTIVES ON KNOWLEDGE TRANSLATION

There is a vast amount of work in medical anthropology, interactional sociolinguistics, conversation analysis, contextual factors and communications skills, narrative medicine, and shared decision-making¹⁶⁻²¹ which all point to the need to understand the patient's perspective and experiences more fully in a medical situation. While much of this literature is concerned with patients' experiences and the cultural contexts of health knowledge, the cultural context is often understood



separately from biomedical knowledge. Within all these strands of research, cultural contexts are considered important to facilitate communication with patients or even to improve care, but culture is rarely understood as part of the curative intervention which is still in most cases defined in biomedical terms.

Kristeva et al.¹⁰ bring this point further and have outlined a new approach to the relation between medical humanities and biomedicine in the paper "Cultural crossing of care: An appeal to the medical humanities." Perhaps the most important message in this paper is that health phenomena must be seen as arenas for translation between health understood as a biomedical phenomenon and healing as lived experience. This goes beyond a phenomenological perspective, where the patient's lifeworld is emphasized. A phenomenological perspective reduces the patient's perspective to "experience" which is understood as a subjective supplement exterior to the "biomedical" sphere. Kristeva et al.¹⁰, p.57 show how the sphere of experience and the sphere of biomedicine are woven together. They maintain that all clinical encounters should be considered as hybrid spaces between culture and nature because they "involve translation between health as a biomedical phenomenon and healing as *lived experience*."

According to this view, translation is essential in all healthcare. But translation in this sense involves more than the simple application of knowledge in new contexts. Translation implies an interactive negotiation of the various contexts, meanings, interpretations, and expertise that are brought into the encounter by the patient *and* the doctor respectively.¹⁰, p.57

The argument presented in the cited paper by Kristeva et al.¹⁰ must be interpreted on the backdrop of Kristeva's theories and contribute to the medical humanities more generally.²² Kristeva has repeatedly criticized the dominant understanding of illness and disability as "incompleteness" and she traces this understanding back to the Aristotelean concept of *steresis*: a lack of being.²³ Blindness is conceived of, for instance, as an incompleteness, a lack of being in one who by nature sees. In medical research and practice, this understanding translates into the study of the "empty" (pathologies) through which "the sciences appropriate the complexities of the 'full' (normal functioning)."²⁴, p.227 Kristeva's theory of the subject fundamentally challenges this notion. Medicine tries to restore something that has never existed, she claims, because human beings are not "states of being" that can be differentiated into conditions of completeness or incompleteness, but constantly emerging subjects. The relation between sickness and health is a continuum and human beings can therefore not be reduced to pathologies or categories of nonbeing.

Failing to consider human beings as singular subjects, discourse in medicine "blends all disabled people *together* without taking into consideration the *specificity* of their sufferings and exclusions." As singular subjects, all human beings are essentially vulnerable, according to Kristeva. She, therefore, rejects the idea that those of us in good health and those who are disabled or sick are distinguished by an essential lack, of a nonbeing. Rather, it binds us together: "Not necessarily because 'it could happen to anyone,' but because it is

already in me/us: in our dreams, our anxieties, our romantic and existential crises, in this *lack of being* that invades us when our resistances crumble and our 'interior castle' cracks."²⁵, p.44 Furthermore, she challenges the strong emphasis on knowledge about general categories and pathologies as the core stone of medical knowledge. Medical discourse seems to be missing an epistemology and a vocabulary for capturing and making sense of singular differences and the continuum between sickness and health characteristics of the individual person. Kristeva's point is not merely to emphasize the importance of subjective experience. Rather she wants to challenge the whole distinction between biomedicine and cultural experience by stressing that health care involves continuous and bidirectional translation between these two modes of knowing.

Accordingly, as emphasized in the previously quoted paper by Kristeva et al.,¹⁰, p.56 cure and care in terms of such a complex interface between the general and the singular, medical humanities should be considered "a cross-disciplinary and cross-cultural space for a bidirectional interrogation for both biomedicine and the humanities." From this space emerges a new way of relating biomedicine and the humanities, they claim. Moreover, they see this new way of relating as a potential for a new, biocultural practice. This practice should be seen as "different from merely considering the individual as a bearer of social/cultural meanings by including patients' preferences in clinical settings."¹⁰, p.57 More radically, "it implies acknowledging that evidence itself is fundamentally singular; it is always evidence *for* a particular decision or a general category."¹⁰, p.57 Knowledge about general categories and pathologies is thus needed to identify the singular case as singular and to create a place for translations between patients and medical specialists.¹⁰ In the context of health literacy and knowledge translation, this means that for instance patient education should involve a simultaneous interrogation of the patient's and the (health professional's) constructions of knowledge and meaning.¹⁰, p.57.

4 | CO-CREATION OF MEANING OF KNOWING IN ENCOUNTER OF KIDNEY TRANSPLANTATION

If we apply Kristeva et al.¹⁰ views to our case, graft function is not merely biology but a complex biocultural fact. How could healthcare providers have related to Jim and his graft function as a combined biocultural fact? To do so, healthcare providers need to view graft function as a phenomenon that embraces translation between health as a biomedical phenomenon and healing as lived experience. Such a view of translation opens up an opportunity for shared meaning-making processes between the patient and the healthcare provider. In Jim's case, this means that we need to rethink the approach to patient education. Patient education in this case is seen as the actual performance of health information whereby a shared meaning-making process between Jim and his healthcare providers creates new meanings of knowing for Jim, seeing him as an individual with his own "projects," and on that basis, as a reflective health literate actor.



One important determinant of whether a person can take advantage of medical treatments and healthcare support is their ability to understand and act upon health information related to different occasions and phases through life. Health information can be confusing, and a huge number of patients' complaints are related to experiences of poor communication with health professionals.²⁶ On the other hand, while health information can be very useful and empowering; it is constantly changing as a result of new research, and there is a wealth of information available through different sources.²⁷ Research has shown that individual tailoring of information could help patients to acquire knowledge related to their own situation in the encounter of kidney transplantation.²⁸⁻³² This is not merely a question of adapting education to individual cases but also of recognizing that patients need to develop individualized knowledge. Understanding how patients gain individualized knowledge is crucial to improve and advance patient education. An ethnographic study of the implementation of a tailored patient education programme²⁸ conducted on the ward where we imagine Jim was admitted for kidney transplantation showed that patients found it difficult to formulate their knowledge needs and interests.²⁸ It was not the lack of generalized information that was the problem but the difficulty patients had assessing and using the generalized information material as a basis for identifying their own knowledge needs and interests. Furthermore, the study showed that information tailoring was limited, "as the nurses balanced between the responsibilities for the programme's principles of individual adaption and patient involvement on the one hand, and the responsibilities of safety and economy from a health systems perspective on the other hand."²⁸, p.1

Although some definitions of health literacy take social and cultural context into account, the idea of the rational health literate patient is the prominent view.¹⁰ In Jim's case, this means he should have approached the norm and nonbiographical ideal of the health literate kidney transplant recipient in his effort to adhere to biomedicine. For their part, the health professionals working with Jim should have communicated with him and transferred biomedical knowledge in accordance with his knowledge needs to shape and substantiate Jim into the ideal health literate person. It is no wonder, then, that Jim did not adhere to a drug regimen when he was confronted with new athletic priorities and goals back home. Although he was given a lot of medical information (printed and oral) and was educated through a tailored evidence-based patient education programme, the programme did not focus on critical thinking and active knowledge management, nor did it take into consideration the singularities of Jim's biographical temporality, with its changes in everyday life, priorities, attitudes, and values. Jim's life is not just a place where the intervention should "work," but Jim's life defines the intervention and its impact. We might ask how it could have ended differently. Jim's motivation for not taking his medication as prescribed was clearly culturally related. According to Kristeva et al.,¹⁰, p.57 we need to see the "cultural dimensions of health as more than a subjective dimension outside the realm of medical science." This represents more than a phenomenological perspective where the patient's lifeworld is taken into account.

A phenomenological perspective reduces the patient's perspective to "experience" which is something else and is outside the "biomedical" sphere. Kristeva shows how these two spheres are woven together. Translating this to Jim's situation, the patient education programme and the informational book represent a type of bio-medical narrative (text and communication by healthcare providers) while Jim's own experience is a first-person narrative. As pointed to earlier, patient education is traditionally based on and oriented towards content (health information) with little regard for how that content is delivered to or integrated by the patient. To put it in a different way, when the importance of shared meaning-making processes that take place in patient education settings is ignored, the content of patient education is not optimized for each patient. Hence, in the perspective of cultural crossings of care,¹⁰ shared meaning-making, and not merely the delivery of the content (e.g., health information) or shared decision-making, should be the aim of patient education. Shared meaning-making is something other than shared decision-making. The difference is that shared decision-making and similar approaches tend to assume that the patient is a "rational actor," willing and able to implement context-free medical knowledge to his/her own body and life. When viewed in terms of these paths, patient education becomes "educating," which involves complex knowledge translation and creation processes in the context of interactions between patients, healthcare providers, and the health systems. In shared meaning-making practices, biomedical and first-person narratives interact and negotiate, resulting in mutual enrichment.

The dominant knowledge translation approach in healthcare "turns the sick into persons who lack [...] e.g. knowledge (health literacy)."¹⁰, p.57 Accordingly, the specificity of individual lives is not taken into consideration, as was the case with Jim. Knowledge about medical facts is needed "both to identify the singular case as singular and to create a linguistic, co-created place for transactions and translations between patients and medical specialists."¹⁰, p.57 The dominant approach to knowledge translation (turning the sick into a person that lacks), however, risks seeing the patient in light of "ideal images or model narratives about "successful patients," here the "empowered" or "health literate patient."¹⁰, p.56 In this perspective, Jim would be considered an unsuccessful patient with low health literacy who is in need of "repair." Patient education in Jim's case is an example of a supplement ("soft" care) in such "repair." Furthermore, Kristeva et al.¹⁰, p.56 point to two types of chronotopic organization of care: "the first to the universal stasis and Platonic non-time of biomedical evidence; the second to the mundane, biographical time of care as an intertextual co-creation of meaning in encounters between practitioners and patients." In the context of the translation of health information (knowledge), the first could illustrate traditional patient education (delivering the information package) and the second a possible new way of doing "patient educating" through processes of shared meaning-making.

In Jim's case, time was an important factor in his decision to not take his medication as prescribed. Jim's everyday life and priorities changed after kidney transplantation. Once he returned home, he had no health communication follow-up support from the hospital.



The patient education programme was delivered at the hospital and structured around his stay there. We know that he was not into high-level sports when he participated in the patient education programme on the ward. Although the education was tailored to Jim's knowledge needs as a transplant patient in the hospital, it did not include discussions on how to prepare for changes in everyday life. This education practice is an example of how health is objectified into a condition of being outside time. Biomedicine (here the narrative of the hospital's patient education programme) is only concerned with the product of the programme (e.g., knowledge, graft function), not the performative act of creating meaning through translations between actors behind individual choices.

The role of co-creation and meaning-making changes with context. If the goal is how the meaningfulness of evidence requires co-creation then the process does not simply end with further advice and skills given by the healthcare provider. Meaning needs to be co-created in each context of patient – healthcare provider interaction. What kind of clinical consequences does this view lead to? Accordingly, patient education programme must be premised on health professionals' being able to focus less on transmitting content and facts once and for all (represented by the patient education programme and the book in Jim's case), and more on facilitating and promoting patients' own judgement, allowing them to become knowledge-reflective actors who know how to navigate through biographical time. In Jim's case, Jim could have gained from an approach to knowledge and health literacy that encouraged his idiosyncratic way of thinking and experiencing – and transformed health information into a means for sustaining Jim's particular life – not life “in general.” Having another layer in the patient education programme focusing on a broader view of knowledge, including first-person narratives of what life was like at home, could have made it easier for Jim to judge and act regarding the sports situation.

We thus argue that, to create an interaction where knowledge translation processes can occur, patient education programmes need to comprise not just “medical knowledge” but also a philosophy (humanistic knowledge), everyday practices, and a philosophy of interpersonal relationships. Following this thinking, the degree of self-understanding is perhaps the most important factor in predicting an individual's behaviour; therein lies the reality and significance of human choice (e.g., Jim's case). So, in Jim's case, if the healthcare providers had the opportunity to discover Jim's situation, it might have resulted in shared reflections (between Jim and the healthcare providers) and negotiations about doing high-level sports while adhering to prescribed medication. This implies that both the biomedical narrative and the first-person narrative must be looked at equally in the encounter of patient education. They equally represent the core data in knowledge translation processes in situations where the patient is the “end consumer” of knowledge. In the final step of knowledge translation, wherein medical knowledge is transferred to patients, the manner in which knowledge is constructed is vital if we want to assess health literacy. In our view, health literacy depends not only on knowledge but also, more importantly, on knowing as an active process. Health literacy is a

“singular biocultural process” dependent on shared reflections between the patient and the healthcare provider. In a broader sense, health literacy goes beyond the individual and relates to the interaction and translations of knowledge between requirements made by the healthcare community and individual skills. Health literacy needs to emphasize healthcare professionals' skills and their attitudes towards patients' making meaning of their own situation rather than simply receiving information and also how patients themselves access, understand, appraise, remember and apply information about health in their everyday life.

5 | CONCLUSION

In this paper, we argue that health literacy as part of knowledge translation must be understood as a simultaneous interrogation of the patient's and the healthcare provider's co-construction of new and shared meanings and that these co-created worlds will create realities with medical consequences. To illustrate our points, we have examined the case of Jim, a kidney transplant recipient who received standard patient education but lost the graft. If we apply Kristeva's view to this case, graft function is not merely biological but a complex biocultural fact and graft function is seen as a phenomenon that arises from translation between health as a biomedical phenomenon and healing as lived experience. This perspective on knowledge translation opens up an opportunity for shared meaning-making processes between the patient and the health care provider in the patient education encounter. Although our paper used the case of kidney transplantation, our arguments have broader implications and we believe could be used in different contexts involving patient education and health information generally.

AUTHOR CONTRIBUTIONS

Astrid K. Wahl and Eivind Engebretsen were involved in the conception of the work. Astrid K. Wahl, Eivind Engebretsen, and John Ødemark drafted the article. All authors were involved in the critical revision of the article and have given final approval of the version to be submitted.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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