Understanding Each Other In The Medical Encounter: Exploring therapists' and patients' understanding of each other's experiential knowledge through the Imitation Game

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Abstract:	The ability of healthcare professionals to understand the lived experiences of their patients has become increasingly important, but has been a difficult topic to investigate empirically because it involves two distinctive research strands: interpretive phenomenological analysis (IPA) and patient-provider communication (PPC). While IPA focuses on experiences and illness narratives of patients, but not on therapist's understanding of those, PPC surveys focus primarily on effective forms of communication without addressing the actual illness experiences of patients. There is a need for empirical research that combines both strands to investigate not only the experiences of patients, but also whether professionals are able to understand these. This study combined both strands by means of a novel research method called the Imitation Game (combined with other qualitative methods). This sociological method was developed to investigate what different social groups know of each other's lifeworld. This article focused on the important domain of eating disorder treatment to investigate whether therapists were able to understand the experiences of their patients and vice versa. The study provide insights into the domains in which therapists and patients were able to develop insights into each other's experiential knowledge (and where they had difficulties in doing so). The findings also implicate the high potential of the Imitation Game as an interdisciplinary research method. We propose that the Imitation Game may be particularly valuable as a 'can opener' that enables the development of in-depth, qualitative insights into the substantive themes that matter in the lifeworlds of patients and therapists.

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Introduction

The increasing prevalence of chronic illness has significant implications for relationships between patients and healthcare professionals (Sullivan, 2003). Whereas acute patients are usually seen to treat a short-term illness or condition for a limited time period, the relationship between professionals and chronic patients (or other longitudinal patients in need of intensive treatment, such as those with an eating disorder) is more extended, developing over a longer time-frame and focusing on managing symptoms in daily life (Thorne & Robinson, 1989). In such situations, it is crucial for healthcare professionals to understand the *lived experiences of patients*: the ways in which individuals characterize and experience their condition, the meaning-making processes they attach to their condition and treatment, and the experiential knowledge of the condition and treatment that individuals gain over time (Greenhalgh, 2009; Tyreman, 2005; Thorne et al., 2003).

The doctor's office is one of the primary locations in which patients can frame the experiences of their illness in the biomedical context. One of the main focuses of chronic illness research is *communication* between professionals and patients during medical encounters (Paterson, 2001; Scambler & Britten, 2001). A significant result of such research is the recognition of the importance of communication for effective care and the development of a well-functioning therapeutic alliance or relationship (Thorne, 2006). Recently, Britten & Maguire (2015) argued that interactions with professionals can be "profoundly damaging" for patients if patients are not taken seriously (2015: 2). Other scholars identified the provider's *sense of understanding* of the patient's lived experiences with an illness as a core condition for a well-functioning therapeutic relationship (Thorne & Paterson 2000; Thorne, 2006, Evans & Crocker, 2013; Tyreman 2005).

Although the ability of healthcare professionals to understand the lived experiences and the experiential knowledge of their patients is highly important, it is a difficult topic to investigate empirically as the two-straded topic has generally been addressed in different ways. The strand of *illness experiences* and experiential knowledge of patients is often investigated by means of Interpretative Phenomenological Analysis (IPA). Using this approach, subjective processes of meaning-making are the primary focus, leading to rich, detailed insights into the lifeworld of patients (Bramley & Eatough, 2005; Osborn & Smith, 2015). While an important advantage of this approach is that it focuses on patients' personal accounts of their illness and treatment experiences, it does not provide insight into how (healthcare) professionals understand these experiences.

In contrast, the research strand of *patient-provider communication* (PPC) predominantly uses validated, patient-report surveys to measure items such as respectful treatment and 'lay-friendly' explanations of medical/treatment information (Schillinger et al., 2004; Gremigni et al., 2008; Haywood Jr et al., 2014). While this research has put patient-centred health communication on many agendas, it does not reveal much about *how well professionals are able to understand the experiences of patients*, as the questionnaires often do not address the *content* of patient experiences.

Whereas IPA-approaches address the experiences and illness narratives of patients, there is a gap in the literature in relation to how professionals are able to understand these experiences and connect to them in therapeutic encounters with patients. Alternatively, PPC-literature does not focus on the actual *content* (e.g. the illness experiences) of patients. There is a clear need for empirical research that combines both strands to investigate the experiences and experiential knowledge of patients and in what ways professionals are able to understand patient experiences and experiential knowledge. The purpose of this article is to present such an empirical investigation by applying a novel research method: the Imitation Game. This method is ideally suitable to empirically investigate these important questions.

The Imitation Game is a blinded, computer-based experiment (often conducted on one location). Each Game consists of three participants in separate roles:

- Judge: developing experience-based questions as member of a particular social/cultural group
- Non-Pretender (NP): member of the same group, answering these questions naturally, from the experiences of being a member
- Pretender (P): not coming from this group, but trying to formulate a plausible answer by pretending to be a member (Collins & Evans, 2014).

When the P and the NP have formulated their answers to the Judge's question, these are sent back (simultaneously and anonymously). The Judge then indicates which of the two answers (s)he believes to be from the Pretender and why. This process is repeated several times: the Judge can formulate a new question (or follow up an earlier question). The Imitation Game was developed as a sociological method to investigate what different social groups know of each other's lifeworld (Collins & Evans, 2014). When applied to healthcare, the method allows for an investigation into the experiential knowledge of patients and into the

degree and depth of knowledge that healthcare professionals have into the experiential knowledge of patients, thereby combining the strands of research identified above (First author, 2015).

This article investigates whether, how, and to what degree therapists specialized in the treatment of eating disorders were able to understand the experiences of the young women in treatment. Simultaneously, the article investigates whether patients were able to understand the experiences of therapists. For both questions, we used the Imitation Game method and focus groups. The second question has been surprisingly absent from the literature on patient-provider relationships, even though research has shown that patients often have distinct expectations about treatment and about therapists (Mahon, 2000) and that a large discrepancy between these expectations and eventual experiences is an important factor in treatment dropout (Clinton, 1996). Insights into these matters may bear important implications for future research, as we will explore in the discussion section.

Eating disorder treatment can be seen as an extremely relevant case study for empirically investigating what therapists know of the lived experiences of their patients by means of the Imitation Game. Patient/provider relationships in eating disorder treatment are often described as adversarial; interactions in treatment are considered highly complex and are often troubled by diverging perspectives and experiences of therapists and patients (Vitousek et al., 1998; Currin et al., 2009). There is a widely acknowledged need for therapists to gain a better understanding of the lived experiences of persons with an eating disorder (Patching & Lawler, 2009; Darcy et al. 2010; Federici & Kaplan, 2008).²

The next section explores the theoretical concepts that are central to the Imitation Game method ('contributory expertise' and 'interactional expertise', the tacit dimension of both, and the process of socialization, which is at the core of acquiring expertise) and elaborates its applicability to eating disorders and eating disorder treatment. The methods section explores the Imitation Game method and the ways in which it has been applied as a method of understanding relationships and expertise; the methods section also

¹ This 'double design' was conducted at the explicit request of the centre for eating disorder treatment that participated in the study. In preparatory meetings, the director of this centre indicated that the question whether patients were able to understand their therapists was a relevant question as well. Furthermore, it was emphasized that such a double design would be more practically feasible and would feel less like a test for the professionals. The Imitation Game software is quite suitable for this double design. In the discussion, we reflect upon the 'serendipitous' consequence of this pragmatist approach of working together with the eating disorder clinic in order to pursue an imitation game set-up that was perceived as relevant and legitimate. ² Even though better understanding does not necessarily imply more agreement (therapists may still disagree

with the sense-making processes of their patients), it does imply more awareness and better articulation of the patient's perspective, which are often viewed as important conditions for a well-functioning therapeutic relationship.

discusses the focus groups, which were conducted to elicit insights into aspects of mutual understanding and lack of understanding. The results section is organized around the particular domains in which therapists were and were not able to articulate their understanding of their patient's lived experiences, and vice versa. In the discussion section, we interpret the empirical results in the light of existing research, offer reflections on the lmitation Game as an interdisciplinary approach, and reflect upon the particular strengths and limitations of the method. The conclusion summarizes the main findings.

Theoretical underpinnings

Contributory and interactional expertise

The Imitation Game has roots in the sociology of scientific knowledge (SSK) and its sub-field 'studies of expertise and experience' (SEE). Central to the field of SSK is the idea that knowledge is a collective and largely tacit phenomenon, which is acquired through a process of socialization into a particular community (Collins et al., 2015). In their studies on expertise and experience, Harry Collins and Rob Evans have conceptualized the acquisition of expertise as a thoroughly social process, involving a shared tacit dimension. It is through the actor's socialization in the practices of expert groups that their expertise is established (Collins & Evans, 2008).

SEE has developed a rich taxonomy of the various forms of expertise. The most important theoretical concepts in relation to the Imitation Game are 'contributory expertise' and 'interactional expertise'.

Contributory expertise refers to the ability to *perform* a skilled practice. Someone who is a contributory expert in a domain is able to contribute to the domain to which this expertise pertains. For example, a surgeon can be seen as a contributory expert in the specialist domain of surgery, being able to conduct the specific, specialist tasks that belong to this domain. This ability requires both extensive formal knowledge *and* shared tacit knowledge.

Interactional expertise refers to expertise in the language of a specialization in the absence of expertise in its practice. This also requires a degree of enculturation into the expert group, but not necessarily requiring full-blown immersion (Collins & Evans, 2008). Persons spending a significant amount of time within a group of contributory experts, becoming 'socialized', may be able to learn the language pertaining to the (contributory) expertise of this group, even without being able to contribute directly to this domain. Building on the surgeon example, an ethnographic researcher could develop interactional expertise in surgery through

long-term observations. The ethnographer would be able to understand the tacit components and experiences of surgeons, the nuances in their work, without being able to actually complete a (successful) surgery.

The concepts of contributory and interactional expertise offer an interesting new conceptualization of both the lived experiences of chronically ill patients and of therapeutic work. Those with a chronic illness or condition have developed the tacit knowledge necessary to deal with their illness in daily life. They 'contribute' to this domain in various ways, such as acting on subtle bodily cues and testing out disease management strategies. Likewise, the ability of healthcare professionals to understand the lived experiences of these patients can be conceptualized in terms of interactional expertise: while many professionals do not have the same actual experiences and do not have to *act* on this illness the way patients do, they nevertheless need to be able to *understand* the tacit components and experiences of their patients.

In a similar sense, these concepts allow us to explore therapeutic work in terms of contributory expertise as well. Therapeutic work does not only consist of propositional knowledge, but also has a tacit, experience-based component (i.e. therapists exchanging tips on how to approach particular patients, what to say or not to say, how to behave, etc.). Although patients may have developed some understanding of these aspects of therapeutic work through their sustained interactions (i.e. 'interactional expertise'), they do not have the experience of doing therapeutic work themselves (i.e. they do not have contributory expertise in this domain).

Based on this framework, it is clear that both patients and therapists have developed experiential knowledge (in 'living with an eating disorder' and in 'providing therapy'). Both can be conceptualized as forms of 'contributory expertise'. Through their sustained interactions in the therapeutic encounter, both therapists and patients become 'socialized' into each other's community (the assumption being that the therapist becomes more socialized into the eating disorder community than the patient as the main focus of the relationship is to help the patient recover and manage an eating disorder). The Imitation Game allows for an investigation into the extent in which therapists and patients developed an understanding of each other's experiential knowledge.

Eating disorders: complicated relationships and 'irrational' experiences?

Such mutual understanding is a particularly relevant topic for eating disorder treatment. Eating disorder patients perceive therapists to be unable to understand what the disorder means in their lived experiences

(Dawson et al., 2014); such understanding has consistently proved to be highly important in how patients perceived the quality of their treatment (De La Rie et al., 2008). When this understanding is missing, it often leads to discontent, frustration, and detrimental effects on how treatment is perceived (Darcy et al., 2010; Dawson et al., 2014).

A range of critical feminist and discourse analytic studies have pointed to a further complication. Within therapeutic encounters, the lived experiences of those with an eating disorder are often depicted as *symptomatic* of the illness, thereby neglecting and trivializing them a priori (Lester, 1997; Gooldin, 2008; Bell, 2009). This vein of scholarship has been persistent and persuasive in contextualizing (and problematizing) why the relationships between therapists and patients in eating disorder treatment are often perceived as adverse. Developing and testing ways, such as the Imitation Game, for therapists to understand the lived experiences of those with an eating disorder has the potential to improve eating disorder care and the relationships between patients and therapists.

Explanatory models of illness

Feminist literature on eating disorders elucidates that the lived experiences of persons with an eating disorder are not simply the irrational expressions of various individuals, but form a coherent frame of sense-making processes that need to be understood in their social and cultural context (Bordo, 1997; Malson, 2004; King, 2004). Simply dismissing such experiences as irrational expressions of the illness is likely to be extremely problematic in terms of establishing a workable therapeutic relationship. Instead, it becomes more important to understand such – often shared - systems of understanding.

A useful theoretical framework for this purpose is provided by Fox et al. (2005), who built on Kleinman's concept of *explanatory models*, understood as narrative frameworks used by lay and professional people to make sense of disease. This concept enables us to understand the lived experiences of patients as a "lay construction of an illness grounded firmly in the experiential and contextual reflections of [its] participants" (2005: 963). Such lay constructions emerge "as a coherent system of understanding, grounded in [...] shared experiences [...], as opposed to externally-imposed models of disease" (2005: 965). The notion of 'explanatory models' provides a frame for understanding differences between medical understandings of eating disorders and the experiences of patients, while sensitizing us to the need for therapists to acquire understanding of the explanatory models constructed by their patients.

The notion of 'explanatory models' clearly resonates with the concepts of 'contributory' and 'interactional expertise'. Together, they emphasize two important points. First, the lived experiences of persons with an eating disorder should not be read as irrational expressions of the illness, but need to be understood as sense making processes. Second, these experiences and sense-making processes are not (only) individual, but often shared through socialization.

When taking these points together, they harbor important implications for both professionals and researchers. Professionals are encouraged to *acquire a frame of reference* that can help them understand the experiences of persons with eating disorders (cf. Vitousek & Watson, 1998). For researchers, the implication is that investigating whether professionals are able to acquire such frames becomes an important empirical topic. The remainder of the article focuses on the results of an empirical study in which this topic was investigated through the utilization of the novel Imitation Game method.

Methods

The history of the Imitation Game can be traced back to the Turing-test for artificial intelligence (Turing, 1950). More recently, it was developed as a social science research method to compare what different social or cultural groups know about each other (Evans & Collins, 2010). As outlined in the introduction, the Imitation Game is a blinded, computer-based experiment with three distinctive roles:

- Judge: developing experience-based questions as member of a particular social/cultural group
- Non-Pretender (NP): drawn from the same group, answering these questions naturally, from the experiences of being a member of this group
- Pretender (P): not coming from this group, but trying to formulate a plausible answer by pretending to be a member of this group (Collins & Evans 2014).

What follows is a recursive cycle in which the two participants (P and NP) formulate answers, which are evaluated by the Judge, who formulates a new question, which is sent to both participants again. Judges formulate their own questions.

Two different Imitation Game set-ups were used. In 'Set-up 1', the roles of Judge and Non-Pretender were played by persons with an eating disorder. Therapists were playing the role of Pretender: they were asked to answer the questions they received as if they had an eating disorder themselves. In 'Set-up 2',

therapists played the role of Judge and Non-Pretender. Patients were playing the role of Pretender: in this setup, they were answering questions regarding experiences of therapists in providing care as if they were therapists themselves.

Because the goal of the Judge is to identify the Pretender, it was emphasized that Judges should try to think of questions they regarded to be particularly informative about their own experiential knowledge (i.e. regarding their experiences with an eating disorder or their experiences as a therapist treating those with an eating disorder). The two designs of the method aim to provide insights into how well *therapists* are able to understand the experiential knowledge of their patients and how well *patients* are able to understand the experiential knowledge of their therapists. Figure 1 and 2 show how the Imitation Game has been utilized:

[FIGURE 1 + 2 ABOUT HERE]

In total, twelve Imitation Games were played in one afternoon session, with a total of 14 participants (8 persons with an eating disorder, 6 therapists), ranging on average 90 minutes per Game. The data produced by these games (automatically recorded by specialized software) consisted of the full dialogues (Judges questions, Pretender and Non-Pretender answers, the Judge's decisions and their rationale for the decision). The Games were conducted on laptops set-up in one large room in the centre.³

Although the developers of the Imitation Game have emphasized the quantitative potential of the method (Collins & Evans, 2014), the way in which we apply the method is methodologically most closely linked to an interpretative qualitative research approach. It is tied to phenomenological approaches through its emphasis on the lifeworld and experiential knowledge, as well as harboring characteristics of ethnographic research through its focus on the 'culture' of the 'contributory experts'. In addition, there is a clear similarity to participatory research approaches (as it is the Judges rather than the researchers who develop the questions).

Other methods

In order to generate additional qualitative insights into aspects of understanding and to elaborate on the results of the Imitation Games, three focus groups were organized immediately after the Imitation Games.

³ The specific seating allocation software of the Imitation Game helped maintain confidentiality as participants were unable to identify against whom they were playing.

First, two separate focus groups were organized (one for patients, the other for therapists). The first focus group was coordinated by a therapist working as an 'experience worker'⁴. The first author coordinated the therapist focus group. Both focus groups had a length of approximately 45 minutes. They consisted of 8 and 6 participants. After these separate focus groups, a combined focus group (14 participants) of approximately one hour was held. All focus groups were recorded and transcribed verbatim.

The focus groups were semi-structured around the following themes: experiences with the game; motivations behind the questions asked as Judges; strategies for answering questions as pretenders; and general suggestions about the method. The joint focus group focused on facilitating discussion amongst both groups of participants, in order to generate participant explanations for why understanding each other's experiences was perceived as challenging or easy.

Research context

The study took place in a specialist centre for eating disorder treatment in the Netherlands. The centre offers outpatient treatment and part-time treatments, both on individual and group level. The therapists involved in this centre all had long-term, specialized knowledge in the treatment of eating disorders. In total, six therapists (one male, five female) and eight persons diagnosed with an eating disorder (all female) participated in the research. Table 1 and Table 2 provide more detailed information about the most important characteristics of both groups:

[TABLE 1 AND TABLE 2 ABOUT HERE]

Participants have been recruited by means of various information flyers provided to them by therapists (the flyers were developed together with the centre) and by means of informal communication.

Ethics

⁴ The term 'experience worker' refers to the Dutch term *ervaringsdeskundige*. This is a term denoting someone who has been a patient and has developed experiential knowledge through the experiences of being a patient, but is now using that knowledge to offer counsel to other patients. It is often an official job description, especially in mental health care.

Research ethics formed an important part of the study. Ethical approvals have been obtained at the relevant ethical review committee. The experience worker informally assessed which participants would be suitable to participate. Only persons involved in the outpatient-program of the centre could participate. Much care was taken to ensure informed consent: all participants have been informed thoroughly in advance about the aims and methods of the research. The voluntary character of participation has also been stressed. All participants were over 18 years of age. All data has been anonymized.

Analytical procedure

A thematic content analysis (Guest et al., 2012) was conducted by the first author. All material (the Imitation Game dialogues and focus groups) has been coded in three substantive steps. No distinction was made between Imitation Game analysis and focus group coding process to allow for comparability of the results. A process of *open coding* allowed for a line-by-line analysis of all transcripts. The process of *axial coding* then enabled a more detailed investigation into the main themes that were emerging from these transcripts (e.g., 'dealing with weight changes'). Finally, the process of *selective coding* allowed for establishing an order and relation between these main themes (e.g., 'dealing with weight changes' as a sub-theme of 'fear of losing control') (Mortelmans, 2007). The emerging themes were discussed between the two authors until consensus was reached. The analysis was done inductively, although theoretical insights were used as 'sensitizing concepts' (ibid.) The research was conducted in Dutch. All quotes have been translated by the first author and checked by the second author, who is a native English speaker.

Results

The thematic analysis led to the identification of various domains in regard to patient's and therapist's understanding and lack of understanding of each other's experiences. The inductively identified domains have been categorized along two axes: 'therapist – patient' and 'showing knowledgeability – lacking knowledgeability' (of each other's experiences), drawing on material from the Imitation Games and the focus groups:

⁵ Protocol number METC-2012-409.

(+) Therapists showing <mark>knowledge</mark> of	(+) Patients showing <mark>knowledge</mark> of
patient experiences	therapist experiences
Domain: Fear of losing control	Domain: Dealing with problematic eating habits in therapy
Sub-domain: Dealing with weight changes	
Sub-domain: Struggling with the unexpected or new	
(-) Therapists lacking <mark>knowledge</mark> of	(-) Patients lacking <mark>knowledge</mark> of
patient experiences	therapist experiences
Domain: Conflicting meaning of everyday objects	Domain: 'Over-rationalized' (i.e. protocol-based,
Domain: Experiencing eating disorder as 'part of the self'	systematic) perception of therapeutic work
	Sub-domain: Emotional labour
	Sub-domain: Negotiating autonomy
	Sub-domain: Tinkering

Therapists showing knowledge of patient experiences

Therapists convincingly expressed knowledge of the patient experience in several domains. The *fear of losing control* was one overarching theme. Therapists recognized that the fear of losing control is a key underlying experience for many patients with an eating disorder. This fear of losing control becomes clear in two subdomains (dealing with weight changes; struggling with the unexpected or new).

The first sub-domain is about dealing with weight changes:

QUESTION OF NON-PRETENDER ANSWER JUDGE'S RATIONALE PROVIDED BY JUDGE (Patient): **PRETENDER** (Therapist): DECISION⁶: JUDGE ABOUT THE DECISION: **ANSWER** (Patient): Non-Pretender Very up-and-down.... It does feel very up-and-down OH GOD! How do you feel, is the sometimes I am happy, when you gain weight. On the Terrible, dirty, when you are Pretender. because I am then one hand, you are happy because fat, ugly, and gaining weight conquering my eating it is part of recovery. But gaining inferior. during your

⁶ The Judge compares the two, anonymous, answers and decides whether 'answer 1' or 'answer 2' comes from the Pretender. In this case, the 'incorrect' identification means that the Judge chose the 'Non-Pretender' answer as the answer coming from the Pretender.

treatment?	disorder, but mostly I	weight remains scary.
	feel scared. Scared that	
	the weight gain won't	
	stop and I'll turn into a	
	big fat pig	

Excerpt from Imitation Game 1

This excerpt shows the therapist's ability to express the ambivalent experiences of the patient in relation to gaining weight during treatment: perceiving it as something good, but nonetheless scary. Furthermore, the therapist recognizes that this patient's primary fear is not the weight gain per se, but the fear of *not being able to control* this weight gain.

The second sub-domain can be labelled 'struggling with the unexpected or new'. Many questions of patient Judges focused on experiences of unusual or new events, such as going on vacation or joining in for Christmas dinner. Fear of losing control is also of great concern. The excerpt below illustrates how one therapist is able to convincingly express this (i.e. the answer is recognized as valid by the Judge⁷):

QUESTION OF	NON-PRETENDER	PRETENDER	JUDGE'S	ARGUMENTATION
JUDGE (Patient):	ANSWER (Patient):	ANSWER	DECISION:	PROVIDED BY JUDGE
		(Therapist):		ABOUT THE DECISION:
What are you	That I am going to feel	Especially that	Non-Pretender is	An eating disorder is mainly
scared of on	inferior. I am scared	everything is	the Pretender.	about having control, and
vacation or in a new	that there will be	different and I don't		not so much about feeling
place?	people that will	know what to		inferior. This only comes
	bulldoze me, which will	expect, when we		later.
	make me feel sad, ugly,	will eat, if there is		
	and like a failure. This	even food that I can		
	can be when I have the	eat, who will be		
	idea that someone is	present during the		
	prettier or very self-	mealsthose kind		
	confident (overruling).	of things.		

Excerpt from Imitation Game 1

This excerpt provides another example of a therapist expressing understanding of the lived experiences of this patient: for the patient, the fear of situations and experiences out of their control is frequently perceived as the most frightening aspect of dealing with a new situation. The review by the patient Judge affirms this concern.

An interesting aspect of the Imitation Game is that simultaneously, the answer of the Non-Pretender did not convince the Judge (at least not sufficiently). Whilst a full analysis of why this is the case is beyond the focus of this article, there is some evidence in the data (i.e. Judge's reasonings) that the Pretender answers addressed more facets of the experience of patients (which is due to therapist's 'pooled expertise' of seeing many patients and being able to draw on many patient stories. Non-Pretender answers often addressed fewer facets of this. Moreover, the experiences of some patients also proved to be idiosyncratic with the Judge's experience. In the discussion, this issue is further discussed.

Therapists lacking knowledge of patient experiences

Our research has revealed the domains in which therapists faced difficulties in convincingly expressing knowledge of patient experiences. These two domains were identified: *conflicting meanings of everyday objects* and *the eating disorder as 'part of the self'*. The *conflicting meanings of everyday objects* can be seen in the following excerpt from the joint focus group; the therapists and patients reflected on how a therapist provided a rather surprising answer about the 'functionality' of a mirror in one of the Imitation Games:

(Discussion leader 1): What was also remarkable was that many questions were asked about `what does it do [with you] when you look into the mirror?', `how does that feel?', and those kinds of questions (. . .)

(Patient 1, addressing therapists in a rather sarcastic voice): Yes, how does that make you feel? (Laughter) The mirror, which was supposedly very functional (ironic emphasis). Who was that? (Loud laughter)

(Therapist 1, reluctantly): I didn't do so well, did I? (Laughs)

(Discussion leader 2): But what was your reasoning then? Why was that question so important for you all?

(Patient 1:) Well, (...) this is more from my own perspective, but what it does for us (...) for me the mirror greatly influences my day, for example. And also that you can use a mirror for positive ends, making yourself pretty (...) but I also looked in the mirror for a long time to see that I was too fat, so seeking negative affirmations, and that was not from my 'healthy me', but it is a large influence the mirror can have in a given moment. And of course [they are] my thoughts but it is also the burden carried by the mirror (Excerpt of joint focus group, 12-09-2013)

This excerpt centers on how one of the patients expressed her surprise about a particular answer about mirrors that was given during one of the Imitation Games. The way in which the patient reacted during the focus group and her subsequent elaboration highlight how this particular therapist seemed to lack knowledge about the ambivalent but very large impact that mirrors have for many patients. As well, the elaboration of this patient provided a detailed understanding of the role of this everyday object (the mirror) in her own lived experience.

The second domain in which therapists experienced difficulties is about how patients experience the eating disorder as 'part of the self'. The excerpt below from the focus group with therapists illustrates this:

(Discussion leader): Can you remember more questions from clients of which you all thought "that is a good question; I had difficulties in answering that one"?

(Therapist 1): Yes: "what did you find the most difficult to share from the point of view of your eating disorder?"

(Therapist 2): Oh yes, yes, that is a very good question indeed.

(Therapist 1): But it is also a question like..." from the point of view of your eating disorder", that is so much....what does that mean then?

(Therapist 2): Yes I also noticed that in the [therapy] sometimes they talk about "my eating disorder". But what is that then? Is that only the part about eating or also all the other shit that accompanies it? They usually only talk about eating. (Therapist focus group, 12-09-2013).

This quote shows how difficult it can be for therapists to understand what a patient means when referring to *their* eating disorder, whether it 'only' refers to eating-related matters or whether it is experienced as a broader part of the patient's identity. As the earlier quote concerning the mirror makes clear, patients also view aspects such as 'seeking negative affirmations' (by obsessively looking in the mirror) as part of their identity as someone with an eating disorder.

3.3 Patients showing knowledge of therapist experiences

The Imitation Games with therapist Judges revealed the differences in the knowledge of patients and therapists in regard to each other's experiences. Overall, patients found it harder to show knowledge of the experiences of therapists. One domain could be identified in which a patient succeeded in understanding the knowledge and experiences of therapists: dealing with problematic eating habits in therapy. The next excerpt discusses how to deal with veganism in therapy:

QUESTION OF JUDGE (Therapist):	NON-PRETENDER ANSWER (Therapist):	PRETENDER ANSWER (Patient):	JUDGE'S DECISION:	ARGUMENTATION PROVIDED BY JUDGE ABOUT THE DECISION:
A patient tells you that she has been vegan for one year. What do you think of that and how do you deal with this in the treatment?	My first reaction is an alarm bell in the sense that I ask myself if this is related to the eating disorder. If the choice of being a vegan falls in the period in which the eating disorder is active, I will express my knowledge and experience, which is: that this choice is often determined by the eating disorder. In a group or in the	I would continue to ask about the motives in becoming a vegan. Is this from the eating disorder or not? In addition, there are regulations about healthy food and how we do this in [the centre]. These basic rules need to be met. The advice to the client	Pretender is the Pretender.	A very good answer of both. Now I am starting to doubt again

This became visible when comparing the number of correct identifications and the confidence levels with which the decision was made. Judges were asked to record their confidence in their judgement on a scale of 1 to 4: 1) I have little to no idea; 2) I am more unsure than sure; 3) I am more sure than unsure; 4) I am pretty sure. The patient Judges correctly identified 2 Pretenders out of 6 Games (but only with confidence level 2). The therapist Judges correctly identified 5 Pretenders out of 6 Games (all but one with confidence level 3 or 4). Although the numbers very small, these results are in line with expectations drawn from the underlying theories and might therefore be generalizable.

clinic, it is difficult, if not impossible, to follow such an eating pattern, and I will elaborate on that. It is also practically not possible because of reactions from	would be that this person can become a vegan again after treatment, but then not dictated by the eating disorder (if that was the	
the group.	case).	

Excerpt from Imitation Game 9

The quote shows that the Pretender (patient) was able to communicate a convincing answer to this question; she was able to make the Judge doubtful about the previous choice. This may be because of experiences with other patients (e.g. in treatment groups) trying to 'use' veganism as a strategy for restricting food intake. In the large majority of the cases, however, patients experienced difficulties in understanding the experiences of therapists.

3.4 Patients lacking knowledge of therapist experiences

The study revealed one main domain in which patients consistently experienced a lack of knowledge regarding the experiences of therapists: the *over-rationalized image of therapeutic work*. Many patients had a very protocol-based and systematic view of therapeutic work and did not understand the large tacit dimension involved in the daily work of therapists. Within this domain, three sub-domains can be identified: *emotional labour*, *negotiating autonomy*, and *tinkering* (Mol et al., 2010)

An example of *emotional labour* is the considerations that go beyond therapy protocols:

QUESTION OF	NON-PRETENDER	PRETENDER ANSWER	JUDGE'S	ARGUMENTATION
JUDGE	ANSWER (Therapist):	(Patient):	DECISION:	PROVIDED BY
(Therapist):			1/2	JUDGE ABOUT THE DECISION:
How do you start your first intake meeting?	You introduce yourself, explain the purpose of the meeting, how the intake procedure will go, and how long the conversation will take. The goal is to provide clear information and make sure the client is at ease.	I introduce myself, who I am and what I do, and why this conversation is taking place. Next I talk about how the conversation is going to go.	Pretender is the Pretender.	The second response is very businesslike While in the first answer it is also mentioned that you need to make someone at ease.

Excerpt from Imitation Game 8

During intake meetings, therapists need to do more than simply discussing the steps of therapy at the centre, such as how to make a patient feel at ease. This more tacit dimension is not recognized by this patient.

The second sub-domain is about *negotiating autonomy*. This is another implicit aspect of therapeutic work that is often missing from the more rationalized view that patients have of therapists, such as when considering hospitalizing a patient:

QUESTION OF JUDGE (Therapist): What do you do when someone actually needs	NON-PRETENDER ANSWER (Therapist): If someone does not want to be hospitalized,	PRETENDER ANSWER (Patient): I would stay in conversation with the	JUDGE'S DECISION:	ARGUMENTATION PROVIDED BY JUDGE ABOUT THE DECISION: The second response
to be hospitalized but definitely does not want this? For instance, someone is severely underweight but only willing to come to [the centre] once a week. While as a therapist you know that this is insufficient and this client is actually in need of more intensive treatment?	there is no point in pushing it through (exception is an acutely life-threatening situation); I would accept the wish of the client and work weekly on agreed goals. When there is insufficient progress in the treatment, more intensive treatment can be considered again.	client. I would involve people in his or her environment in the treatment and inform them about the seriousness of the problem. I do not accept the wishes of the client. If necessary, I would state that hospitalization is the only option.	the Pretender.	is something you exactly should <i>not</i> do, because it doesn't make sense. If someone is not behind the treatment, it is futile.

Excerpt from Imitation Game 8

This excerpt shows that therapeutic work is not only based on the 'rational' decision of the therapist (as assumed here by the pretending patient). Instead, therapeutic work is a delicate process of negotiating the patient's autonomy: trying to determine when someone is ready to change while recognizing the patient's autonomy in this change process.

The third sub-domain could be described as tinkering (a term coined by Annemarie Mol, Ingunn Moser, and Jeannette Pols (2010) to describe the 'attentive experimentation' done by caregivers in order to adapt to specific situations). Many patients viewed therapeutic work as only protocol-based, whereas therapists emphasized the continuous balancing, experimenting, and compromising involved in providing therapy. However, an excerpt from the joint focus group reveals how the patient understands therapeutic work:

(Therapist): What did you find hard about pretending to be a therapist? (Patient): I think I tried too hard about...using protocols and fancy terms and such. [...] I really tried to pretend to be someone with a systematic approach (Joint focus group, 12-09-2013, emphasis added).

It was primarily this strategy of overemphasizing the systematic approach that revealed most patients as pretenders. While patients had some knowledge of the work of therapists, they did not have a 'feel' for it.

In sum, there are many implicit aspects of how therapists experience their work that are not well understood by patients. In contrast, therapists were able to express knowledge of particular aspects of the lived experiences of those with an eating disorder (the fear of losing control), but had difficulties in relation to more subtle aspects (the conflicting meanings patients experienced in objects like mirrors or the identification of the eating disorder as 'part of the self').

Discussion

This research investigated the ways in which patients and therapists involved in eating disorder treatment were or were not knowledgeable of each other's experiences. The Imitation Game was a valuable method for unravelling the domains in which such substantive understanding did or did not develop. This discussion interprets the empirical results in the light of existing research on eating disorder experiences and the therapeutic relationship. Given the novel character of the method and the new application of this method to the context of health research, the discussion also reflects on the strengths and limitations of the Imitation Game as an interdisciplinary method.

Interpreting the results

The empirical results resonate with phenomenological literature on eating disorder experiences and with ethnographic accounts on therapeutic work. Both the importance of 'control' and the view that the eating disorder constitutes a 'part of the self' have been noted in previous literature (Rich, 2006; Tiggemann & Raven, 1998; Warin, 2005; Walters et al., 2015). The large tacit dimensions of therapeutic work have also been regularly discussed in ethnographic literature (Mol et al., 2010; Welsh & Lyons, 2001). Most research in the eating disorder field focuses solely on the lack of understanding *therapists* have about the experiences of patients. The results of this study indicate, however, that there are also many aspects in which patients lack understanding of therapist's experiences and the implicit aspects of therapeutic work. This points to important new directions for research; this could include researching how such differences in understanding contribute to the complicated relationships between therapists and patients and whether increased insights into the tacit dimensions of therapeutic work can lead to improved mutual understanding and, ultimately, better outcomes for both the patients and their therapists.

The Imitation Game and interdisciplinarity

The complex nature of many health problems, including eating disorders, necessitates interdisciplinary approaches. When exploring health concerns such as eating disorders, it is important to utilize concepts, insights, and methodological approaches from other fields. While previously used in the sociology of knowledge, the Imitation Game is a useful methodology for exploring patients' and therapists' experiences. Based on this empirical study, two beneficial aspects of applying this novel method can be identified.

First, the Imitation Game is able to *connect* strands of research that have been mostly separate.

Although numerous studies investigated the lived experiences of patients, they seldom investigate whether professionals are able to understand these experiences. On the other hand, literature in the domain of patient-provider communication focuses primarily on effective forms of patient-provider communication, while largely neglecting the actual *content* of patients' illness experiences. As an innovative methodological approach, the Imitation Game is able to connect these different strands and deliver clear data on both patient-provider communication and on the content of illness and treatment experiences.

Secondly, although the notion 'explanatory models' sensitizes us to differences between medical understandings of illness and the lived experiences of patients, the core concepts underlying the Imitation Game ('contributory expertise' and 'interactional expertise') can offer a broader *interpretative frame* for understanding the experiential knowledge of patients, its shared component (socialization), and the various 'explanatory models' of illness. The notion of 'contributory expertise' offers an interpretative frame to understand the experiential knowledge chronically ill patients develop through their lived experiences with a specific condition (an eating disorder, in this case). Likewise, the notion of 'interactional expertise' offers a frame to understand (and empirically investigate) the ability of healthcare professionals related to understanding the lived experiences of patients with eating disorders.

The Imitation Game as 'can opener'

This is one of the first studies worldwide that utilizes the Imitation Game method in a healthcare context.

Through this approach, the study was able to provide an in-depth understanding of therapists' and patients' understanding of each other's lived experiences in the context of eating disorder treatment.

As an innovative method, the Imitation Game also raises questions. One question is how in-group variety can be taken into account, as not every patient has similar experiences. While this could become

problematic when the Imitation Game is utilized only as a *quantitative test* to find out the percentage of therapists able to 'pass' as pretender⁹, such issues are much less problematic when the Imitation Game is used for qualitative purposes. As such, it can render these differences visible through a detailed analysis of the dialogues.

Second, as the Imitation Game is a form of written communication, this raises the question of how much language skills (how well someone is able to express him/herself) influence the Judge's decision.

However, the influence of language skills is likely to be mostly problematic for a quantitative comparison (as it may be read as a 'contamination' of the results), whereas for a *qualitative* analysis the *content* of dialogues is most relevant.

Based on this study, we propose that the Imitation Game can best be conceptualized as a 'can opener' that enables the development of in-depth, qualitative insights into the substantive themes that matter in the lifeworlds of patients and therapists.

Conclusion

The question of whether healthcare professionals are able to understand the lived experiences of their patients is very important, but is under-investigated empirically. While interpretive phenomenological analyses focus on patient experiences and illness narratives (but not on therapist's understanding), patient-provider communication surveys focus primarily on effective forms of communication without addressing the actual illness experiences of patients. There is a need for empirical research that combines both strands of research to investigate not only the experiences of patients, but also whether professionals are able to understand these experiences. This study combined both strands by means of a novel research method called the lmitation Game. This article focused on eating disorder treatment to investigate whether therapists were able to understand the experiences of their patients and vice versa. The study showed that there are domains in which therapists developed substantive knowledge about the lived experiences of patients, but also domains in which they had more difficulties. Furthermore, patients were able to develop substantive knowledge about the experiences of their therapists, but overall had a rather rationalized understanding of therapeutic work.

⁹ This quantitative comparison is considered to be an important goal by Collins et al. (2015). They use a basic summary statistic called the 'pass rate', which they argue can be taken as a proxy for the extent to which one group understands the other.

The application of the Imitation Game to research patient experiences and patient-provider communication proved advantageous in two ways. First, the method was able to connect strands of research that have hitherto been mostly separate. Second, the core concepts underlying the Imitation Game offered a broader interpretative frame for understanding the experiential knowledge of patients and the various 'explanatory models' of illness. Based on this study, we propose that the Imitation Game may be particularly valuable as a 'can opener' that enables the development of in-depth, qualitative insights into themes that matter in the lifeworlds of patients and therapists.



REFERENCES

(Author, 2015)

Bell M (2009) '@ the doctor's office': Pro-anorexia and the medical gaze. Surveillance & Society 6(2): 151-162.

Bordo S (1997) Anorexia nervosa: Psychopathology as the crystallisation of culture. In: Counihan C and Van Esterik P (eds) *Food and Culture, A Reader*. Abingdon: Routledge, pp. 226–250.

Bramley N and Eatough V (2005) The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health* 20(2): 223-235.

Britten N and Maguire K (2015) Lay knowledge, social movements and the use of medicines: Personal reflections. *Health*. DOI: 1363459315619021.

Caron-Flinterman JF (2005) A new voice in science. Patient participation in decision-making on biomedical research.

Clinton DN (1996) Why do eating disorder patients drop-out? Evaluating the role of patient-therapist frame of reference. *Psychotherapy and Psychosomatics* (65):29-35.

Collins H and Evans R (2008) Rethinking expertise. Chicago: University of Chicago Press.

Collins H (2011) A New Method for Cross-Cultural and Cross-Temporal Comparison of Societies. European Research Council (269463 IMGAME)

Collins H and Evans R (2014) Quantifying the Tacit: The Imitation Game and Social Fluency. *Sociology* 48(1): 3-19.

Collins H, Evans R, Weinel M, Lyttleton-Smith J, Bartlett A and Hall M (2015) The Imitation Game and the Nature of Mixed Methods. *Journal of Mixed Methods Research*. DOI: 1558689815619824.

Currin L, Waller G and Schmidt U (2009) Primary care physicians' knowledge of and attitudes toward the eating disorders: do they affect clinical actions? *International Journal of Eating Disorders* 42(5): 453-458.

Darcy AM, Katz S, Fitzpatrick KK, Forsberg S, Utzinger L and Lock J (2010) All better? How former anorexia nervosa patients define recovery and engaged in treatment. *European Eating Disorders Review* 18(4): 260-270.

Dawson L, Rhodes P and Touyz S (2014) "Doing the impossible": the process of recovery from chronic anorexia nervosa. *Qualitative health research* 24(4): 494-505.

De La Rie S, Noordenbos G, Donker M and Van Furth E (2008) The quality of treatment of eating disorders: A comparison of the therapists' and the patients' perspective. *International Journal of Eating Disorders* 41(4): 307-317.

Evans R & Collins H (2010) Interactional expertise and the imitation game. In: Gorman ME (ed) *Trading zones and interactional expertise: Creating new kinds of collaboration.* MIT Press, pp. 53-70.

Evans R & Crocker H (2013) The imitation game as a method for exploring knowledge(s) of chronic illness. *Methodological Innovations Online* 8(1): 34-52.

Federici A and Kaplan AS (2008) The patient's account of relapse and recovery in anorexia nervosa: A qualitative study. *European Eating Disorders Review* 16(1): 1-10.

Fox N, Ward K and O'Rourke A (2005) Pro-anorexia, weight-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia. *Sociology of health & illness* 27(7): 944-971.

Gooldin S (2008) Being anorexic. Medical anthropology quarterly 22(3): 274-296.

Greenhalgh T (2009) Chronic illness: beyond the expert patient. *BMJ: British Medical Journal*, 338(7695): 629-631.

Gremigni P, Sommaruga M and Peltenburg M (2008) Validation of the Health Care Communication Questionnaire (HCCQ) to measure outpatients' experience of communication with hospital staff. *Patient education and counseling* 71(1): 57-64.

Guest, G, MacQueen KM & Namey EE (2012). *Applied thematic analysis*. Thousand Oaks, California: Sage.

Haywood Jr CH, Bediako S, Lanzkron S, Diener-West M, Strouse J, Haythornthwaite J, Onojobi G and Beach MC (2014) An unequal burden: Poor patient—provider communication and sickle cell disease. *Patient education and counseling* 96(2): 159-164.

King A (2004) The prisoner of gender: Foucault and the disciplining of the female body. *Journal of International Women's Studies* 5(2): 29–39.

Lester RJ (1997) The (dis) embodied self in anorexia nervosa. *Social Science & Medicine* 44(4): 479-489.

Mahon J (2000) Dropping out from psychological treatment for eating disorders: What are the issues? European Eating Disorders Review 8(3):198-216.

Malson H (2004) The Thin Woman: Feminism, Post-Structuralism and the Social Psychology of Anorexia Nervosa. Oxford: Taylor & Francis.

Mol A, Moser I and Pols AJ (2010) Care in practice: On tinkering in clinics, homes and farms. Bielefeld: Transcript Verlag.

Mortelmans D (2007) Handboek kwalitatieve onderzoeksmethoden. Leuven/Den Haag: Acco.

Osborn M and Smith JA (2015) The Personal Experience of Chronic Benign Lower Back Pain: An Interpretative Phenomenological Analysis. *British Journal of Pain* 9(1): 65-83.

Patching J and Lawler J (2009) Understanding women's experiences of developing an eating disorder and recovering: a life-history approach. *Nursing inquiry* 16(1): 10-21.

Paterson B (2001) Myth of empowerment in chronic illness. *Journal of advanced nursing* 34(5): 574-581.

Rich, E. (2006). Anorexic dis (connection): managing anorexia as an illness and an identity. *Sociology of Health & Illness*, 28(3), 284-305.

Scambler G. & Britten N (2001) System, lifeworld and doctor-patient interaction: issues of trust in a changing world. In: Scambler G (ed) *Habermas, critical theory and health*. London and New York.: Routledge, pp. 45-68.

Schillinger D, Bindman A., Wang F, Stewart A and Piette J (2004) Functional health literacy and the quality of physician–patient communication among diabetes patients. *Patient education and counseling* 52(3): 315-323.

Sullivan M (2003) The new subjective medicine: taking the patient's point of view on health care and health. *Social science & medicine* 56(7): 1595-1604.

Thorne S (2006) Patient-Provider Communication in Chronic Illness: A Health Promotion Window Of Opportunity. *Family & Community Health* 29(1): 4S-11S.

Thorne SE and Paterson BL (2000). Two decades of insider research: what we know and don't know about chronic illness experience. *Annual review of nursing research* 18(1): 3-25.

Thorne SE and Robinson CA (1989) Guarded Alliance: Health Care Relationships in Chronic Illness. *Image: the Journal of Nursing Scholarship* 21(3): 153-157.

Thorne S, Paterson B and Russell C (2003) The Structure of Everyday Self-Care Decision Making in Chronic Illness. *Qualitative health research* 13(10): 1337-1352.

Tiggemann M and Raven M (1998) Dimensions of control in bulimia and anorexia nervosa: Internal control, desire for control, or fear of losing self-control? *Eating Disorders* 6(1): 65-71.

Turing AM (1950) Computing Machinery and Intelligence. *Mind* 59(236): 433-460.

Tyreman S (2005) An expert in what?: The need to clarify meaning and expectations in "The Expert Patient". *Medicine, Health Care and Philosophy* 8(2): 153-157.

Vitousek K, Watson S and Wilson GT (1998) Enhancing motivation for change in treatment-resistant eating disorders. *Clinical psychology review* 18(4): 391-420.

Walters, B. H., Adams, S., Broer, T., & Bal, R. (2015). Proud2Bme: Exploratory research on care and control in young women's online eating disorder narratives. *Health*:, 1363459315574118.

Warin M (2005) Transformations of intimacy and sociality in anorexia: Bedrooms in Public Institutions. *Body & Society* 11(3): 97-113.

Welsh I and Lyons CM (2001) Evidence-based care and the case for intuition and tacit knowledge in clinical assessment and decision making in mental health nursing practice: an empirical contribution to the debate. *Journal of psychiatric and mental health nursing* 8(4): 299-305.

Participation number	Age at research	Type of treatment	Duration of ED (years)	Diagnosis
IG2a	23	Outpatient	9	Bulimia nervosa
IG2b	22	Outpatient	7	ED - NOS
IG 4a	24	Outpatient	6	Bulimia nervosa
IG 4b	26	Outpatient	3	ED - NOS
IG 6	36	Outpatient	15	Anorexia nervosa
IG 8	22	Outpatient	5	ED - NOS
IG 10	29	Outpatient	2	Anorexia nervosa
IG 12	27	Outpatient	13	ED - NOS

Table 1. Participating patients: age, type of treatment, details of eating disorder.

Participation number	Age at research	Work history in mental health	Work history in ED	Previous diagnosis of ED
		care	treatment	
IG1	38	12 years	12 years	No
IG3	42	17 years	14 years	No
IG5	55	25 years	25 years	No
IG7	51	32 years	20 years	No
IG 9	52	14 years	3 years	No
IG11	41	12 years	12 years	No

Table 2. Participating therapists: age and details of work experience.







