## The narrative in qualitative research in health

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**Abstract** The marked interest of the human and social sciences in health in narrative studies has led to many forms of incorporation of these contributions in qualitative research in health. It is important to reflect on the contexts and characteristics of this incorporation. To accomplish this, we highlight the core theoretical issues involved and also situate this incorporation in the broader context of the scientific production in the human and social sciences in health. We also stress the contribution of the narrative studies for reflection upon the relations between social structure and action or between specific contexts of social interaction and broader societal contexts. This contribution can be identified in relations established through narrative between interpretation, experience and action throughout the health-disease-care process. It is argued that narratives not only organize interpretations, but can also represent a specific form of social agency. In this sense, the narrative interpretations and narrative performances can be seen as core elements in the social construction of experiences and trajectories of illness and care. Keywords Narratives on illness, Narration, Qualitative research, Sociology of health, Anthropology of health, Narrative analysis

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### Introduction

To raise the question of the nature of narrative is to invite reflection on the very nature of culture and [...] of humanity [...] As a panglobal fact of culture [...] narrative might well be considered a solution to a problem of general human concern, namely, the problem of how to translate knowing into telling, the problem of fashioning human experience into a form assimilable to structures of meaning that are generally human rather than culture-specific¹.

Narratives permeate our lives, at different moments, in different places, shaping the texture of life. From birth to death, we are enmeshed in narrative. Not only personal or family narratives, but also in big narratives about the world and life. For this reason, narratives provoke interest in many areas of the arts and fields of knowledge – film, theatre, literary texts, philosophy, linguistics, literary theory, psychology, and the social sciences.

This has been the case since the time of classical philosophy, when Aristotle pointed out the existence of a range of narrative (or dramatic) genres, such as tragedy, epic and comedy. Recently, other genres have emerged, such as soap operas, chronicles and stories.

We live immersed in "big" and "small" 3,4 narratives. The big ones locate us in cosmologies and systems of a religious, scientific and philosophical nature in order to explain the world. At the same time that they order events and activities in mundane or sacred temporalities, these narratives are reconfirmed or transformed through actions and events that affect such temporalities (the Copernican Revolution, the Enlightenment, etc.). Small narratives are present in a range of daily contexts, such as family, school, work, and clinic. These narratives may consist of short stories, produced in interactive, daily contexts; but they may also be guided by a biographical perspective. In both cases we can identify instances of meaning for the "I/world" relationship. Indeed, since modernity, the biographical dimension has become the central mode of organizing narratives of personal experience and feelings of being in the world and, more broadly, in society.

Interest in small narratives has grown significantly in an historical context in which the scientific theories and ideological frameworks that supply big narratives<sup>2</sup> about the world are weakened. We are experiencing a crisis in the

legitimacy of those social institutions (work, school, etc.) responsible, to a certain degree of stability, for integrating specific groups into wider social contexts, or for including social problems in explanatory frameworks and plans of action (for example in the universalist interpretations of history and of society). According to some authors<sup>5,6</sup>, contemporary society is characterised by a crisis in the legitimacy of institutions as the central organizers of social life, in contrast to an affirmation of the more volatile and ephemeral nature of contemporary social relations, such as in the presence of the notion of risk<sup>7</sup> in daily relationships, registering threat and uncertainty in the processes for the signification of living. These circumstances are conducive to the (re) construction of identity through reflexivity about oneself.

Social and human sciences have experienced a real shift towards narrative studies in recent decades, strongly influencing the social sciences of health (SSH)<sup>8-12</sup>. This influence is expressed, for example, in the various ways that contributions from narrative studies have been incorporated into qualitative health research. It is important therefore to reflect on the contexts and characteristics of this incorporation.

In this work, we seek to locate the interest and place of narratives in qualitative health research. We will concentrate on theoretical issues related to narrative studies in health, without neglecting certain important methodological reflections.

Firstly, we point to elements in the SSH theoretical debate that form the backdrop to a growing interest in narrative studies about illness and care, noting their repercussions on the directions and limitations of this interest. Then, we will describe the passage of narratives from the standpoint of research technique to object of knowledge. Next, we will discuss the challenges faced in the relationship between the recording, analysis and presentation of narratives in qualitative research. Finally, we will discuss certain issues explored in (auto)biographical narrative studies about the experience of chronic illness.

# Narratives in social sciences in health: contexts, use and places

Critics of social medicalization and of macro-social theoretical frameworks (of functionalism, in particular) constitute the backdrop to SSH, out of which has grown an interest in the illness narratives explored by qualitative research.

Medicalization engenders a wide-ranging process for the social disciplinarization of the body<sup>13</sup>,

related to the social stratification of care practices<sup>14</sup> and produces iatrogenic effects<sup>15</sup>. If the project for social medicalization and the expansion of technological medicine has made great strides, academic positions critical of "medical imperialism"<sup>16</sup> have also intensified, while social practices that contest the biomedical model in favour of therapeutic pluralism and a diversity of medical rationalities have increased<sup>17</sup>. Foucault<sup>18</sup> put forward how a modern clinical gaze is based on discourse and knowledge produced by an epistemological turn related to a specific mode of spatialization of knowledge and intervention on the body, responsible for shifting the focus from patient to disease (biomedically defined).

These factors reinforced (bio) medical domination in the definition of problems and therapeutic interventions in health, in detriment to other perspectives and subjects. In this context, the interest in personal illness narratives has emerged as a counterpoint to the biomedical perspective, by seeking to "give voice" to those who should be at the centre of attention (patients), but who remain subordinate to biomedical practices and "hidden" from functionalist analyses of such practices.

In the 1950s, Parsonian functionalism contributed to an understanding of medical practice as a social practice - defined as an agency for the social regulation of deviant situations. However, this analysis does not address conflicts inherent in the doctor-patient relationship<sup>19</sup>. Parsonian concepts of the "doctor role" and the "patient role" envisaged the existence of abstract subjects who assume their duties homogeneously and uncritically. In the case of the doctor, the duty is to judge the reality of the deviant situation (the pathology) and re-establish normality for the organism (enabling the individual to return to their daily activities), based on neutral and ethical behaviour, supported by socially legitimated esoteric knowledge. The patient's duty is to desire cure or re-establishment and to adhere to diagnosis and treatment. Thus, if Parsonian functionalism adopted an "outsider perspective" regarding health practices and concepts, the critics of Parsonian view embarked on an "insider perspective", predominantly expressed through the subjective dimension of illness and care as experienced by the patient in a range of care contexts<sup>20</sup>. This trend was specifically seen in North American medical sociology and anthropology literature referring to chronic illness<sup>21</sup>, with the significant use of narrative studies<sup>16</sup>, particularly from the 1980s onwards.

Studies guided by grounded theory, symbolic interactionism, labelling theory and ethnometh-

odology began to explore the different perspectives and relationships of conflict<sup>16,19</sup> established in health practices within a range of daily arenas, from concepts such as the patient's career, the illness trajectory, stigmatization, the normalization process, and others that explore the procedural and relational dimension of illness. Theoretical frameworks, which had previously addressed the macro-structural perspective, began to be guided by micro-social contexts.

The definition of illness as a personal and social experience, through the concepts of illness and sickness<sup>22</sup>, and the formulation of the concept of explanatory models<sup>23</sup>, also enhanced interest in illness narratives. Kleinman, one of the main representatives of the "internal" perspective, is interested in an analysis of chronic illness narratives in reference to personal experience<sup>24</sup>. These works have influenced the Brazilian SSH literature, particularly in studies that explore the concepts of social representation and narrative<sup>25-27</sup>.

Given this broad theoretical context, which favours interest in SSH narratives, it has become relevant to discuss some of the places and uses of narrative in qualitative research.

Initially, anthropology and sociology used narratives instrumentally, utilizing them as a strategy of access to the objectified reality in a given theoretical plan. Thus, the interviews Malinowski conducted with "key informants" were resources to access information about the social life of Trobriand Islanders in the 19<sup>th</sup> century using a nascent social anthropology frame of reference. In the 1930s and 40s, the Chicago School used life histories to cross-reference biographically obtained data with data relating to wider social contexts, aimed at an analysis of nascent urban sociability in North American society. In these studies, narratives figure as a research technique (something still found in certain current investigations).

However, over the course of the 20<sup>th</sup> century, with the growing theorization of narratives conducted in a range of knowledge fields, qualitative health research began to take on narratives as objects of knowledge.

In order to do this, research was supported by theoretical formulations for narratives produced within different fields of knowledge, such as those of the Russian formalists, of socio-linguistics, of hermeneutic phenomenology, and others.

The works of the Russian formalists contributed to the construction of a theoretical framework dedicated to the identification and analysis of internal narrative structures (and to making the narrative an autonomous object of study). In this

approach<sup>28</sup>, every part of the narrative must be seen through its relationship to the whole, through its function in the development of the story organized by the plot. Characters and events must be analysed as functions relating to the passage from an initial situation through a phase of transformation, culminating in a final situation. Therein lies the principle of narrative coherence, more heavily characterised by the presence of continuity than by the absence of contradictions.

Labov, who was heavily influenced by Russian formalism, sought to identify a narrative's minimal structural elements using the socio-linguistics approach. He identified structural functions that drive not only the narrative's internal analysis but also its evaluative dimension. In the latter case, attention is drawn to the value judgements woven throughout the narrative through reflections from the narrator about positions relating to the narrated events, explaining motivations for the actions undertaken. The elements the author identified are: abstract, orientation, complicating action, evaluation, resolution, coda. These elements enable the easy identification of the narrative units for analysis; however, they do not take into account the contextual elements present in narrative production, which are extremely important in any analysis of experience.

Gradually, narrative began to be taken on by the social sciences as the favoured locus for an analysis of culture, social action and experience (personal and social). In this case, narrative is considered to be a universal form for the construction, mediation and representation of the real, which participates in the formulation of social experience, calling into question the nature of culture and the human condition (as indicated in the article's epigraph).

Narratives, therefore, achieve mediations between the "interior" and the "exterior" of the "I" in the being-in-the-world relationship.

Narrative is a fundamentally human way of giving meaning to experience. In both telling and interpreting experiences, narrative mediates between an inner world of thought-feeling and an outer world of observable actions and states of affairs<sup>11</sup>.

Narratives maintain an intimate relationship with the domain of culture, since they employ diacritical signs<sup>1</sup> from the social/symbolic system itself, which activate culturally ordered forms of narrative that define the identities, moral judgements and classification categories that guide and shape our social experiences and interpretations.

A potential trigger question for an analysis of existing relationships between the context of

production and the narrative structure (and those with a broader cultural universe) might be: why was the story told in this manner?<sup>10</sup> The answer may be sought by identifying, for example, the narrator's position in relation to the produced narrative and the narrative's focus and genre.

Hydén<sup>29</sup> proposes the existence of "illness as narrative", where narrator, illness and narrative combine in a single person (patient), thereby producing "first person" narratives (about their own experience); "narrative about illness", regarding another person's illness experience, presenting knowledge and ideas about the illness and related events (e.g. doctors, family members etc.); "narrative as illness", where an illness involves lost in ability to formulate narrative. This typology focuses on the effects of the narrator's position in relation to the constructed narrative.

Bury<sup>30</sup> puts forward a typology that emphasizes the principal themes, foci and styles of illness narratives. Contingent narratives describe events that function as proximate causes of an illness or that express its more immediate effects on the body, self and daily life. They contain a "spectral" view of biomedical knowledge appropriated by patients and integrated into personal narratives based on categories and values that are not based on "professional" culture, but rather on the illness experience. Moral narratives express a more properly evaluative dimension of the personal dynamics and positions involved in changes to the relationships between body, self and society engendered by the illness and care process. They may constitute a strategy to maintain social distance from or moral control over the related events, through a performance narrative that defends a specific view of itself and of its illness and care experience. Nuclear narratives establish connections between illness experiences and deeper levels of meaning about suffering. These involve a more formal analysis of the narrative, for example the identification of its genres (heroic, tragic, comic, etc.) and the particular use of language and metaphor (clichés, symbolic and linguistic repertoires). They enable one to analyse the direction of the narrative's illness trajectory (stable, progressive or regressive)<sup>31</sup>.

These typologies are highly useful in highlighting the more general aspects of narratives, although they do not delineate a specific theoretical basis for the analysis process.

Ricoeur's hermeneutic phenomenology provides a theoretical epistemological basis for understanding of the density of the significance of human experience within an analysis of the narrative moment. The world unfolded by every narrative work is always a temporal world [...] Time becomes human time to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence<sup>32</sup>.

For the author, narrative, as an essential modality for the organization of the complex relationships between experience-language-interpretation, establishes the temporalities of the lived experience. With Ricoeur, one may say that man is necessarily a narrativized being, in contrast to the idea of the death of the narrator<sup>33</sup> seen in urban-industrial societies.

If studies based on the contributions of the Russian formalists favour an analysis of the narrative's internal structure, those based on hermeneutics focus on the narrative's approach as a textual work, enabling different interpretative relationships.

A third strand is provided by a reflection on the context of the narrative production, and is interested, for example, in narrative performances<sup>34</sup>. In this instance, the narrative production is considered a relational act that involves narrator and audience – an act situated at the crossroads between the broader cultural context and the social interactions caught up in the specific situation of the narrative production.

Creating a narrative, as well as attending to one, is an active and constructive process – one that depends on both personal and cultural resources<sup>11</sup>.

We may therefore say that narratives have a performative, situational and relational nature. There is no neutrality in the production of a narrative<sup>35</sup>, since language and speech are not transparent, nor should they be reduced to neutral instruments of communication<sup>36</sup>. Narrative is an object inscribed with symbolic materiality, which is not constituted as a closed system, but rather suggests fields of possibilities for feelings and structural forms. Narratives call into question the contexts of production and the legitimation of different interpretations inscribed on the social contexts in which they are produced.

Attending an illness narrative involves witnessing the suffering of others through active listening. This listening may involve varying degrees of understanding, comprehension and recognition in relation to the report, conferring legitimacy on it or not, opening itself up to the establishment of empathy for the story and the narrator, or not.

Frank<sup>37</sup> fervently defends the idea that narratives are a resource for dealing with suffering and for the "remoralization" of ill subjects whose identity has been threatened. Thus, for this author,

the most common and immediate problem of those who relate an illness story is to be listened to, to find someone who will answer the call of their story in order to establish an ethical (rather than merely an intellectual) relationship between the researched and the researcher, for example. In this sense, restricting narrative to a text for analysis may lose sight of the purpose that motivated those engaged in the account.

These positions invite us to reflect on the relationships established between researched and researchers when using specific narrative production techniques, such as interviews. They also led to reflection on the investigations' ethical parameters and wider (micro) political relationships. For those who conduct qualitative research in the field of health, the implications of these reflections are complex and profound. These implications should not immobilize us; on the contrary, they should motivate us to bring together dialogue relationships and scientific rigour, in scientific and ethical attitudes committed to analysing and legitimizing polyphony. They therefore deal with interest and critical spirit jointly directed at narratives.

One way of avoiding a naïve analysis of narratives is to consider them as an instance of social agency – thus, at the same, asking ourselves about their specificity and their relationships with different dimensions of social action.

At the beginning of the twenty-first century, narration and narrative modes are cast as key elements in several theories oriented toward the epistemology of social action (e.g., Bakhtin, Foucault, Rorty)<sup>38</sup>.

Narrative is a social action that should be analysed within the specific contexts of interaction in which it is produced, but also in the interpellation of social structures (taking into consideration the power and social distribution relationships of the capital at play within our narrative contexts).

Narrative should not be held up in opposition to the dominance of social action, as if the interpretations engendered within it are inscribed on a reflective moment entirely separate from other types of social agency. If, on the one hand, reports obtained in interviews do not correspond to a direct observation of events and actions; on the other, all observation presupposes an interpretative moment (often narratively organized) and narrative performances that both support the observer's position in these interaction contexts and guide an interpretation of observed events.

These provisos have important ramifications for the exploration of fields of research. In considering narrative to be a specific form of social agency, we consider, for example, that social interactions captured in the research context involve narrative performances in which choices are made (consciously or unconsciously) about the forms of (re)presentation of the I (both of the researcher and the researched) and the motivations, values and interests that permeate such interactions.

Good<sup>39</sup> and Good and Good<sup>40</sup> analysed narratives about epilepsy in Turkey as representations and social agency that were characterized as: guided by a broader cultural context; open to the uncertainties related to chronicity and; sensitive to the specific context of social interaction in which they were produced. They identified what they called the "subjunctivizing" effect of the reality produced in the narrative performances ("tactics") they analysed. They noted that such tactics manifested different arrangements between the social position occupied by the narrators (voices) and the types of juxtaposition of the stories told, producing a subjunctive mode which supports the ambiguous nature of the suffering experience, in a cultural context conducive to the interpenetration of several explanatory models (magic, religious, scientific) of epilepsy.

The incorporation of significant degrees of theorization about narratives – either in relation to their internal structure, their participation in the development of the social experience or their performative dimension – in narrative studies about health enables us to extend their criticality and analytical rigour.

Atkinson has put forward several criticisms of the lack of scientific rigour in some of these studies. Such criticisms should not be taken as absolute truths, but certainly contribute to a debate about the purpose and basis of knowledge production in social sciences in health.<sup>41</sup>

Without overlooking Kleinman's contributions to an understanding of the suffering experience, Atkinson<sup>12</sup> sets out the limitations of his approach, in part, because this disregards the non-neutrality of narrative performances. Furthermore, Kleinman makes an undue approximation between ethnography and the clinical, by emphasizing that consultations and interviews serve as strategies to produce revealing narrative performances of an "authentic" biographical experience, since they are carried out by "real" people, who have experienced suffering. In fact, Kleinman asserts that the professional, in both ethnography and in the clinic, must listen to narratives empathically, given that the clinical encounter is a form of individual "mini ethnography". For Atkinson, ethnography is not just an empathic approach to people and their stories, and Kleinman exaggerates the value of the individual sufferer's point of view. Hence, by favouring a specific domain of meanings (of the patient) and accentuating the self-revelatory power of the narrative ("authentic"), Kleinman ends up imposing a first-order interpretation (of the researched) on a second-order interpretation (of the researcher), establishing a hierarchy that is the reverse of positivism.

This collage of narrative experience is, therefore, connected to what Atkinson considers a "neoromantic" vision of the social actor. In exaggerating the centrality of this actor in detriment to an analysis of the social interactions in the development of the illness narrative experience, methodological rigour is substituted for therapeutic ethics (of clinical activities, but also of research) and a critical evaluation of several forms of the representation of the "I" is substituted for an assertion of the authenticity of an autobiographical revelation.

Atkinson considers the ethical commitment of researchers to be important, provided that it does not lead to a weakening in critical methodological attitudes.

We need to put narrative in its place, therefore, by approaching it in the context of the multiple modes of performance, of ordering, of remembering, of interacting. Narrative is but one form of social action<sup>12</sup>.

The narrative approach of health professionals, for example, may increase our understanding of the narrative contexts within which the patient's perspective is constructed. Finally, it is worth recalling Henderson, in an interview with a patient:

You should hear, firstly, what he wants to tell you, secondly, what he does not want to tell you and, thirdly, what he cannot tell you<sup>42</sup>.

To describe a case is an essential element in clinical practice and is responsible for integrating different biomedical representations of body/ suffering – dispersed across time and space by diagnostic technology and therapeutics – into a coherent and convincing narrative about the illness<sup>43,44</sup>. Hunter<sup>45</sup> fully explored the interpretative nature of the medical clinic, by analysing a range of narrative contexts and practices in the profession. The narrative dimension is present in the educational and professional practices of clinical medicine, which even embodies narrative competency<sup>46</sup>.

Atkinson<sup>12</sup> reminds us that the narrative performances of doctors are present in their formal meetings with patients or professionals, as well as in informal dialogue arenas, and involve reporting not only exemplar, rare or surprising cases, but also anecdotal ones. The different ways that members

of the medical team participate in the development of narratives is based on power relations. Thus, not only do senior doctors dominate dialogue but they are also authorized to talk freely about their personal experiences, including anecdotal histories, stories and other narrative genres. Junior doctors operate as an attentive audience, limited to small additional comments. This situation demonstrates the close relationship between narrative, memory and professional hierarchy (and the existence of a symbolic economy performed through narrative exchange).

Extrapolating from health services, we can make interesting analyses in relation to narrative contexts where there are strong conflicts or disputes – for example, when mental health issues are confronted in the judicial sphere. Exploring the polyphonic nature of narrative contexts related to compulsory hospital admissions, Atkinson<sup>12</sup> identified the formation of conspiracies and alliances in which different power relations arise between dominant and subordinate voices.

In short, we can see that the narrative perspective is intimately related to a general picture of theoretical discussion and knowledge production in SSH, and has become an important theme for reflection. If there are no widely accepted definitions of what is seen to be a narrative11, this is because definitions vary according to the theoretical perspective occupied in relation to the narrative, the research and the analysed object. Therefore, according to a given arrangement of the methodological strands<sup>47</sup> of investigative practice - epistemological, theoretical, technical and morphological - we will find a certain correlation between the definition, place and use of narrative in qualitative research. However, whatever this correlation is, it is essential that it address the specificity of narrative and, in the absence of this specificity, the classification of research as narrative study should be avoided.

Without prejudice to other definitions, we assume from a more formal point of view in this work that narrative is characterized by: the sequential ordination of actions and events; the shaping of characters and scenes in which these actions and events take place, calling into question their relationship with diegetic contexts (spaces narratively structured or internal to the narrative); and the weaving together of these elements into stories (which form a whole or a temporal diegetic universe). However, beyond a mere sequential description of actions and events, we understand that narrative is a means of establishing a feeling of being-in-the-world, in that it locates the events

and actions in "dramas" instituted in the temporal order of those who experience them. In this sense, narratives are ways of developing social experience. This occurs not only in autobiographical or first person narratives, but also in narratives that describe the situations experienced by characters who do not represent the narrator.

## The logic of the investigation and presentation of narrative studies

Narrative may be considered an aesthetic and scientific undertaking<sup>48</sup>, which, when inserted into the post-positivist context, seeks to relocate the relationships between researched and researchers. It enables different connections between first-order and second-order interpretations<sup>16</sup>, challenging the relationships established between observation, recording and interpretation, and questioning existing relationships between the logic of the investigation and presentation of knowledge.

We have reflected on this issue in a recent work<sup>49</sup>. Here, we recall that not only the interview format, but also the characteristics of the location, the interviewer and the presentation strategies themselves, may influence the way narratives produced within the context of the investigation are addressed.

The narrative interview<sup>50</sup> has been valued<sup>51</sup> as a specific technical resource for narrative production. Without wishing to disregard the contribution this resource has made to the development of narrative studies in qualitative research (specifically the technical strand), it is important to recognize that good narratives may also be generated by in-depth<sup>52</sup> or semi-structured interviews<sup>43</sup>. Furthermore, one may identify narratives in daily conversations not motivated by a research context, but which nevertheless are of great scientific interest<sup>3</sup>.

Narrative analysis pre-supposes a demarcation of the narrative units of analysis. It therefore has a theoretical orientation, which not only traverses the narrative concept, but also the choices that confer materiality on it, such as, for example, the model of transcribing narratives<sup>10</sup>. Without disagreeing with this premise, we propose a challenge<sup>49</sup> to break away from a first narrative instance (delineated in a transcription of what the respondent says) towards a narrative reconstruction (undertaken by the researcher).

We defend the notion that the "researcher narrative" consists of a second level interpretation, which, although distinct from the first, may also be the object of analysis, in the same way as the

respondent's narrative. This position is founded on three ideas. Firstly, we should consider that the respondent's narrative is affected by the research context, so that its originality cannot be taken for granted, nor assumed as a neutral reality. In the second place, the transcription itself and the identification of the narrative units present in the statement are products of the theoretical choices that guide the research. Finally, the researcher's perspective can and must be an object of analysis in narrative studies, in an exercise of methodological reflection which advances towards a third level interpretation – in other words, one about the way a narrative summary is analysed, which expresses the researcher's interpretation of the analysed material.

This narrative analysis presents a possibility which needs to be more radically tested in future studies, without thereby intending to diminish the importance of taking the narrative of the researched as an established material for analysis in narrative studies.

The above comments indicate that there is not necessarily any relationship between the methodological strands of narrative research. Different arrangements of these strands may result in relevant analytical perspectives, if they include reflection, sensitivity, theory and creativity, in the logic of the research's investigation and presentation. In this sense, rigour is not necessarily the same as rigidity.

## Self-narratives in the context of chronic illness

Given the importance of the biographical approach in narrative studies, with an emphasis on those that address the experience of chronic illness, we now consider certain issues of interest to this discussion, without dealing with them systematically. Contemporary thought offers a broad context for reflection on the "self".

The publicization of the private sphere of individual life can be widely identified in social and media networks<sup>53</sup>, as well as in illness experiences<sup>35</sup>. Thus, when the spread of HIV/AIDS leads to militancy<sup>54</sup>, the publicization of the I-patient is a relevant social practice for the transformation of chronicity into function<sup>19</sup>. These narrativization practices of the "self" take place within both institutional and non-institutional arenas.

Bourdieu<sup>55</sup> reminds us that, at every step, we are asked to reconfirm our biographical identity through our names, in identity documents and in other markers responsible for producing what he provocatively calls the "biographical illusion".

Furthermore, inspired by Foucault's<sup>56</sup> approach, we may assert that health institutions behave as "confessional" intersubjective architectures, driven by discursive technologies of the self, present in counselling, interviews, guidance etc. On exploring the presentation of the "self" as a social dramaturgy, Goffman<sup>57</sup> draws attention to the conflictual process of negotiating the interpretations and meanings of personal identities present in social interaction contexts. In this sense, words, gestures and clothes may be considered performative strategies to present the "self".

There is a close relationship between the biographical approach and narrative studies<sup>58</sup>. The work of Ochs and Capps<sup>59</sup> stands out from a raft of studies more properly directed at the narrativization of the self. For the authors,

Personal narrative simultaneously is born out of experience and gives shape to experience. In this sense, narrative and self are inseparable. Self is here broadly understood to be an unfolding reflective awareness of being-in-the-world, including a sense of one's past and future<sup>59</sup>.

Bruner<sup>60</sup> considers narratives to be a way of ordering experience through the creation of scenarios: of action, which focuses on what the actors do in particular situations, and of awareness, referring to what the characters know, think and feel or do not know, think or feel. Autobiographical narratives allow us to analyse the choices made in the form of the (re)presentation of the "self", referring both to the "inner world of thought-feeling" (the awareness scenario) and the "outer world of observable actions and states of affairs" (the action scenario) described by the narrator.

Narrative reconstructions take place throughout the process of chronic illness<sup>61</sup> and are responsible for reframing life trajectories to locate the illness within new contexts of meaning. In a classic work about the sociology of chronic illnesses, looking at the narratives of women with rheumatoid arthritis, Bury62 formulates the concept of biographical disruption to analyse the way in which the experience of chronic illness crucially affects life trajectories. In parallel, Charmaz<sup>63</sup> seeks to understand how chronic illness may be distressing for self, requiring the (re)elaboration of feelings about life and living (or its narrative re-elaboration). These works show how narratives operate as important elements of agency in the dynamics that embody the experience of chronic illness, by organizing interpretations and guiding actions about the body, life, care and identity.

Chronic illness narratives may therefore negotiate the re-signification of daily experience, "re-

pairing" disruptive events that have threatened the relationships between mind, body and world<sup>61</sup>, by supporting the reestablishment of such relationships within new terms and contexts. Chronicity involves movements of stabilization and destabilization, not only of symptoms and treatment, but also of identities and life projects that come into play in different interaction contexts<sup>64</sup>, which in themselves require intense work<sup>65</sup> throughout the illness trajectory. Narrative reconstruction<sup>61</sup> is one dimension of this work, which may activate resources and alter power relations<sup>66,67</sup>.

The chronic condition takes the patient and their carers to a place of uncertainty, feeding their concerns about both becoming and the reinterpretation of the past. It fosters the intertwining of the illness experience with narrative elaborations about the life trajectory. In a study about the social construction of chronic illness in children with either asthma or cystic fibrosis, we sought to analyse illness and care narratives in a biographical framework that took into account individual and family trajectories<sup>43</sup>. When asking "why me?" and "why now?" the respondents produced narratives that established (more than simply portraying) the direction of their personal and family trajectories. In this sense,

Narrative imitates life, life imitates the narrative [...] There is no such thing psychologicallyas "life itself." At very least, it is a selective achievement of memory recall; beyond that, recounting one's life is an interpretive feat<sup>60</sup>.

An analysis of the narratives demonstrated that the respondents resorted to their life stories to identify elements (of disruption<sup>62</sup> and biographical reassertion<sup>54</sup>) central to the organization of their experiences and to directing their actions throughout the chronic illness. In doing so, they integrated three types of typologies: of illness, of life and of the narratives themselves<sup>31</sup>.

That is not, therefore, to reify the "self", presupposing direct access to personal experience through dialogue (interview), nor to suggest a supposedly limitless interpretative freedom. Starting from the principle that respondents adopt narrative performances to present themselves as competent and committed carers of their children, for example, we understand that, in their narratives they seek to legitimate themselves in front of a representative of established knowledge (interviewer-researcher). This does not diminish the scientific relevance of these narratives; on the contrary, it enables reflection about the choices responsible for establishing relationships between experience and life trajectories, as well as between researcher and researched.

### **Conclusions**

We have sought to demonstrate that narrative studies raise fundamental issues for SSH knowledge production, provoking intense debate about their relevance and analytical rigour. These issues lead us back to the contributions and limitations of the large-scale theoretical frameworks and epistemological foundations of social sciences, in that they consider the possibility of analysing the relationships between subject and structure, action and experience, public and private, individual and social. Their consolidation and theoretical, technical and morphological specificities operate on the methodological strands of qualitative research, opening up new possibilities for tackling old questions. An analysis of the connections between narrative and social action, without reducing one term or the other, has been highlighted as one of the main challenges faced in certain narrative studies. To this end, investment in an analysis of social experience represents a productive pathway. We assert that narrative studies open up pathways for the exercise of differentiated theoretical and methodological orientations and researcher attitudes in relation to knowledge production, for exploration within the field of social sciences in health<sup>41</sup>.

We did not focus on the empirical contributions of qualitative research centred on narrative analysis, since we preferred to focus on a presentation and discussion of theoretical and methodological issues of greater interest. We focused on certain approaches in detriment to others. We emphasized a description of the contexts of existing narrative studies in SSH, without more closely exploring its thematic diversity.

We finish by remembering that small and big narratives permeate our experiences as researchers within certain scientific fields. If there is a crisis of grand totalizing narratives, this does not, nevertheless, diminish the importance of integrating our experiences as researchers into wider narratives regarding these fields. In collective health – perhaps, more than in other fields – this leads us to Penelope's eternal task, in other words, to intense narrative reconstructions towards desired objects, thereby treading the old and new pathways that these describe.

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